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Adolescents' Adherence to Chronic Medical Regimens: Parent-Adolescent Conflict and Adolescent Autonomy in Relation to Adherence to Insulin Dependent Diabetes Treatment Regimens.

Volume One.

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VOLUME ONE.

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Abstract.

The principal aim of this thesis was to examine adherence to medical recommendations amongst adolescents with insulin-dependent diabetes. The relationships between adolescents' adherence and their experience of conflict with parents and of personal autonomy were examined. In addition, the relationships between adolescents' adherence and a range of factors proposed to relate to adherence in the Six-Factor Model of Adherence (DiMatteo & DiNicola, 1982) were also examined.

Measures of general and diabetes-specific adherence were completed by 135 adolescents and their parents attending Diabetes Outpatient Clinics at the Women's and Children's Hospital, Adelaide. Objective data of blood glucose monitoring adherence was obtained from the electronic memory of glucose sensors amongst a subsample of the adolescents. All adherence measures addressed behaviour over the four weeks prior to assessment. During clinic attendance, adolescents and parents also completed measures of parent-adolescent conflict and adolescent autonomy, as well as measures assessing factors included in the Six-Factor Model of Adherence. Metabolic control was assessed by HbA_{1c} assays recorded in the clinics.

Large correlations were detected between each of the adherence measures. Reports of adherence were significantly associated with the adolescents' level of metabolic control. Blood glucose monitoring adherence levels varied over the four weeks prior to assessment, increasing with a linear trend as clinic appointments approached.

The findings of this research supported the hypothesis that adherence would be lower amongst adolescents who experienced high levels of conflict with their parents than amongst adolescents who experienced less conflict with their parents.

The findings of this research did not provide support for the hypothesised direct association between adolescents' experience of autonomy and their level of medical adherence. However, it seems premature to conclude that adolescents' medical adherence is unrelated to their experience of autonomy.

The findings of this research also provided support for the relevance, and general support for the structure, of the Six-Factor Model of Adherence in understanding adolescents' medical adherence. These findings further supported the inclusion of parent-adolescent conflict and adolescent autonomy with this model when assessing adolescents' medical adherence.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

I consent to the thesis, when deposited in the University Library, being made available for loan and photocopying if accepted for the award of the degree of Doctor of Philosophy.

Michael John Fotheringham.

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List of Abbreviations.

ADQ	Adherence Determinants Questionnaire
AFC	Autonomous Functioning Checklist
ANOVA	Analysis of Variance
BGM	Blood Glucose Monitoring
CBQ	Conflict Behaviour Questionnaire
CHBM	Children's Health Belief Model
DFBC	Diabetes Family Behavior Checklist
DSAS	Diabetes Specific Adherence Scale
FACES-III	Family Adaptability and Cohesion Evaluation Scales
FES	Family Environment Scale
GAS	General Adherence Scale
HbA_{1c}	Haemoglobin A_{1c}
HBM	Health Belief Model
HMRA	Hierarchical Multiple Regression Analysis
IDDM	Insulin Dependent Diabetes Mellitus
IMCHB	Interaction Model of Client Health Behaviour
NIDDM	Non-Insulin Dependent Diabetes Mellitus
PARQ	Parent-Adolescent Relationships Questionnaire
PM	Protection Motivation Theory
SD	Standard Deviation
SFMA	Six Factor Model of Adherence
SMRA	Stepwise Multiple Regression Analysis
TRA	Theory of Reasoned Action

PREFACE: THE NATURE AND MANAGEMENT OF INSULIN-DEPENDENT DIABETES MELLITUS.

This preface is intended to provide a brief background on the nature and management of Insulin-Dependent Diabetes Mellitus (IDDM). It is not intended to be comprehensive, but to furnish the reader with an essential understanding of the nature of the illness and its management by young people and their families. The development of this thesis, including the review of the previous literature and the research design, is based on an understanding of the importance of these issues.

The Nature of Insulin-Dependent Diabetes Mellitus.

Diabetes Mellitus is a metabolic disorder caused by insufficient insulin action (Silink, 1990). Insulin is normally produced by the pancreas, and released into the bloodstream. In IDDM, the pancreas produces decreased amounts of insulin (Krall & Beaser, 1989). This condition is characterised by insulinopenia (lack of insulin) and dependence on exogenous insulin to prevent ketoacidosis and preserve life (Sperling, 1992). Hence, this condition is termed Insulin Dependent Diabetes Mellitus[1].

Complications associated with IDDM can be categorised as acute and long-term (Krall & Beaser, 1989). Acute complications include Hypoglycaemia and

[1] In the United States of America, the term IDDM has recently been abandoned in favour of "Type 1 diabetes" (Expert Committee on the Diagnosis and Classification of Diabetes Mellitus, 1997). However, this change in nomenclature has not been widely adopted in Australian clinical practice. In this thesis, the terms IDDM, insulin dependent diabetes, and diabetes will be used to identify this condition.

Ketoacidosis. Long-term complications include Retinopathy, Neuropathy, and Nephropathy.

Hypoglycaemia, meaning low blood glucose, occurs when too much insulin has been taken, not enough food has been consumed, or too much exercise has been performed without adjusting food intake (Silink, 1990). This is treated by eating or drinking something with a high level of sugar, or by injection of glucagon - a hormone that releases stored glucogen from the liver and helps convert it into glucose in the bloodstream (Krall & Beaser, 1989).

Ketoacidosis is defined by absolute insulin deficiency (H Fishbein & Palumbo, 1995). When insulin levels are low, the body uses fat as a source of energy; a by-product of this is the production of ketones in the bloodstream, making the blood more acidic (i.e., ketoacidosis). Dehydration also occurs. Untreated, this process will lead to coma and death (H Fishbein & Palumbo, 1995). Treatment involves hospitalisation, and the urgent replacement of insulin and fluids (Krall & Beaser, 1989).

The microvascular complications of IDDM are retinopathy, neuropathy, and nephropathy. Macrovascular complications are coronary artery disease, cerebral artery disease, and peripheral artery disease. Adolescents attending the Women's and Children's Hospital (WCH) Diabetes Outpatient clinics are aware of these complications and are regularly screened for early signs of these complications.

The risk of long-term microvascular complications of IDDM is reduced optimal metabolic control (Diabetes Control and Complications Trial Research Group, 1993). The accepted method of assessing metabolic control is by haemoglobin A_{1c} assay.

Haemoglobin A_{1c} (HbA_{1c}) comprises 3 to 6 per cent of the total haemoglobin in persons without IDDM, and is increased to between 6 to 12 per cent of the total haemoglobin in those with IDDM (Koenig, et al. 1976). HbA_{1c} assays provide an indication of the patient's level of blood glucose control over the preceding weeks, in effect giving a value that integrates the blood glucose concentration over that period (Koenig, et al. 1976; Olson, 1988; Scobie & Sönksen, 1984; Sperling, 1992).

Good metabolic control is achieved by the careful management of IDDM. As with many chronic illnesses, the responsibility for the management of IDDM rests largely with the patient and their family, under the guidance of health professionals.

The Behavioural Management of Insulin-Dependent Diabetes Mellitus.

Children and adolescents with IDDM are recommended to adhere to a range of management activities to control their illness. These behaviours include insulin administration, the monitoring of blood glucose, the observance of nutritional planning, and regular exercise (Hanson & Onikul-Ross, 1990; Scobie & Sönksen, 1984).

Blood glucose monitoring (BGM) is an important aspect of IDDM management. Adolescents are typically recommended to test their blood glucose level at least twice

each day (Scobie & Sönksen, 1984). This is the recommendation given to the adolescents attending the WCH outpatient clinics. In addition, blood glucose should be tested when the adolescent is unwell, symptomatic (high or low blood glucose) and with increased exercise.

Insulin injection is the most crucial aspect of IDDM management. Human insulin is laboratory manufactured, including short-acting, intermediate-acting and long-acting preparations (Davidson, 1991b; Hanson & Onikul-Ross, 1990; SB Johnson, 1995). Actual schedules of insulin doses vary, though adolescents typically are prescribed two, three or four daily injections, using a combination of short-acting and intermediate-acting preparations. When blood glucose levels are increased or decreased over several days, insulin doses should be adjusted.

Dietary management of IDDM consists of three parts: the quantity of food eaten, the type of food eaten, and the timing of eating (Krall & Beaser, 1989). The quantity of food eaten is important because this dictates the amount of sugar absorbed into the bloodstream (Davidson & Botnick, 1991; Krall & Beaser, 1989). The type of food consumed is important because of the differing carbohydrate content in various foods. Foods with complex carbohydrates are absorbed more slowly, whereas foods with simple carbohydrates are absorbed rapidly, causing faster increases in blood glucose concentrations. Exchange lists and the Glycemic Index are two approaches that have been used to rate the influence of different foods on blood glucose (e.g., Davidson & Botnick, 1991; Foster-Powell & Miller, 1995; Hanson & Onikul-Ross, 1990; Wolever & Bolognesi, 1996; Wolever, Jenkins, Jenkins, & Josse, 1991). The regularity of meal timing is important because meals should be timed to coincide with peak periods

of insulin action (Hanson & Onikul-Ross, 1990). For this reason, unplanned snacks, particularly when high in sugar, may be problematic for children and adolescents with IDDM.

Exercise is another important component of IDDM management. During exercise, the muscles use the glucose available in the bloodstream for fuel. The increased use of blood glucose can increase the risk of hypoglycaemia if food intake and insulin levels are not appropriately balanced. The balance of exercise with food and insulin levels is easiest if exercise is regular, although unusual amounts of exercise can be prepared for by the adjustment of insulin levels and dietary consumption (Hanson & Onikul-Ross, 1990). For this reason, the testing of blood glucose levels (i.e., BGM) before or after exercise is important.

In addition, proper management of IDDM involves preventative behaviours, such as the maintenance of good foot hygiene and carrying a supply of glucose in case of hypoglycaemia. Cigarette smoking increases the risk of long-term complications in IDDM, including neuropathy and retinopathy, and must therefore be avoided (Chaturvedi, Stephenson, & Fuller, 1995; Reichard, et al. 1991; Spallone & Menzinger, 1997; Zoppini, et al. 1996).

As this brief overview has indicated, the management of IDDM is complex; involving a range of inter-related behaviours. Further, this management is vital to prevent (or minimise risk of) severe long-term complications. As such, the assessment of IDDM management, and influences on the management of IDDM by adolescents, are worthy of investigation.

CHAPTER ONE.

LITERATURE REVIEW.

This chapter reviews the published literature relating to the development of this thesis. Three major topics are addressed in this chapter. First, the historical context of patient adherence research is discussed, including the definition and assessment of patient adherence, and the use of theoretical models of health behaviour to describe patient adherence. Second, factors reported to influence patient adherence are discussed, including patients' characteristics, the nature of the illness and its regimen, and patients' relationships with health professionals. Third, issues in adolescent development are discussed in relation to regimen adherence.

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1 LITERATURE REVIEW.

1.0 Introduction.

This literature review was conducted initially by searching citation databases (*MedLine* and *PsycLIT*) for publications addressing the issue of patient adherence. These searches took two forms. First, keywords such as *adherence, compliance, co-operation, self-care, self-management, regimen, recommendation, autonomy, responsibility,* and *conflict*, were used to establish a database of publications relating to these topics. Second, MedLine Index Terms such as *adherence, compliance*, and *parent-child-relations* were used in conjunction with more specific keywords to further probe the databases.

Subsequent searches were performed to gather further publications produced by the authors whose work was identified in the initial searches. Relevant citations in the gathered publications were also collected. In addition, peer-reviewed journals with foci relevant to the issues addressed by this thesis were examined issue by issue, including *Diabetes, Diabetes Care, Health Psychology, Journal of Adolescence, Journal of Adolescent Health, Journal of Adolescent Health Care, Journal of Behavioral Medicine, Journal of Child Psychology and Psychiatry, Journal of Chronic Diseases, Journal of Pediatric Psychology, Journal of Pediatrics, Medical Care,* and *Social Science and Medicine.*

1.1 The Historical Context of Research into Patient Adherence to Medical Recommendations.

This section discusses the historical context of research into patient adherence. This section consists of three parts. The first part discusses the merits and use of different definitions of patient adherence. The second part discusses the assessment of patient adherence. The third part discusses the use of explanatory models of health behaviour to explain patient adherence.

1.1.1 The Definition of Patient Adherence.

Adherence to medical regimens has become an important focus of psychological and medical research in recent years. Previously, the term compliance has been used to describe the extent to which patients correctly manage their treatment. As patients have become increasingly regarded as decision makers, rather than passive recipients of treatment, the term compliance has been superseded by the term adherence. The term compliance is disfavoured because of its implication that the patient's role is to obey the orders of the practitioner, rather than act as a member of a partnership (Dunbar, 1979, 1980; Janis, 1984a; Leventhal, 1983; Shope, 1981). The term adherence is intended to change the focus of researchers, from examining what patients are (i.e., compliers or noncompliers), to examining what patients do (Leventhal, Zimmerman, & Gutmann, 1984).

A methodological limitation characteristic of the patient adherence literature is the inconsistent manner in which adherence has been defined (DiMatteo, Sherbourne, et al. 1993; Dunbar-Jacob, Dwyer, & Dunning, 1991; Marston, 1970). Adherence has been defined in three fundamental ways by various researchers; ratio, category, and index definitions (Cromer & Tarnowski, 1989; Dunbar, 1979, 1980). Ratio definitions focus on the ratio of behaviours completed to behaviours prescribed. This form of definition is usually measured by counts of pills remaining from prescriptions after a set interval.

Category definitions involve classification of patients. For example, patients may be classified as good, fair or poor adherers, or as nonadherers. Unfortunately, most research using this form of adherence definition has failed to specify the criteria by which these categories are delimited. These are probably the most common definitions of adherence, although specific characteristics vary between investigations. For example, adherence has been defined as "the degree to which an individual's behaviour coincides with medical advice relative to lifestyle changes, following diets, or taking medicine" (Rickert, Jay, & Gottlieb, 1990). Other researchers have added components to this definition including medication knowledge, appointment attendance or prescription filling (Becker, Drachman, & Kirscht, 1972; Nessman, Carnahan, & Nugent, 1980). Gordis (1976) described a criterion definition of adherence, in which adherence was conceptualised as "the point below which the desired preventive or therapeutic result is unlikely to be achieved" (p 52).

The third type of adherence definition is the index definition. Index definitions are used to rate patients' adherence to a series of recommended activities. This form of

definition, used in Health Belief Model research, assesses adherence involving various aspects of the patients' regimen, such as keeping appointments and knowledge of the treatment. Individual components of the regimen are weighted according to the importance attributed to them by the investigator, and combined to form an overall index of the patient's adherence.

The lack of uniformity with which adherence is defined in the literature has been an impediment to the advancement of adherence research (Marston, 1970; Rapoff & Christophersen, 1982).

Adherence to medical regimens requires patients to undertake a range of activities including attending clinic appointments, pill taking and dietary modifications (Gordis, 1979; Kirscht & Rosenstock, 1979). Often patients' level of adherence to the different components of a regimen are poorly related to one another and are unstable over time (Kasl, 1983). Given the wide spectrum of activities involved in patient adherence research, it is possible for patients to be fully adherent to one aspect of a medical regimen, whilst being partially or completely nonadherent with other aspects of the treatment (Orme & Binik, 1989).

Because various forms of health behaviour are involved in patient adherence, different methods have to be used to measure different aspects of patients' adherence. A range of methods has been employed by researchers with varying levels of success. The most common of these methods are discussed in **Section 1.1.2.1** of this chapter.

Unfortunately, the majority of investigations of patient adherence have described patients as either "adherent" or "nonadherent". This approach ignores the continuum along which adherence can vary. Describing patients as either adherent or nonadherent to a treatment program ignores the complexity and range of adherence behaviour; adhering to a medical regimen involves a wide range of activities, each of which can be adhered to to varying extents by the patient. Patients who are highly adherent to some aspects of a regimen may at the same time adhere very poorly to other aspects of the regimen (La Greca, 1990a). Due in part to these considerations, and in part to the measurement issues discussed in the next part of this chapter, there is at present no single highly reliable, valid method of predicting adherence or nonadherence before the initiation of treatment, or of evaluating adherence during treatment (Cockburn, Gibberd, Reid, & Sanson-Fisher, 1987; TG Wilson, 1987).

1.1.2 The Assessment of Patient Adherence.

The measurement of patient adherence has been the topic of considerable controversy in recent years (RD Hays & DiMatteo, 1987; La Greca, 1990a). The methods used to assess adherence and the experimental design of studies focusing on adherence have received attention in a number of reviews (e.g., Dunbar, 1980, 1983; LH Epstein & Cluss, 1982; Gritz, DiMatteo & Hays, 1989; RD Hays & DiMatteo, 1987; La Greca, 1988a, 1990a). This section provides an overview of the main methods employed to assess adherence that have been referred to in the literature, as well as discussing key research design features appropriate to the investigation of patient adherence.

1.1.2.1 Measures of Patient Adherence.

The most commonly used methods of assessing patient adherence are self-reports, collateral reports, behavioural observations, permanent products, health provider estimates, and biological assays. These methods are reviewed in turn.

Self-Reports.

Self-Report measures are the patients' own reports of their adherence to their treatment regimen. Several basic forms of self-report have been used, such as diary keeping, questionnaires, and scenario testing. *Diaries* or *Log books* can be maintained by patients as a regular record of their regimen-related behaviours, as they occur. *Questionnaires* or *Interviews* can be used for patients to report on their past behaviour in relation to their regimen.

Self-report questionnaires are probably the most commonly used assessment of adherence, and can be used to measure adherence with any form of health behaviour. For example, questionnaires may be used to assess adherence to medication prescriptions, exercise recommendations and dietary restrictions. Advantages of self-report questionnaires include that they are easy to use and inexpensive, and that their reliability and validity may readily be tested. However, self-report measures may be vulnerable to bias or falsification. (SB Johnson, 1991a).

Self-report interviews are another commonly used form of adherence assessment. A benefit of interviews is that they are able to examine more closely the issues detected

by self-report measures, and are adaptable to each patient's needs. A disadvantage of using interviews is that as well as being vulnerable to the self-report biases which limit questionnaire self-reports, interviews also are limited by possible interviewer biases.

Collateral Reports.

Collateral reports of adherence include reports obtained from the patients' family members or friends. These measures may take the same forms as the self-report measures. These measures, like the self-reports are typically easy to administer, and are vulnerable to the same biases as the self-reports. The accuracy of collateral reports also is likely to be influenced by the level of familiarity of the respondent with the patient. That is, reports from parents about the adherence of their children are likely to be comparatively accurate, while the reports of friends or more distant family members may be less accurate (RD Hays & DiMatteo, 1987).

Behavioural Observation.

Behavioural Observation has been used in a select number of studies. In this instance the patients' actual adherence behaviour is observed by the researcher. The benefit of this measure is that it provides a more complete picture of the adherence behaviour of the individual, potentially covering all aspects of adherence to the treatment regimen. A disadvantage of using behavioural observation as a measure of adherence is that this method can only be used with certain limited groups of patients. Also, the presence of an observer may influence the behaviour of patients. Finally, the expense and

difficulty of obtaining this form of information make direct observations prohibitive (Ley, 1992).

Permanent Products.

In recent years a number of products have become available that are supplied to patients and employed both in the assessment of adherence and for health care purposes. An early version of a permanent product is the performance of pill counts, that is, counting the amount of medication left in a pill bottle after a defined period (Caron, 1985; RD Hays & DiMatteo, 1987). Pill counts are vulnerable to poor co-operation from patients. For example, patients may forget to bring pill bottles to clinic visits, or may throw away medication they have not consumed. A further disadvantage of the pill count is that no information about the timing of medication use is available.

More recently, microprocessors were employed in pill bottles to record the timing of each opening of the bottle, and presumed dose (e.g., Cramer, Mattson, Prevey, Scheyer, & Ouellette, 1989; Cramer, Scheyer, & Mattson, 1990; Eisen, 1991; Feinstein, 1990). These devices were limited by their expense and cumbersome nature. Further, their assessment was of a presumed dose rather than of an actual dose - patients may have opened the bottle and not consumed an appropriate dose (Lee, Nicholson, Souhami, & Deshmukh, 1992).

Another device developed to record objectively the performance of a regimen behaviour is the Nebuliser Chronolog. The Nebuliser Chronolog may be used to

assess objectively the use of metered-dose inhalers, principally used in the treatment of asthma. The Nebuliser Chronolog is a small portable device that houses a standard metered-dose inhaler. Each actuation of the inhaler is recorded in the electronic memory of the chronolog according to date and time, records can be read out using a Chronolog Interpreter (Mawhinney, et al. 1991; Rand, et al. 1992; Spector, et al. 1986; Spector & Mawhinney, 1991). A shortcoming of the Nebuliser Chronolog is that its use involves some level of change in routine for the patient - the device is larger than the basic inhaler, and the process of obtaining records is cumbersome. It is possible, therefore, that the use of the Nebuliser Chronolog is reactive, that is, it may influence the behaviour being assessed - inhaler use (Rand, 1990; Rand, et al., 1992; Spector & Mawhinney, 1991).

A more recent development in this line includes monitors for testing blood glucose levels for patients with insulin-dependent diabetes mellitus. These monitors are designed with large memory capacities to record the timing and results of blood glucose tests (e.g., MediSense, 1995; Tieszen, Burton, Dornan, Matthews, & McMurray, 1995; Wysocki, Green, & Huxtable, 1991). An advantage of these monitors is their ability to measure variations of adherence over time. Further, data can be obtained from these monitors in an unobtrusive manner. Previous studies have found that the use of new sensors with electronic memories has not influenced blood glucose monitoring (BGM) adherence (Mazze, et al. 1984; DP Wilson & Endres, 1986). A limitation of the monitors is that they focus on only one aspect of regimen adherence.

Health Provider Estimates.

Health provider estimates are descriptions of the adherence of the patient from the perspective of the health provider. These estimates of adherence are obtained using the same methods as self-reports or interviews, except that the clinician, rather than the patient, is involved in the process. The only advantage gained by using clinician estimates is that they are less reactive than most forms of adherence measure, as patients may be kept unaware of the examination of their adherence. However, clinician estimates are perhaps the poorest measure of patient adherence (Caron & Roth, 1968; SB Johnson, 1991a). These reports typically confound adherence with health status (SB Johnson, 1991a; La Greca & Schuman, 1995).

Biological Assays.

Biological assays are direct measures of the level of drug present in the body. Assays are taken by recording the amount of prescribed drug present in blood, urine, etc, as an indication of the amount of medication that has been taken, or how closely patients have adhered to dietary restrictions. Biological assays are a direct measure of the presence of medicine. However, although they are a direct measure, assays are a measure of the physiological results of treatment not of behaviour. There are several disadvantages in using assays as measures of adherence. First, assays are only applicable to a limited range of drugs, so adherence with many regimens cannot be determined by this measure (Dahlquist, 1990). Second, assays are only measures of the level of drug present, and so do not provide any indication of the frequency with which doses have been taken (La Greca, 1988a). Finally, inter- and intra-individual

variation in the rate of absorption or metabolism of the drugs makes this a poor indication of the adherence to drug treatment (Dunbar, 1980).

1.1.2.2 The Comparison of Patient Adherence to Differing Regimens.

This section reports on studies addressing the variation of adherence to different regimen demands. There are two points to be considered in relation to this issue. First, the variation in the extent to which patients adhere to different regimen demands. This includes the variation in adherence levels between different treatment regimens, as well as the variation in adherence to different components of complex regimens such as diabetes self-management. Second, the measurement of adherence across different regimen demands should be considered. For example, global measures of adherence do not account for the variation in adherence levels to different components of complex regimens. These topics will be considered in turn.

The Consistency of Adherence Across Regimen Demands.

Previous studies have reported widely varying adherence rates, ranging from almost complete nonadherence to complete adherence (Burke & Dunbar-Jacob, 1997; DiMatteo, 1994; DiNicola & DiMatteo, 1984; SB Johnson, 1992a, 1992c; La Greca, 1988a). This variation is partly accounted for by the inconsistency in the manner in which adherence has been assessed (see **Section 1.1.2.1**). However, this inconsistency does not account fully for the variation in reported adherence. Studies using identical adherence measures have produced varied estimates of adherence, as have single

studies examining more than one group of patients. One of the reasons for the variation in adherence rates reported in different studies is the variation in the degree to which patients adhere to different regimens, and different regimen components.

Patient adherence is not a unidimensional construct or personality trait (Becker, 1985; Cox, Gonder-Frederick, Pohl, & Pennebaker, 1986; SB Johnson, 1991a; Orme & Binik, 1989). Health behaviours requiring adherence range from simple, one-off activities such as immunisations, to changes in lifestyle that include numerous components and are lifelong, such as IDDM self-management (Becker, 1985). Further, individual patients are likely to adhere to different regimen activities to different degrees.

For example, Schafer, Glasgow, McCaul and Dreher (1983) found that adolescents' adherence to seven components of the IDDM regimen, including diet, insulin injection, glucose testing, and exercise components, were not related. Similarly, SB Johnson and her colleagues (1986) reported that a factor analysis of adherence by children and adolescents with IDDM to thirteen diabetes management behaviours produced five independent factors. These authors point out that if adherence to diabetes treatment were a unitary construct, this analysis would have produced a single factor. In sum, patients' adherence to one aspect of a multicomponent regimen is not necessarily predictive of adherence to other aspects of the regimen (see also RE Glasgow, 1991; SB Johnson, 1991a, 1991b; Orme and Binik, 1989).

One of the more commonly reported findings in reviews of patient adherence is that adherence levels vary between regimen demands. This finding may be considered at

two levels. First, adherence levels are likely to vary between treatment regimens for different illnesses. Second, and particularly for complex treatments such as diabetes self-management, adherence levels are likely to vary between individual components of regimens.

Reviews of the literature suggest that there are at least five major characteristics of medical regimens that influence patients' adherence (Fotheringham & Sawyer, 1995). These are the regimen's complexity, duration, side-effects or discomfort, costs, and need for lifestyle changes or limitations (Becker & Maiman, 1975, 1980; Brand, Smith, & Brand, 1977; La Greca, 1990a; Rorer, Tucker, & Blake, 1988). The influence of these regimen characteristics on patient adherence are addressed individually in **Section 1.2.2**.

The Measurement of Adherence Across Regimen Demands.

Most studies of patient adherence have been small scale, and have focused on only a single condition (preventing cross-illness comparisons). Typically these studies have focused on a single treatment activity within the illness group under consideration, and have employed arbitrary definitions of adherence, often with minimal or no clinical relevance (Kravitz, et al. 1993). For several years reviewers have called for more methodologically sophisticated investigations into patient adherence, yet these calls largely have gone unheeded.

Further, the lack of a consistent methodology between studies inhibits the pooling of information from different trials. Definitions of adherence, even within similar

patient samples, typically have been divergent, as have the means employed to collect adherence information (Fotheringham & Sawyer, 1995).

The lack of consistency between studies is perhaps most visible in investigations into the adherence of child and adolescent patients. Research into the medical adherence of children and adolescents is complicated by the triadic nature of the doctor-parent-child relationship. The management of childhood illnesses involves more complex relationships than the treatment of illness in adults (La Greca, 1988a, 1988b). Young children often lack the skills required to follow their regimen without the guidance and assistance of an adult. As a result, adherence to the young child's regimen depends on both the adherence of the adult and the adherence of the child (Litt & Cuskey, 1980). Further, as children grow older, they are expected to take greater responsibility for their illness management. Most studies have examined the adherence of parents, without addressing the adherence of the child. This approach is likely to be appropriate for young children, but is clearly inadequate for the study of adolescent adherence (Fotheringham & Sawyer, 1995; Tebbi, 1993; Tebbi, et al. 1986).

One of the primary reasons for the lack of a consistent methodology in adherence research has been the debate over which form of data gathering is most appropriate. The use of global measures to assess adherence to complex regimens such as IDDM self-management may not be adequate (Fotheringham, Couper, Taylor, & Sawyer, submitted; SB Johnson, 1984). Measures which assess adherence to specific components of complex regimens provide greater insight into the adherence behaviour of patients.

An approach that has been developed recently, and which has proved efficacious, is the combination of general and specific measures of adherence. When used in combination, these self-report measures overcome one of the principal limitations of previous self-reports - their lack of comparability between investigations. A general measure of adherence may be used across a diversity of patient populations, without limitation to specific treatment regimens. These measures provide broad assessments of adherence, using a standardised measure. The chief benefit of these measures is their facilitation of comparisons between groups. In contrast, and as a complement to the general measure, specific adherence measures can be developed for each patient population or treatment group. The specific measures provide detailed information about adherence to individual components of complex treatment programs. The combination of these two approaches greatly enhances the level of information obtained (DiMatteo, Hays, & Sherbourne, 1992; RD Hays & DiMatteo, 1987).

1.1.2.3 The Employment of Multiple Measures of Adherence.

An important development in the investigation of patient adherence to medical recommendations is the inclusion of multiple measures of adherence (Dunbar, 1983; Dunbar-Jacob, Dwyer, & Dunning, 1991; Eraker, Kirscht, & Becker, 1984; Fotheringham, et al. submitted; RE Glasgow & Osteen, 1992; Gritz, et al. 1989; RD Hays & DiMatteo, 1987; SB Johnson, 1991a, 1991b; La Greca, 1990b). There are several reasons why the use of multiple measures of adherence is important. First, as reviewed in **Section 1.1.2.2**, adherence to one aspect of a complex regimen is

typically independent of adherence to other aspects of the regimen. The use of multiple measures of adherence allows the examination of adherence to diverse activities involved in multifaceted regimens such as IDDM self-care (SB Johnson, 1991a).

As discussed in **Section 1.1.2.1**, each form of adherence measure has inherent limitations. The use of multiple forms of adherence measure in combination has benefits in that the information gathered by the different sources is supplementary, rather than duplicative (Dunbar, 1983; Dunbar-Jacob, et al. 1991; Fotheringham, et al. submitted; RD Hays & DiMatteo, 1987; La Greca, 1990b). For example, the use of self-reports and parent reports in addition to behavioural observations provides a multi-person perspective of adherence behaviour (Dunbar, 1983).

Eraker, et al. (1984) suggested that the accuracy of adherence reports, particularly self-reports, may be improved by making respondents aware that other forms of adherence assessments are being used to verify the information collected. Further, it has been suggested that the use of collateral reports in addition to self-reports may overcome one of the major problems associated with the use of self-reports: errors of memory (SB Johnson, 1991b).

RD Hays and DiMatteo (1987) recommended that more studies be conducted using multiple sources of adherence information. For example, studies employing self-reports can also include spouse reports or sibling reports without greatly increasing the difficulty or cost of collecting data. The inclusion of multiple sources of adherence

information will help to establish the validity of adherence reports from each source under various conditions (RD Hays & DiMatteo, 1987).

Consideration also should be given to which combination of measures is employed. Including more than one measure that duplicates information adds little to the assessment of adherence. The use of a combination of measures that provides supplementary information would be more beneficial. For example, the combination of an interview or self-report measure of adherence with some form of direct observation or electronic monitoring of behaviour. This combination allows for the collection of in-depth information from the perspective of the patient as well as providing an objective validation of adherence to one aspect of the regimen (Dunbar, 1983). Rand (1990) cautioned that the addition of an objective measure to a self-report might be reactive. At the time of Rand's review, the Permanent Products available for use by researchers were somewhat obtrusive - requiring a change in routine for the patient. Electronic monitors, such as the blood glucose sensors, are now available which are unobtrusive - their use is part of the normal self-care of chronically ill patients (CS Rand, personal communication, 18 June, 1997).

As in many other areas of behavioural assessment, the assessment of regimen adherence amongst children and adolescents is more complex than the assessment of adults. La Greca (1990b) contended that the first principle of child assessment is that it involves the perspective of multiple informants, that is, child self-reports are typically employed in conjunction with reports from parents, teachers, siblings or peers. La Greca further contended that in most areas of child assessment, multiple methods of assessment are desirable (La Greca, 1990b). These contentions are

particularly applicable to the assessment of regimen adherence amongst children. Bush, Iannotti and Davidson (1985) noted that most studies of children's use of medicine have obtained information from the mother or primary caretaker only. These authors reported finding that children also were a valuable source of information about their medicine use.

Parents' reports of their children's adherence are especially important when examining younger children. Older children and adolescents tend to act somewhat independently of their parents, but younger children are more often dependent on their parents for the performance of regimen activities. When the parent is the individual responsible for the administration of insulin or the observation of dietary restrictions, their report of adherence is of primary importance. For older children, where responsibility for regimen activities may be shared with the child, reports of adherence from both the parent and the child are essential. For older adolescents, who take responsibility for their regimen, parents' reports of adherence provide useful validations of the adolescents' self-reports.

1.1.2.4 The Use of Longitudinal Research Designs.

Another key issue in the assessment of patient adherence is the use of longitudinal research designs. Most studies examining patient adherence have been cross-sectional, examining the relationship between adherence levels and demographic characteristics of study participants (RE Glasgow, 1991; RE Glasgow & Anderson, 1995; SB Johnson, 1992c; Rapoff & Christophersen, 1982; Youngleson & Joubert,

1991). In recent years, a number of reviewers have called for more widespread use of longitudinal study designs to examine the relationship over time of adherence with a variety of factors (RE Glasgow, 1991; RE Glasgow & Anderson, 1995; SB Johnson, 1985, 1990, 1992c; Kobasa, 1985; Rapoff & Christophersen, 1982).

This should not imply that only longitudinal studies are informative, or that cross-sectional studies are of little benefit. Both approaches have benefits and limitations. The examination of patient adherence is best conducted using a variety of research designs under varying conditions (SB Johnson, 1985). As Rutter (1994) put it, "longitudinal studies are expensive, time-consuming, and need to be reserved for circumstances when their considerable research power can be used to maximum advantage and not wasted on exploratory investigative forays into new territories" (p 928).

One of the strengths of cross-sectional designs is that they are relatively inexpensive, when compared with longitudinal studies. Tracking groups of study participants for extended periods of time incurs considerable expense. Further, in planning longitudinal designs participant attrition rates must be considered, often necessitating oversampling when collecting initial samples to ensure that final samples are sufficiently large for the performance of meaningful analysis (HA Feldman & McKinlay, 1994). Participant attrition and resistance are likely to become increasingly problematic over the duration of a study, particularly for extended investigations where many assessments are planned (Farrington, 1991). Further, participant attrition can be particularly problematic when investigating adolescent study populations (e.g., Hansen, Collins, Malotte, Johnson, & Fielding, 1985; Irwin,

Millstein, & Ellen, 1993; Kosky, Sawyer, & Fotheringham, 1996; Snow, Tebes, & Arthur, 1992; AH Winefield, Tiggemann, Winefield, 1991).

Cross-sectional designs can be used to determine whether associations exist between adherence and other factors. Relationships which have been demonstrated in cross-sectional studies can then be more closely examined in longitudinal investigations. Relationships which demonstrate no association with adherence need not be explored in more expensive studies using longitudinal methods. Replication of association in repeated cross-sectional studies in different settings provides evidence that relationships between variables are genuine, rather than the result of unmeasured confounding variables (Rutter, 1994). This evidence should be treated as a prerequisite to the use of longitudinal research designs (Rutter, 1994). For example, SB Johnson and colleagues examined the relationship between regimen adherence and health status amongst children and adolescents with IDDM in a series of cross-sectional studies (Freund, Johnson, Silverstein, & Malone, 1991; SB Johnson, Freund, Silverstein, Hansen, & Malone, 1990; SB Johnson, et al. 1986; Spevack, Johnson, Riley, & Silverstein, 1991). Only after the association between these variables had been examined in different study populations was a longitudinal analysis of the relationship between IDDM regimen adherence and health performed (SB Johnson, et al. 1992).

Cross-sectional designs are limited, however, in that they can only determine correlational relationships. The direction of cause and effect cannot be established. Causal inferences can only be drawn from longitudinal studies (Rapoff & Christophersen, 1982). Longitudinal designs enable the researcher to determine the

time ordering of events. Causal effects can be demonstrated by showing that changes in one variable are followed by changes in another variable (Farrington, 1991; Rutter, 1994). For example, previous research has noted a correlation between family functioning and metabolic control in children with IDDM (e.g., Hanson, Henggeler, Harris, Burghen, & Moore, 1989; Marteau, Bloch, & Baum, 1987). This correlation is generally assumed to indicate that family functioning influences adherence, which in turn affects disease control. However, as illustrated by Baranowski & Nader (1985), it is equally possible that poor diabetes control leads to additional problems to be faced by the family, which in turn leads to poorer family functioning. Alternatively, some other variable may influence both metabolic control and family functioning. The use of a longitudinal study design would enable the researcher to determine the causal relations amongst these variables.

There are a number of advantages to using longitudinal data. For example, longitudinal data provides multiple assessment points over time; having multiple data points increases the reliability and decreases vulnerability to biases due to situational influences or reporting variations (S Epstein, 1983; Rutter, 1994). Further, unlike cross-sectional data, longitudinal data can provide information about cumulative phenomena and sequential patterns (Farrington, 1991; Rutter, 1994).

Longitudinal studies allow the testing of interventions designed, for instance, to improve patient adherence. These interventions are typically based upon knowledge drawn from previous cross-sectional studies. For example, Delamater (1993) reviewed 14 interventions designed to improve adherence to IDDM regimens amongst children and adolescents. These interventions were all based on an understanding,

drawn from previous cross-sectional investigations, of factors which influence adherence.

Cross-sectional studies are restricted to making comparisons between individuals, whereas longitudinal studies can be used to examine changes within individuals over time, as well as variation between individuals (Farrington, 1988, 1991; Kobasa, 1985; Robinson & Marsland, 1994; Rutter, 1988; Uncles, 1988). For example, longitudinal studies can examine the variation in adherence over time. Further, longitudinal studies may be used to examine the interaction between variables over time, in order to better understand the relationships amongst them. This may be particularly important in areas associated with the functioning and behaviour of children and adolescents. The behaviour of young people is not static; longitudinal studies allow the examination of the development over time of adolescents' regimen adherence in relation to the presence of other 'predicting' factors (Hanson, De Guire, Schinkel, Henggeler, & Burghen, 1992; SB Johnson, 1985).

The Variation of Patient Adherence Over Time.

Few studies have examined the variation of adherence over time. Most longitudinal studies of patient adherence have focused on the influence of psychosocial factors on adherence over time (e.g., Hauser, et al. 1990; Jacobson, et al. 1990; Kovacs, et al. 1990). Hauser, et al. (1990), in examining the long-term regimen adherence of adolescents with IDDM, noted that initial adherence assessment rates were significantly related to adherence over a prospective four-year period. However, the size of the association between initial adherence and long-term adherence suggested

that fluctuation in adherence occurred. This possibility was not explored by the authors (La Greca, 1990a).

One of the few studies to examine the variation of adherence over time was conducted by Youngleson and Joubert (1991). These authors examined the adherence of tuberculosis patients to their treatment, using both a cross-sectional and a longitudinal research design. The results of this study suggested that the cross-sectional assessment of adherence produced overestimates of adherence, and that adherence levels varied over time. This finding has not been tested in subsequent investigations.

The longitudinal assessment of adherence to IDDM self-care regimens, and more specifically to blood glucose monitoring, is greatly facilitated by the development in recent years of blood glucose sensors with electronic memory capacities (see **Section 1.1.2.1**). These products objectively record blood glucose monitoring behaviour, and their records can be downloaded, with minimal intrusion or impact upon the participant. In addition, the ongoing use of this data is less vulnerable to response bias resulting from practice effects or resistance to the ongoing study. Further, as noted by Farrington (1991) and Rutter (1994), longitudinal data does not have to be collected prospectively. With the large memories built into commercially available blood glucose sensors, downloaded records of BGM can provide an accurate assessment of monitoring behaviour extending back over a number of weeks or months.

The utilisation of blood glucose sensors in the published literature is increasing (BJ Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Brodows, 1992; Gonder-

Frederick, Julian, Cox, Clarke, & Carter, 1988; Hoskins, Alford, Handelsman, Yue, & Turtle, 1988; NB Johnson, Kronz, Fineberg, & Golden, 1992; Landon, Langer, Gabbe, Schick, & Brustman, 1992; N Langer & O Langer, 1994; O Langer, et al. 1994; Lustman, et al. 1995; Meyerhoff, Bischof, & Pfeiffer, 1994; Parfitt, Clark, Turner, & Hartog, 1992, 1993; Rosenn, Miodovnik, Holcberg, Khoury, & Siddiqi, 1995; Tate, Clements, & Walters, 1992; Wolfsdorf, Laffel, Pasquarello, Vernon, & Herskowitz, 1991; Wysocki, Hough, et al. 1992). However, these studies have not used this information to assess participants' variation in BGM adherence over time. For example, Wysocki, Hough, et al. (1992) examined the BGM adherence over 28 days of forty-seven children and adolescents with IDDM. The mean number of blood glucose tests performed over the 28 day period was reported, but variation over time, or within-subject variation, was not reported.

One study which did report variations in adherence to BGM over time was conducted by Wysocki and colleagues (1991). In this study, the authors examined the adherence to blood glucose monitoring of a group of 30 adolescents with IDDM over a period of 16 weeks. This study assessed the impact of an intervention designed to improve adherence to BGM, using the blood glucose sensors with memory capabilities as a tool in the intervention. This study did report the variation of adherence to BGM over time, however this reporting was in relation to the intervention being performed at the time. Data relating to the variation in BGM adherence prior to the intervention, or after the intervention was completed, were not reported.

Perhaps the only study to have reported on the variation in adherence over time without the influence of an intervention was conducted by Cramer and colleagues

(1990). These authors examined the variation over time of adherence to pill-taking recommendations amongst a sample of 20 adults prescribed an antiepileptic medication. In this study, sharp declines in adherence between clinic visits were observed, with increased adherence observed in the days immediately before and after outpatient clinic attendance.

Clearly, the use of this technology offers the opportunity to objectively assess the variation in adherence over time of an important aspect of adherence to IDDM self-care regimens.

1.1.2.5 The Relationship Between Patient Adherence and Health Status.

It often has been assumed in the patient adherence literature that patients' adherence is associated with their health status, that is, that high levels of adherence are associated with good health and that low levels of adherence are associated with poor health. However, studies which have examined this relationship have produced inconsistent results (e.g., BJ Anderson, Auslander, Jung, Miller & Santiago, 1990; Auslander, Anderson, Bubb, Jung, & Santiago, 1990; Bond, Aiken, & Somerville, 1992; Brownlee-Duffeck, et al. 1987; Freund, et al. 1991; RE Glasgow, McCaul, & Schafer, 1987; Gonder-Frederick, et al. 1988; Hanson, et al. 1996; Hanson, Henggeler, & Burghen, 1987a, 1987b, 1987c; Hanson, Henggeler, et al. 1992; SB Johnson, Freund, et al. 1990; SB Johnson, Kelly, et al. 1992; SB Johnson, et al. 1986; RM Kaplan, Chadwick, & Schimmel, 1985; Kovacs, Goldston, Obrosky, & Iyengar, 1992; La Greca, Swales, Klemp, Madigan, & Skyler, 1995; Miller-Johnson, et al. 1994;

Schafer, et al. 1983; Schafer, McCaul, & Glasgow, 1986; Spevack, et al. 1991; Weist, Finney, Barnard, Davis, & Ollendick, 1993; DP Wilson & Endres, 1986; Wing, et al. 1985; Wysocki, Hough, Ward, Allen, & Murgai, 1992).

It has been suggested that much of this inconsistency is due to variations in the methods employed by researchers to assess adherence (Freund, et al. 1991; Hanson, et al. 1996; SB Johnson, 1990). While some of the inconsistency may be attributed to methodological variations in study design and particularly variations in the adherence measures employed, this variation does not appear to provide a complete explanation for the incongruity of adherence-health relationships reported in different studies.

For example, the explanation of this inconsistency is complicated by the confounded measurements employed in some studies. Research progress has been retarded by some investigations in which the measurement of adherence and health status has been confounded (Dahlquist, 1990; Eraker, et al. 1984; SB Johnson, 1985, 1991a). Further, some studies have employed health status as an assessment of adherence (e.g., Clarke, Snyder, & Nowacek, 1985; Herskowitz, Wertlieb, & Watt, 1987).

In short, the relationship between patients' adherence and their health status has been the source of some confusion in the published literature (SB Johnson, 1991a, 1993). This section reviews the available literature examining this relationship. First, studies which have inferred a relationship between health and adherence without any empirical testing are reviewed. Second, studies which have shown a significant relationship between these variables are discussed, followed by a review of studies

which have failed to establish this link. Finally, methodological considerations important to the consolidation of research of this relationship are considered.

Studies Which Have Inferred a Relationship Between Patient Adherence and Health Status.

A large proportion of studies investigating patient adherence have implied that adherence is closely, and causally, related to patients' health status (e.g., La Greca, Auslander, et al. 1995). However, the proportion of adherence studies which have actually examined this presumed link is small. SB Johnson's (1984) review of the literature examining correlates of health in childhood insulin-dependent diabetes mellitus (IDDM) reported that few studies had directly assessed the relationship between adherence and diabetic control. Similarly, Spevack and colleagues (1991) noted that few of the studies examining adherence to diabetes management regimens have documented the association of adherence to this regimen with the metabolic control of patients with IDDM. SB Johnson (1992b) noted that the number of studies documenting the prevalence of poor adherence to IDDM self-care regimens outweighs the number of studies which explore the relationship between adherence to these regimens and the health outcomes of patients.

A number of studies have reported collecting information about the adherence of young people with insulin dependent diabetes, as well as about their health status (i.e., metabolic control), but have not reported whether or not a (clinically or statistically) significant relationship existed between these variables (e.g., Bobrow, AvRuskin & Siller, 1985; Ingersoll, Orr, Herrold & Golden, 1986; Jacobson, et al. 1987;

SB Johnson, Silverstein, Rosenbloom, Carter & Cunningham, 1986; Schlenk & Hart, 1984).

Other authors have reported collecting information about study participants' adherence, but have only reported its association with illness control indirectly. For example, La Greca, Swales, et al. (1995) used a self-care inventory and a measure of blood glucose monitoring to assess the adherence of adolescents with IDDM. Metabolic control was assessed by HbA_{1c} assay. Although a direct association between adherence and metabolic control was not reported, adherence was introduced into analyses intended to explain gender differences in metabolic control. The inability of the adherence variables to explain the gender difference in HbA_{1c} suggests that these measures may not have been correlated, but this issue was not explored. Instead the authors stated that similar adherence measures had been associated with metabolic control in previous studies.

The assumption of a direct link between adherence and health status extends beyond studies addressing adherence directly. For example, the implications of this assumption can be seen in the work of Jessop and Stein (1985), who discussed the impact of chronic illnesses on the psychological and social functioning of children and their families. These authors suggested that the health behaviour, adherence, and health outcomes of these children were influenced by the children's functioning. This last suggestion implies a correspondence between the health behaviour and adherence of children with chronic illnesses, and their health outcomes. This implied link was not tested by the authors.

Another example of studies based on the assumed relationship between adherence and health are those studies which employ indices of health as methods of assessing adherence. For example, estimates of adherence to IDDM regimens often have been based upon glycosylated haemoglobin (HbA_{1c}) assays (Clarke, et al. 1985; SB Johnson, 1991a, 1991b). The use of HbA_{1c} as an estimate of adherence would only be appropriate if a one-to-one correspondence had been established between HbA_{1c} and adherence. This correspondence has not been found (RE Glasgow, et al. 1989; SB Johnson, 1990, 1991a, 1991b, 1992a, 1992b). Another method of estimating patient adherence that is likely to be dependent on the assumed association between adherence and health status is the health provider estimate. These estimates of adherence are frequently based upon, or confounded with, patients' health status (SB Johnson, 1991a, 1991b).

The published literature now contains many reports of interventions designed to improve adherence to medical recommendations (e.g., Agras, 1993; BJ Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989; Delamater, et al. 1990; LH Epstein, et al. 1981; Gilbert, et al. 1982; Janis, 1984b; RM Kaplan, et al. 1985; Méndez & Beléndez, 1997; Satin, La Greca, Zigo, & Skyler, 1989; Stratton, Wilson, Endres, & Goldstein, 1987; Wysocki, Green, & Huxtable, 1989, 1991; Wysocki, White, Bubb, Harris, & Greco, 1995). The import with which these interventions are credited is based upon the assumption that improvements in adherence will result in improvements in health status (e.g., Dahlquist, 1990). Delamater (1993) reviewed the literature of interventions intended to improve adherence to paediatric chronic illness regimens. This author recommended that adherence interventions be guided by an understanding of the importance of adherence to individual aspects of a regimen - the expense and

effort involved in intervention programs may be wasted if these interventions target behaviours which have little influence on the health outcomes of the patients.

Similarly, some research has been designed with the assumption that patients' satisfaction with their medical treatment influences their health status by impacting upon their medical adherence, that is, that dissatisfied patients adhere poorly to their treatment, and consequently experience poor health, while satisfied patients adhere closely to their treatment and as a result experience good health (e.g., SH Kaplan, Greenfield, & Ware, 1989). The assumption of the mediating link between satisfaction with medical services and health status exacerbates the methodological weakness of assuming a causal relationship between adherence and health.

Studies Which Have Shown a Relationship Between Patient Adherence and Health Status.

A number of studies have reported significant relationships between the adherence and health status of patients. This section briefly reviews studies which have reported significant relationships between these factors. The focus of this review is directed toward studies examining children and adolescents with insulin dependent diabetes.

A series of studies by Hanson and colleagues have examined the association between metabolic control and adherence in adolescents with insulin dependent diabetes (e.g., Hanson, Cigrang, et al. 1989; Hanson, De Guire, Schinkel, & Kolterman, 1995; Hanson, Henggeler & Burghen, 1987a, 1987b). In these studies, significant relationships were observed between adherence, assessed with a semistructured

interview addressing dietary behaviours, insulin adjustment, glucose testing, and hypoglycaemia preparedness, and metabolic control, assessed using HbA_{1c} assays.

SB Johnson and colleagues have reported on a number of studies which have examined the association between adherence and health status of children with IDDM (Freund, et al. 1991; SB Johnson, 1984, 1985, 1990, 1991a, 1991b, 1992a, 1992b, 1994, 1995; SB Johnson, Freund, et al. 1990; SB Johnson, et al. 1992; SB Johnson, et al. 1982; SB Johnson, et al. 1986; SB Johnson, Tomer, Cunningham, & Henretta, 1990; Spevack, et al. 1987; Spevack, et al. 1991). These studies examined adherence using a 24-hour recall interview completed by the participating children and their mothers, developed by SB Johnson and colleagues (1986). Haemoglobin A_{1c} assays were used as indices of metabolic control. In two of these studies, reported linkages between adherence and metabolic control were significant, but weak.

Significant relationships between adherence and health status have been shown in several other studies. The regimen adherence of adolescents with IDDM has been related to metabolic control in studies by Bond, Aiken and Somerville (1992), Brownlee-Duffeck, et al. (1987), RM Kaplan and colleagues (1985), La Greca (1982), and Schafer, and colleagues (1983). Studies involving children with IDDM by BJ Anderson and colleagues (1990), Auslander and colleagues (1990), and Kovacs and colleagues (1992) have detected significant associations between the children's adherence and their metabolic control.

Studies Which Have Shown No Relationship Between Patient Adherence and Health Status.

A number of studies have reported finding no significant relationships between the adherence and health status of patients, or very limited relationships.

One of the most prolific groups of investigators examining adherence and health status amongst children and adolescents with insulin dependent diabetes is that of SB Johnson and colleagues (Freund, et al. 1991; SB Johnson, 1984, 1985, 1990, 1991a, 1991b, 1992a, 1992b, 1994, 1995; SB Johnson, Freund, et al. 1990; SB Johnson, et al. 1992; SB Johnson, et al. 1982; SB Johnson, et al. 1986; SB Johnson, Tomer, et al. 1990; Spevack, et al. 1987; Spevack, et al. 1991). SB Johnson and coworkers have completed a number of studies which have examined the relationship between adherence and health status in children and adolescents with IDDM. These studies have included the development of a 24-hour recall interview assessing adherence to 13 dimensions of the IDDM self-care regimen. However, the association between this measure of adherence to aspects of IDDM treatment and the metabolic control (HbA_{1c}) of participants in these studies, has been inconsistent. Two studies were described in the previous section which found significant relationships between these measures of adherence and the measure of metabolic control. However, other studies by these authors have not detected associations between adherence and metabolic control in IDDM. SB Johnson recently published a review of psychosocial aspects of Insulin Dependent Diabetes Mellitus in childhood (SB Johnson, 1995). This review suggested that the majority of studies which have examined the relationship between adherence and health status amongst young people

with IDDM had either reported no relationship between adherence and metabolic control, or a weak association.

Another group to report a series of studies examining the adherence-health status relationship amongst children and adolescents with insulin dependent diabetes is that of Hanson and colleagues. These authors have developed a semistructured adherence interview, which assesses adherence to dietary recommendations, insulin adjustment, glucose testing, and hypoglycaemia preparedness. As in many other studies of IDDM, health status is assessed using HbA_{1c} assays. In the previous section, four studies by this group were described which found significant relationships between measures of adherence and metabolic control. However, three other studies by the same group of researchers were unable to detect significant relationships between adherence and health status amongst children and adolescents with IDDM (Hanson, et al. 1987c; Hanson, De Guire, Schinkel, & Henggeler, 1992; Hanson, et al. 1996). The authors suggest that the inconsistency between the findings of these three studies and the four studies identified in the previous section may be due to the nature of the adherence measures. The more specific measures used here may relate to glycaemic control over the previous few days, while the broader measures may be better associated with glycaemic control over longer periods. This issue is worthy of further investigation.

Other studies of children and adolescents with IDDM have also been unable to relate adherence to metabolic control (e.g., Gonder-Frederick, et al. 1988; Miller-Johnson, et al. 1994; Weist, et al. 1993; DP Wilson & Endres, 1986; Wing, et al. 1985; Wysocki, Hough, et al. 1992). Two studies by RE Glasgow, Schafer and their colleagues examined the adherence and health of adolescents and adults with insulin dependent

diabetes (RE Glasgow, et al. 1987; Schafer, et al. 1986). Despite the complex assessment methods employed and the rigorous analyses used in these studies, the expected relationship between adherence and glycaemic control was not detected. One of the few criticisms that can be made of the design of this study is that the measures of adherence and glycaemic control were not temporally congruent - the time frame addressed by the adherence measures was not the same as that addressed by the measure of glycaemic control. However, this criticism may be directed at almost all published investigations of adherence and health status. The move toward temporally congruent measures is a recent one. This development offers the opportunity to improve our understanding of the relationship between adherence and health outcomes amongst groups of chronically ill patients such as these.

Studies in Which the Measurement of Patient Adherence and Health Status were Confounded.

In many studies that have reported on the relationship between adherence and health status, the measurement of adherence and of health status has been confounded. That is, the methods used to assess adherence in some studies are not measures of actual behaviour, but are indices of health outcome. For example, some studies have reported the use of biological assays as measures of adherence (e.g., Allen, Tennen, McGrade, Affleck, & Ratzan, 1983; Hill & Holmbeck, 1986). SB Johnson (1991a) refers to this concept as "Construct Independence," that is, the measures of different constructs, in this case adherence and health status, should be independent. Put simply, the relationship between two variables cannot be determined if a single measure is used to assess both variables. The use of HbA_{1c} assays as a measure of

IDDM patients' adherence is an example of construct dependence: the use of this assay to assess adherence prevents the relationship between adherence and metabolic control from being examined (SB Johnson, 1985).

Examples of investigations which are limited by a lack of construct independence in their assessments of adherence and health status are readily observed. For example, a study of 34 children and adolescents with IDDM and their parents used diabetes clinic staff ratings to assess adherence (Allen, et al. 1983). These ratings were moderately correlated with observed metabolic control (HbA_{1c}), but not with parents' estimates of metabolic control. It should be noted that the association between health workers' estimates of adherence and the observed health of patients may be the artifice of the assessment method - these adherence estimates may be based in part on the patients' level of health (SB Johnson, 1991a; La Greca & Schuman, 1995).

For example, MR Sanders, Gravestock, Wanstall and Dunne (1991) examined the adherence of children with cystic fibrosis. Parent ratings of adherence problems and physician ratings of adherence were employed, as well as physician ratings of health status. Not surprisingly, physician ratings of adherence and health status were correlated, although the physician estimates of health status were not associated with parent reports of adherence. While this result was reported as an association between adherence and health status, this result is better interpreted as evidence that health providers' estimates of adherence are influenced by their perceptions of patients' health status. If the parents' reports of adherence had also been associated with the physicians' health estimates, this may have suggested that these measures were valid, but the lack of association found suggests a confounded assessment of adherence and

health. Other studies have used similarly confounded measures of adherence and health (e.g., Cockburn, Gibberd, et al. 1987; Gaut & Kieckhefer, 1988; Herskowitz, et al. 1987; Kurtin, Landgraf & Abetz, 1994). Health provider ratings of adherence typically confound adherence with health status (Caron and Roth, 1968; Charney, et al. 1967; Davis, 1968; SB Johnson 1991a).

The interpretation of medical indices as measures of adherence stems from the assumption of a direct correspondence between adherence and health outcomes (SB Johnson, 1991a). This assumption has not been justified by the findings of research to date. There are several problems with this use of medical indices as adherence measures. First, the results of assays such as HbA_{1c} levels for IDDM patients are insensitive to fluctuations over the short-term in adherence levels (Dahlquist, 1990; La Greca, 1988a). Second, the assumption that patients' adherence to a regimen determines their health status ignores that possibility that the regimen may be inappropriate. For example, patients' prescribed inappropriate dosages of a medication may adhere closely to their prescription and experience poor health as a result of the unsuitable prescription. Third, individual patients' physiological responses to treatments may vary. As such, two patients prescribed the same regimen and adhering equally to their regimens, may experience differing levels of health (Dahlquist, 1990; La Greca, 1988a).

Further, because many studies have not carefully assessed the relationship between adherence and health status, or have simply reported correlational statistics, the direction of the relationship between adherence and health status is unclear. Although it often is assumed that good health is the consequence of a high level of adherence, it

also is possible that high levels of adherence are encouraged by the patients' experience of good health - or that poor health causes patients' to become discouraged and abandon their treatment (RE Glasgow, 1991; SB Johnson, 1984).

Appropriate Methodologies for the Examination of the Relationship Between Patient Adherence and Health Status.

The merits of various types of adherence measure were addressed in **Section 1.1.2.1**. However, there are specific considerations that should be acknowledged in the examination of the relationship between adherence and health status. Previous studies have often been limited by their failure to consider these issues.

First, the measures of adherence and health status employed should be temporally congruent (SB Johnson, 1990, 1992b). To properly assess the relationship between these factors, it is important that the measures used examine the same time frame. For example, the commonly accepted measure of metabolic control in IDDM is glycosylated haemoglobin (HbA_{1c}), a measure of blood glucose levels during the previous 4-6 weeks (Diabetes Control and Complications Trial Research Group, 1995; Nathan, Singer, Hurxthal, & Goodson, 1984; Olson, 1988). To assess the relationship between this measure and adherence, the adherence measure should address the past 4-6 weeks, and be administered at the time of the HbA_{1c} assay. The comparison of HbA_{1c} assays with adherence measures addressing only the past 1-3 days would not be expected to reveal the true relationship between adherence and metabolic control (Freund, et al. 1991; Hanson, et al. 1996; SB Johnson, 1990, 1992b).

Second, the use of multiple measures of adherence and health status would provide additional information about the nature of the link between adherence and health (see also **Section 1.1.2.3** for a discussion on the use of multiple measures). Some authors have noted that different regimen activities have varying associations with health status. For example, RE Glasgow and Anderson (1995) and SB Johnson (1990) noted that adherence to insulin injection regimens related poorly to health status because of the lack of variability in adherence to this aspect of IDDM treatment. That is, adherence to insulin administration recommendations tends to be complete or near complete; poor adherence to this aspect of IDDM management is rare (RE Glasgow & Anderson, 1995; SB Johnson, 1990). Further, Schmidt and colleagues (1992) found that dietary intake was weakly associated with metabolic control in adolescents with IDDM, but that adherence to other aspects of the regimen may be more closely linked with control (Schmidt, Klover, Arfken, Delamater, & Hobson, 1992).

The variation in associations between different regimen activities and health outcomes is associated with the variation in adherence to these different activities. **Section 1.1.2.2** addressed the issue of variations in adherence to different regimens and regimen activities.

1.1.3 Explanatory Models of Health Behaviour - Applicability to Patient Adherence.

Over the past three decades, various theoretical frameworks have been proposed to explain health behaviour. None of these theories can be considered comprehensive. In fact it may not be possible for a truly comprehensive model of all health behaviour

to develop in a form that can be applied feasibly in empirical research (GC Stone, 1979a). One form of health behaviour that has received increasing attention in the literature is patient adherence to medical recommendations. Research into patient adherence almost exclusively has been atheoretical (McKevitt, Jones, Lane, & Marion, 1990; Wolcott, Maida, Diamond, & Nissenson, 1986). As a result, the adherence literature generally is unintegrated, with little or no ability to explain or predict patient adherence (Dunbar-Jacob, et al. 1991; Fotheringham & Sawyer, 1995). This pattern is echoed in research into other forms of health behaviour.

In the late 1970s, reviewers described the general characteristics of health behaviour research as being oriented toward either psychological or sociological paradigms (Kirscht & Rosenstock, 1979; GC Stone, 1979b). Today a more multidisciplinary approach is appropriate as other disciplines and subdisciplines, such as nursing, health promotion and epidemiology, contribute to the wider understanding of health behaviour. A synopsis of multidisciplinary developments is particularly important as the need for multidisciplinary approaches to research and practice increasingly is recognised (Addleton, Tratnack, & Donat, 1991; George & Hancock, 1993; Hinde, 1992; Perry, Klepp, & Shultz, 1988; Suedfeld, 1982). This section provides a multidisciplinary perspective on health behaviour research, paying particular attention to research investigating patient adherence.

Clearly, a model or theory of adherence behaviour is needed for research to progress, and to integrate the various influences with which adherence behaviour has been associated (Godin & Shepard, 1990; Leventhal, Meyer, & Nerenz, 1980; Ried & Christensen, 1988). A more uniform approach to the investigation of patient

adherence potentially would increase the rate of progress made in understanding this form of health behaviour (Fotheringham & Sawyer, 1995). The employment of theoretically-sound research designs would facilitate this uniformity. The purpose of this section is not to advance a new theory; the preponderance of theories already available has led to their being used inconsistently or not at all. Put simply, there are too many theories from which to choose, and researchers can waste valuable time trying to determine the appropriate model from which to operate. This section will present four of the most useful and potentially useful theories of adherence and health behaviour.

The models that will be examined are (1) the Health Belief Model, (2) the Theory of Reasoned Action, (3) Protection Motivation Theory, and (4) the Six-Factor Model of Adherence. These models were chosen on the basis of their contributions to adherence research. Some of the models, such as the Health Belief Model and the Theory of Reasoned Action, have strongly influenced research into patient adherence across a range of disciplines. Other models, such as the Six Factor Model of Adherence, represent noteworthy improvements upon earlier formulations, and have been included for this reason. The structure of each model as well as its strengths and deficiencies will be reviewed, and examples of its use in research will be cited. The final part of this section will discuss the relative value of these models, and their potential importance to future developments in health behaviour research.

Many other models could have been included in this review, such as Bandura's Learning Theory, Self-Regulation Theory, the Trans-theoretical Model, Triandis' Theory of Social Behaviour, the Interaction Model of Client Health Behaviour, or the

Health Promotion Model (Bandura, 1986; Cox, 1982; Cox & Roghmann, 1984; Leventhal, et al. 1984; Pender 1987; Prochaska & DiClemente, 1983; Triandis, 1964, 1977). While these models have merit, the intention of this paper is to describe interdisciplinary influences, rather than focusing exclusively on the theories developed within one perspective, as other reviews have done (e.g. Cummings, Becker, & Maile, 1980; BS Wallston & KA Wallston, 1984).

1.1.3.1 The Health Belief Model.

The most influential model of health behaviour in the literature has been the Health Belief Model (HBM; Becker, 1974; Becker & Maiman, 1983; Rimer, 1990; Rosenstock, 1960, 1974; Rosenstock & Kirscht, 1974). The HBM takes a value-expectancy approach, which holds that behaviour is determined by beliefs, including an expectation of the value of the behaviour (Feather, 1959; Lewin, Dembo, Festinger, & Sears, 1944). The HBM suggests that people's beliefs about health consist of the dimensions "perceived susceptibility", "perceived severity", "perceived benefits", and "perceived barriers" (**Figure 1.1**).

Unfortunately, researchers from a range of disciplines have accepted the model without criticism, so refinement of the model has been minimal. One study attempted to increase the explanatory power of the HBM by expanding the model to include self-efficacy (Rosenstock, Strecher, & Becker, 1988). Self-efficacy can be described as one's confidence in one's ability to perform a required action (Bandura, 1977). This notion was not included in the original HBM because the focus of the model had been

on short term, one-shot actions, where self-efficacy was not considered an influence (Rosenstock, 1990).

Criticisms of the HBM centre on several key deficiencies. First, the relationship between the model's variables has not been clearly defined. Second, some determinants have not received sufficient empirical testing, such as "cue to action" or "intention to comply" as described by Becker and Maiman (1975). Third, there has been little standardisation of the measurement of psychosocial variables described in the model (Ried & Christensen, 1988; BS Wallston & KA Wallston, 1984). It may be questioned whether the HBM is a model at all; there are too many variables involved to be tested in a single study, and the relationships between the variables are unspecified, so the theory is impossible to falsify (de Groot, 1969; Shaw & Costanzo, 1970). Further, the HBM is a multiplicative model, though most studies testing the model have been conducted in a linear fashion (BS Wallston & KA Wallston, 1984).

A Children's Health Belief Model (CHBM), based upon the HBM, was proposed by Bush and Iannotti (1988). The CHBM places children's health beliefs and behaviours in a family and social context (Iannotti & Bush, 1993; Rapoff, 1996). In this model, children's health beliefs are derived from their primary caretaker's beliefs (usually the children's mothers). As children grow older, their health beliefs are posited to become more like those of their caretaker. This model is suggested to be especially applicable to health behaviours, but also to health beliefs (Bush & Iannotti, 1988). The CHBM is illustrated in **Figure 1.2**. At present the CHBM has received little empirical testing. One investigation of the CHBM examining medicine use of school

children has provided support for the model (Bush & Iannotti, 1988, 1990). Further empirical testing of this model is needed.

1.1.3.2 The Theory of Reasoned Action.

Fishbein and Ajzen's Theory of Reasoned Action (TRA) is a theory of behaviour developed from cognitive psychological traditions (Ajzen & Fishbein, 1980; M Fishbein, 1965, 1972, 1980; M Fishbein & Ajzen, 1975). According to this model, an individual's performance of a volitional health behaviour may be predicted from their intention to perform that behaviour (Egger, Spark, & Lawson, 1991). The individual's intention to perform a health behaviour is a function of their attitudes to that behaviour, and of the relevant social norms. These authors describe the individual's attitudes to the health behaviour as their beliefs in the consequence of that behaviour, weighed by the value of that consequence. In turn, the social norms are described as the expectations of the individual's significant others, modified by the individual's desire to comply with those expectations (**Figure 1.3**).

In contrast to the lack of structural relationships of the HBM variables, the formulation of the Theory of Reasoned Action is highly specific, both in the relationship between the elements of the model, and in the measurement of these elements (Kippax & Crawford, 1993; Mullen, Hershey, & Iverson, 1987; Ried & Christensen, 1988). While this specificity eases cross-study comparisons, it also means that new belief items must be generated when investigating new behaviours (Mullen, et al. 1987). The TRA, unlike other models of health behaviour, describes

health behaviour in purely rational or cognitive terms; there is no emotional component in this model. Personality and other psychosocial variables only influence behaviours and behavioural intentions indirectly by influencing the weighting of the model's components (M Fishbein, 1972; Mullen, et al. 1987; BS Wallston & KA Wallston, 1984). Further, the TRA does not take into account the barriers and supports to the individual in carrying out their behavioural intentions (BS Wallston & KA Wallston, 1984).

1.1.3.3 Protection Motivation Theory.

Protection Motivation theory (PM; Maddux & Rogers, 1983; Prentice-Dunn & Rogers, 1986; Rogers, 1975, 1983) was originally developed to explain the use of fear appeals used in health promotion messages, and was later expanded to encompass all health-related behaviour. According to this model, fear appeals consist of three components: (*i*) the degree of noxiousness of a threatened event; (*ii*) the probability of the event; and (*iii*) the efficacy of a protective response (Rogers, 1975).

The PM model posits that information of various sources, both environmental and intrapersonal, initiate two cognitive processes: threat appraisal and coping appraisal, which appraise maladaptive and adaptive responses respectively. The threat appraisal consists of intrinsic and extrinsic rewards to the maladaptive response, minus the severity of the threat and the probability of being exposed to it. Coping appraisal consists of an appraisal of one's ability to cope with or avert a health threat, mediated by the costs of the adaptive response. The amount of protection motivation elicited by

an information source is described as a function of the threat and coping appraisals. It is suggested that protection motivation is best measured in terms of behavioural intentions, as described in the Theory of Reasoned Action (Rogers, 1983). A recent revision of the PM model included the sequential ordering of the appraisal components, and the social context of the health threat (Tanner, Hunt, & Eppright, 1991; **Figure 1.4**). The introduction of sequential ordering is consistent with the finding that the processing of appraisal information and the appraisal outcome are sequentially ordered (Scherer, 1984, 1988).

Unlike the Theory of Reasoned Action, Protection Motivation theory does not assume that the individual acts in a purely rational manner. This model adds an emotional component to the constructs of the TRA. A limitation of the PM model is its focus on fear appeals and other health promotion messages. As such, the application of this model is restricted to intervention studies, where patients' health behaviour is examined before and after a health education campaign. The PM model is less applicable to long-term maintenance of health behaviour in the absence of intervention.

1.1.3.4 The Six-Factor Model of Adherence.

The Six-Factor Model of Adherence (SFMA) has been developed by researchers at the University of California to explain adherence behaviour (DiMatteo & DiNicola, 1982; DiMatteo, et al. 1992; DiMatteo, Sherbourne, Hays, et al. 1993; Gritz, et al. 1989; Sherbourne, et al. 1992). In this model, six factors provide a heuristic framework for

understanding adherence behaviour. The factors involved are: (1) effective communication of information; (2) rapport with the health professional; (3) client's beliefs and attitudes; (4) client's social climate and norms; (5) behavioural intentions; and (6) supports for and barriers to adherence. The first two factors are prerequisites for the last four factors, which are sequentially ordered (Gritz, et al. 1989; **Figure 1.5**).

According to the SFMA, patients' understanding of what is expected of them is an essential requirement for their adherence to the treatment. Given this understanding, the model holds that the doctor-patient relationship is a primary ingredient in maintaining patient adherence. Central to this factor is the notion of rapport, "a relationship of mutual trust, caring, understanding" (DiMatteo & DiNicola, 1982, p 82). This suggests that the interaction between physician and patient is not under the sole control of the physician, but is characterised by mutuality. If the characteristics required by the first two factors are met, adherence is facilitated. However, the SFMA postulates further influences on the likelihood of adherence. The third factor relates to the beliefs and attitudes of the patient, which must be consistent with regimen demands. This factor bears a close resemblance to the Health Belief Model described in **Section 1.1.3.1**. A closely related factor is the social climate surrounding the patient, including the attitudes and values of the patient's family and friends and the wider cultural norms. Social expectations that support adherence have a facilitative effect on the adherence of the individual patient (Gritz, et al. 1989). Next, the patient's adherence to his or her regimen is dependent on his or her behavioural intentions, which are shaped by the above factors. This model posits that these intentions are strengthened by the patient making an overt commitment to adhere to

the treatment (Gritz, et al. 1989; cf. Levy, Yamashita, & Pow, 1979). Even if all of the above factors are supportive of the patient's adherence the expected behaviour may not occur. The final component in the SFMA accounts for barriers that may prevent adherent behaviour, including physical factors, habituation, locus of control, and coping (Gritz, et al. 1989).

It can be seen that the Six-Factor Model of Adherence bears a close resemblance to the Theory of Reasoned Action; both models include social norms and expectations along with behavioural intention. Unlike the TRA, however, the SFMA takes as its final factor the barriers to adherence which may prevent an individual's intention from being enacted. As previously mentioned, the lack of attention given to this factor has been a criticism of the TRA. In light of this, the Six-Factor Model may be viewed as an improvement upon Fishbein's theory; by including factors found lacking in the TRA.

Use of the Six-Factor Model of Adherence in the literature has been limited. More studies using the SFMA are needed to determine the generalisability of this model, for example its value with younger patients.

1.1.3.5 Summary: Models of Health Behaviour.

The purpose of this section has been to describe a selection of theories of health behaviour relevant to the investigation of patient adherence. This final section

highlights key considerations in interpreting the models presented here, and makes recommendations regarding their importance to further research.

Two primary cautions should be considered in understanding the models presented in this section. The first applies to the Health Belief Model, the Theory of Reasoned Action, and the Protection Motivation model. These models all relate to the psychosocial characteristics of the patient, an emphasis upon which tends to limit the explanatory power of the models insofar as these characteristics explain health behaviour (Janz & Becker, 1984; Rosenstock, 1990). That is, factors external to the patient, such as the social expectations of others and the quality of the doctor-patient relationship, appear to influence health behaviour (Fotheringham & Sawyer, 1995). To the extent that these factors are predictive of health behaviour, models which exclude them limit their ability to account for health behaviour. The second consideration is related to the first: by focusing on aspects of the individual these models may facilitate victim-blaming (Rosenstock, 1990). The need for an integration of research findings and a more systematic approach to health behaviour research has been noted elsewhere (Ried & Christensen, 1988). This review of models of health behaviour has adopted a multidisciplinary approach, in recognition of the various research traditions that have contributed to the investigation of adherence behaviour.

Of the models presented in this section, the Health Belief Model has thus far been the most influential on adherence research. However, refinement of the HBM has been minimal and some aspects of the model have rarely been applied in empirical evaluations. The Theory of Reasoned Action, in contrast, has been tested in a more specific manner, a process made easier by the more detailed formulation of this

model. The Six-Factor model is closely related to the Theory of Reasoned Action, but with the additional consideration of supports and barriers to health behaviour, a factor omitted in the TRA. Protection Motivation theory has developed from a perspective similar to that of the HBM, but has focused on the use of fear arousal in health-promoting messages.

The value of the HBM and TRA may be diminishing in light of the more recent models presented in this section. The later models build on the foundations of these early formulations, with the added perspectives of the various disciplines from which they have emerged. This has enabled the more recent theories to broaden their scope, and therefore better account for health behaviour. An emphasis of future investigations should be the evaluation of these largely untested but more theoretically advanced formulations. Perhaps the most promising of this new generation of models is the Six-Factor Model of Adherence. However, this model remains largely untested, particularly with younger patients. Future investigations implementing this model should include patients of various backgrounds, experiencing both acute and chronic conditions, selected from a variety of health care settings and communities. This represents a potentially valuable line of future investigation.

1.2 Factors Influencing Patient Adherence to Medical Recommendations.

Studies investigating patient adherence have reported widely varying estimates of the number of patients who fail to adhere to their treatment regimens (LH Epstein & Cluss, 1982; Jones, Jones, & Katz, 1987). This variation is due in part to the broad

range of regimen demands that are involved in treatment. Some treatment activities are more easily, and more frequently, adhered to than others. As a result, a patient may be fully adherent to some aspects of a medical regimen, while being partially or completely nonadherent to other aspects of the same regimen (RM Kaplan & Simon, 1990; Kasl, 1983; Orme & Binik, 1989). For example, patients whose regimen involves dietary restrictions and regular exercise may follow their recommended diet closely, but fail to perform their recommended exercise. In light of this, a study may classify the same patient as adherent or nonadherent depending upon which aspect of the regimen it focuses. This is an important issue as most research investigating patient adherence has focused on only one element of patients' treatment behaviour, that of patients' adherence with prescribed medications (Caron, 1985; DiMatteo, Sherbourne, et al. 1993; Kravitz, et al. 1993).

Several methodological limitations have made it difficult to interpret the results of research into patient adherence. Most studies have been cross-sectional, examining only a single treatment condition with only one measure of patient adherence (Caron, 1985; DiMatteo, Sherbourne, et al. 1993; Kravitz, et al. 1993). The use of longitudinal study designs would assist in the examination of these relationships. Most studies have focused on patient variables such as regimen knowledge, health beliefs and motivation for health, while physician variables have largely been ignored. Studies employing measures of more than one such variable have been rare, and represent an important step toward a scientific understanding of the relationship between adherence behaviour and its antecedents (DiMatteo, Hays, et al. 1993).

This section reviews current knowledge in three key areas of research examining factors which influence patient adherence to medical regimens. These areas are: (1) characteristics of the patient; (2) characteristics of the treatment; and (3) the nature of the doctor-patient relationship. In each area the quality of the research underpinning current knowledge will be considered. The final part of this section suggests directions for the further development of adherence research.

1.2.1 The Influence of Patient Characteristics on Patient Adherence.

The major patient characteristics which influence adherence are the patients' age and knowledge of their treatment, their motivation to achieve good health, the value they assign to health, their perceptions of their ability to control their level of health, and their experience of social support (Abella & Heslin, 1984; Becker, 1985; Becker & Maiman, 1975; Christensen, et al. 1992; Creer & Burns, 1979; Dunbar, 1990; Dunbar & Agras, 1980; SB Johnson, et al. 1982; La Greca, 1988a; Lewis, Morisky, & Flynn, 1978; Litt & Cuskey, 1980; Schlenk & Hart, 1984; KA Wallston & BS Wallston, 1982).

1.2.1.1 Patients' Age.

Two principal findings have been reported which describe the relationship between patients' age and their level of adherence. First, several studies have reported that the level of adherence of children and adolescents is lower than that of adults (Blackwell, 1973; RB Stewart & Caranasos, 1989; Weintraub, 1990). A possible reason for this is

that the management of childhood illness involves more complex relationships than the treatment of adults. Young children often lack the skills required to follow their regimen without the guidance and assistance of an adult. As a result, adherence to the young child's regimen depends on both the adherence of the adult and the adherence of the child (Creer & Burns, 1979; Korsch, Fine, & Negrete, 1978; Litt & Cuskey, 1980).

Second, in many studies adolescents have been found to be less adherent than younger children (Dolgin, Katz, Doctors, & Siegel, 1986; Hanson, et al. 1987a; SB Johnson, 1984; SB Johnson, et al. 1986; La Greca, 1982; Litt & Cuskey, 1980; Litt, Cuskey, & Rudd, 1980; Weinberger, 1987). For example, AM Glasgow and colleagues (1991) found that adolescents with IDDM missed insulin injections and fabricated blood glucose results more often than younger children. Garrison and coworkers reported that adherence by adolescents to dietary, glucose monitoring, and insulin injection recommendations for IDDM was poorer than adherence by younger children (Garrison, Biggs, & Morris, 1988).

As children enter and progress through adolescence, they struggle for greater autonomy (Lidz, 1981). The authority of their parents is increasingly challenged, and the importance of negotiation between parents and children increases. In light of this, the nonadherence of adolescents may reflect rebellion against the regimens' control over their lives (Dolgin, et al. 1986; Dunbar, 1983; SB Johnson, 1984; La Greca, 1982, 1990a; Litt & Cuskey, 1980; Litt, Cuskey, & Rudd, 1980; Weinberger, 1987; Zeltzer, 1980). Further, in the families of adolescent patients there is often confusion

over the allocation of responsibility for medicine-taking (Tebbi, 1993; Tebbi, et al. 1986).

Hanson and colleagues (1987a) suggested that as adolescents mature and are given more responsibility for their illness management, they may test the extent to which they can deviate from the regimen without serious consequences to their health. These authors hypothesise that older adolescents may be showing increasing rebellion against regimen demands, or may simply be less adherent because they are spending more time with peers and do not want to be seen to be different (Hanson, et al. 1987a).

1.2.1.2 Understanding of the Illness.

Patient's possession of a sound knowledge of their regimen is not consistently associated with good adherence. Patients' prior experience of a treatment regimen may enhance their adherence, by virtue of their understanding of the behaviour required. However, it appears that while patients must have a reasonable knowledge of their regimen, the possession of this knowledge alone does not guarantee their adherence (Becker, 1985; Dunbar & Agras, 1980; Stuart, 1982). Knowledge of the regimen may be thought of as a necessary, but not sufficient, antecedent to adherence. This interpretation is consistent with the long-recognised finding that knowledge, attitudes and behaviour are not causally linked (e.g., Bettinghaus, 1986; LaPiere, 1934; Raven & Rubin, 1983). That is, a patient may have a sound knowledge of their regimen, but this knowledge does not guarantee that the patient will hold a favourable

attitude toward the regimen, or that the knowledge will be translated into action. However, it is clear that patients are unlikely to adhere to regimens about which their knowledge is limited or inaccurate.

1.2.1.3 Health Motivation.

A number of empirical investigations have found that patients' level of adherence is positively associated with their motivation to achieve or maintain good health (Becker & Maiman, 1975; Creer & Burns, 1979; Dishman, 1982; Dishman & Gettman, 1980; Dishman & Ickes, 1981). For example, Creer and Burns (1979) reported that many paediatric asthma patients were nonadherent to their regimens as a result of basic indifference to their level of health. Dishman and his colleagues have found that long-term regimen adherence is related to motivational factors (Dishman, 1982; Dishman & Gettman, 1980; Dishman & Ickes, 1981). Patient adherence also may be motivated by factors other than health. For example, adolescents in particular may be motivated to adhere to their treatment by their desires to be socially and physically active (R Anderson, 1983; IM Friedman & Litt, 1986; Gochman, 1982; Research Unit in Health and Behavioural Change, 1989). However, such motivations also may conflict with treatment adherence. For example, adolescents may wish to eat popular foods that violate the restrictions of their regimen (Caplan, Robinson, French, Caldwell, & Shinn, 1976; Maslow, 1968).

1.2.1.4 Health Locus of Control.

The basis of Locus of Control theory is that individuals differ in generalised expectancies regarding the control of events. People with internal control orientations tend to expect themselves to be in control of situations, whereas people with external control orientations expect not to have such control (Lefcourt, 1981, 1983; Rotter, 1966).

Nowicki and Duke (1983) reviewed the relationship between health behaviour and locus of control and found that there was a close relationship "between locus of control and how people respond to and take part in their treatment programs" (p 32). Specifically, people with internal loci of control adhere more closely to their treatment regimens. This concept has been refined with the development of the Health Locus of Control (HLC) construct: one's locus of control expectations regarding one's health. The relationship between HLC and adherence behaviour has been investigated, including the development of Health Locus of Control measures for adults (O'Looney & Barrett, 1983; BS Wallston, KA Wallston, Kaplan, & Maides, 1976; KA Wallston & BS Wallston, 1981; KA Wallston, BS Wallston, & DeVellis, 1978; HR Winefield, 1982) and children (Parcel & Meyer, 1981). The results of studies employing these measures suggest that patients with internal HLC orientations have better adherence than patients with external HLC orientations (Abella & Heslin, 1984; Dabbs & Kirscht, 1971; Harvey, 1992; Kristiansen, 1986; Lau, Hartman, & Ware, 1986; Lewis, et al. 1978; Rokeach, 1973; Seeman & Seeman, 1983; BS Wallston & KA Wallston, 1978; KA Wallston & BS Wallston, 1982).

1.2.1.5 Health Value.

Health value has been described as the importance people assign to their health (Kristiansen, 1986). Health value was largely neglected by research until the mid-1980s. Earlier research conducted by Rokeach (1973) into the measurement of human values ignored health as a value, assuming that all people uniformly placed a high value on health (Lau, et al. 1986). This assumption led early researchers to presuppose that health value was not worthy of investigation. However, since the value of health has come under the scrutiny of investigators it has proven to be a fertile area of research (Kristiansen, 1986; Lau, et al. 1986; Lonnquist, Weiss, & Larsen, 1992; Schlenk & Hart, 1984; KA Wallston & BS Wallston, 1980; Ware & Young, 1979). For example, persons who are relatively healthy have been found not to place a uniformly high value on health (Ware & Young, 1979).

Several studies have shown that patient adherence may be explained partially in terms of the value patients attribute to their health, in combination with their Health Locus of Control (Abella & Heslin, 1984; Kennedy, Probart, & Dorman, 1991; Schlenk & Hart, 1984; Ware & Young, 1979). For example, Abella and Heslin (1984) proposed that the adherence of persons with internal HLC orientations was influenced by the value they placed on health, while the adherence of persons with external HLC orientations was influenced more strongly by the behaviour of their family and friends. This possibility has clear implications for the usefulness of health education interventions with internally and externally oriented individuals. That is, externally oriented individuals are more likely to be influenced by health education messages than are internally oriented individuals.

1.2.1.6 Social Support.

Cobb and Jones (1984) suggested that social support encompasses *(i)* the supportive behaviour of individuals' family and friends; *(ii)* the nature of the social network surrounding individuals; and *(iii)* the individuals' perceptions of the support provided by their family and friends. Some of the most methodologically sound research into patient adherence has dealt with the influence of social support. Studies conducted in this area have more often used longitudinal designs than perhaps any other area of adherence research.

These studies have found that patients who perceive their families or friends to be supportive are more adherent than patients whose family members are not seen to be supportive (Christensen, et al. 1992; Langlie, 1977; GS Sanders, 1982; Schlenk & Hart, 1984). The effect of social support on adherence has been particularly evident with children and individuals with external loci of control (Abella & Heslin, 1984; Caplan, 1979; Dunbar & Agras, 1980). Social support also has been found to indirectly influence patient adherence by enabling patients to overcome barriers to adherence such as psychological strain or environmental stressors (R Anderson, 1983; Christensen, et al. 1992; DiNicola & DiMatteo, 1984). However, social support also may exert a stressful influence on the patient when the level of support is perceived as threatening to the patient's autonomy (Caplan, et al. 1976). This influence is likely to be of greatest importance with adolescent patients. Also, the influence of social

support may be directed against adherence, if members of one's social network are opposed to the regimen.

1.2.2 The Influence of Illness and Regimen Characteristics on Patient Adherence.

Current evidence suggests that there are five major characteristics of medical regimens that influence patients' adherence: (1) the duration of the treatment; (2) the complexity of the regimen; (3) the level of discomfort or unwanted side-effects; (4) the requirements for lifestyle changes; and (5) the financial costs of the regimen (Becker & Maiman, 1975, 1980; Brand, et al. 1977; La Greca, 1990a; Rorer, et al. 1988).

1.2.2.1 Duration of the Regimen - Acute versus Chronic Regimens.

Several studies have found that adherence to long-term regimens is poorer than adherence to short-term regimens (Blackwell, 1976a, 1976b; Dowse & Futter, 1991; Rorer, et al. 1988). This finding appears to contradict the finding noted in **Section 1.2.1.2** that experience with an illness and its treatment is positively related to adherence. A possible explanation is that patients' adherence is improved by experience as they develop mastery over the regimen, so long as the regimen remains challenging or novel. As the regimen becomes familiar, it requires less of the patients' attention, and adherence wanes. This explanation is supported by the finding that adherence to long-term regimens is boosted by periodic modifications of the

treatment pattern, designed to maintain novelty, and thus attention (Becker & Maiman, 1980).

1.2.2.2 Complexity of the Regimen.

Evidence that the complexity of the regimen is an influence on adherence is based on the observation that simplifying the regimen leads to improved adherence (Cockburn, Reid, Bowman, & Sanson-Fisher, 1987; Corrigan, Liberman, & Engel, 1990; Dunbar & Stunkard, 1979; Hulka, Cassel, Kupper, & Burdette, 1976; Matthews & Hingson, 1977; Tinkelman, Vanderpool, Carroll, Page, & Spangler, 1980). For example, one study found that the number of medication errors made by patients increased with the number of drugs involved in their regimen (Hulka, et al. 1976). This observation is supported by the finding that when components of a regimen are introduced gradually, patients are more adherent than when the entire regimen is introduced at once (Becker & Maiman, 1980; Matthews & Hingson, 1977). In other words, adherence is facilitated by making the regimen less difficult for the patient to understand. This interpretation is likely to be linked to the finding reported in **Section 1.2.1.2** that regimen knowledge is a necessary antecedent to adherence (Becker, 1985; Bettinghaus, 1986; Dunbar & Agras, 1980; Stuart, 1982).

1.2.2.3 Regimen Side-Effects and Regimens that Cause Discomfort.

Patients prescribed a treatment program that is painful or aversive tend to be less adherent than patients prescribed a regimen that is not aversive (Creer & Burns,

1979). Patients also adhere less well to regimens that have side effects than to regimens with no side-effects (Cockburn, Reid, et al. 1987; Dolgin, et al. 1986; Litt & Cuskey, 1980; Ruley, 1978).

1.2.2.4 Lifestyle Changes.

Regimens that involve major lifestyle changes or otherwise are inconvenient to the patient (or to their family) also are less likely to be adhered to than regimens that can be readily absorbed into daily routines (Becker, Drachman, Kirscht, 1972; Dunbar & Stunkard, 1979; Tinkelman, et al. 1980). This last finding may be associated with the finding noted in **Section 1.2.1.3** that patients who are more motivated to maintain or achieve good health are more likely to be adherent to their regimen. The level of health motivation required for a patient to make a behavioural change varies in direct relation to the magnitude of the behavioural change. Thus, patients who are highly motivated to maintain good health will be willing to make substantial changes to their lifestyle, while patients who are less health motivated will be unwilling to make major changes to their lifestyle, but may be willing to make less substantial changes. This is a potentially profitable area of investigation for patient adherence research.

1.2.2.5 Expense of the Regimen.

Finally, the financial cost to patients of medical treatment may be a barrier to their adherence, particularly in filling medication prescriptions and attending medical appointments (Brand, et al. 1977; Creer & Burns, 1979). Intuitively, it is appealing to

conclude from this finding that socio-economically disadvantaged patients are less likely to adhere to their treatment than patients of higher socio-economic status. However, research has failed to establish a consistent relationship between patient adherence and patient socio-economic status (Becker & Maiman, 1975; Kirscht & Rosenstock, 1979; Rapoff & Christophersen, 1982). One interpretation of these findings is that more expensive treatments require a greater motivation to maintain good health, whereas cheaper treatments require less health motivation. This interpretation has not been tested by empirical research to date.

1.2.3 The Influence of the Doctor-Patient Relationship on Patient Adherence.

The quality of patients' relationships with their doctors influences their adherence in several ways. For example, patients who perceive their doctors to be friendly and attentive are more likely to adhere to their treatment than patients who feel that their doctors are indifferent to their problems (Ley, 1992). Further, patients who are treated consistently by the same physician show higher adherence rates than patients treated by different physicians on different occasions (Litt & Cuskey, 1980). In contrast, when the doctor-patient encounter is brief and is characterised by impersonality, patient adherence is reduced (Becker, 1985; Becker & Maiman, 1975; Coe & Wessen, 1965). When doctors are excessively formal, rejecting, or controlling, their patients are less likely to agree with them and to follow their recommendations than when they do not display these patterns (Davis, 1968; Engel, 1977). Doctors' verbal and nonverbal communication skills, as well as doctors' satisfaction with clinic encounters, have been associated with patient adherence (DiMatteo, Hays, & Prince,

1986; DiMatteo, Taranta, Friedman, & Prince, 1980; RM Kaplan & Simon, 1990). Friedman has found that patients are very sensitive to these aspects of care (HS Friedman, 1979, 1982).

In many studies patient adherence has been related to how satisfied patients feel about their treatment (Barsky, 1976; Hall, Roter, & Katz, 1988; RM Kaplan, et al. 1989; Ley, 1982, 1992; Meichenbaum & Turk, 1987). Patients who are dissatisfied with the way their doctors explain their illnesses or treatments are less likely to adhere to their treatment than patients who are happy with the manner in which explanations are given (Barsky, 1976).

1.2.3.1 The Doctor-Patient-Parent Relationship: Interpersonal Aspects of Paediatric Care.

Adherence to paediatric regimens is complicated by the triadic nature of the doctor-parent-child relationship. The adherence of children and parents to the recommendations of the doctor must be considered, as well as the adherence of the child to the parent's directions (Forehand, 1977; Kochanska, Kuczynski, Radke-Yarrow, & Welsh, 1987; Kuczynski & Kochanska, 1990; McMahon, Forehand, & Griest, 1982). This complication has not been adequately considered in the design of research examining children's adherence to treatment regimens. Most investigations have simply examined parents' understanding, parents' satisfaction, or parents' reports of adherence with paediatric treatment regimens. They have not included an examination of the views of the child (e.g., Deaton, 1985; Peri, Molinari, & Taverna,

1991; Reimers & Lee, 1991; Wasserman, Inui, Barriatua, Carter, & Lippincott, 1984). Approaches that ignore the involvement of children are particularly inappropriate with older children and adolescents, who are likely to take more responsibility for their adherence (Tebbi, 1993; Tebbi, et al. 1986). As children adopt greater responsibility for their health behaviour, the understanding, satisfaction and reports of parents become less relevant, and children's views assume greater importance.

1.2.4 Current Status of Investigations of Factors Influencing Patient Adherence.

Five key issues deserve greater attention in patient adherence research. First, the examination of both parents' and children's (or adolescents') beliefs, knowledge, or perceptions of adherence should be incorporated into future study designs. As discussed, many studies have been limited by examining only the views of parents, to the exclusion of the views of children, thereby only looking at half of the picture. Future studies should investigate the health related behaviour and beliefs of both parents and children. The adherence of both children and parents to doctors' recommendations should be assessed, as well as the adherence of children to parents' directions (Forehand, 1977; Kochanska, et al. 1987; Kuczynski & Kochanska, 1990).

The second issue deserving greater research attention is the allocation of responsibility for the performance of therapeutic activities. When investigating child adherence, future research should examine the allocation of responsibility between children and parents, and the perceptions of children and parents regarding this allocation (Dolgin, et al. 1986; Tebbi, 1993; Tebbi, et al. 1986). Obviously, the age or level of cognitive

development of the child is an important consideration in allocating this responsibility.

Third, a limitation of current research that should be addressed in future studies is the tendency to depict adherence as a univariate, dichotomous phenomenon, rather than as a continuum varying along multiple dimensions (Inui, Carter, Pecoraro, Pearlman, & Dohan, 1980; La Greca, 1990a; Roth & Caron, 1978). Describing adherence as a univariate phenomenon masks differences in the level of adherence to various therapeutic activities, which are likely to vary in importance (Cromer & Tarnowski, 1989; Dunbar, 1979, 1980).

Fourth, research to date that has investigated patient adherence almost exclusively has been cross-sectional. A limitation of this approach is that these studies are unable to establish the direction of causal relationships between the variables investigated and the level of patient adherence. Future investigations need to employ longitudinal study designs to explore these causal relationships. These longitudinal studies should be able to determine the variation in influence of a variety of factors, and the interaction between their effects (Kirscht & Rosenstock, 1979; Rapoff & Christophersen, 1982). The short periods of time over which most studies have been conducted may have limited the accuracy of their findings regarding overall patient adherence levels, as adherence rates are likely to vary over time (La Greca, 1988a). One study found that cross-sectional designs produce higher rates of adherence in a population, when compared with the outcomes produced by longitudinal measures (Youngleson & Joubert, 1991).

Finally, because different investigations have used different criteria for measuring adherence, it is not possible to interpret the meaning of results across studies (La Greca, 1990a). A more uniform approach to the measurement of patient adherence would greatly assist the accumulation of results from different studies. This accumulation would potentially increase the rate of progress made in patient adherence research.

1.3 Adolescents' Adherence to Medical Regimens.

This section reviews the literature addressing issues of particular importance to adolescents, and in particular to the medical treatment of adolescents. The medical treatment of adolescents differs in many respects from the treatment of children or adults (Black, Sawyer, & Fotheringham, 1995). It has been suggested that the greatest threats to the health of adolescents are behavioural, rather than biomedical (Adger & DeAngelis, 1994). Certainly, the health behaviour of adolescents can be expected to differ from that of adults or young children. Factors relating to the adherence or lack of adherence of adolescents to medical recommendations are likely to differ from those relating to the adherence or nonadherence of younger children, or of adults (Litt & Cuskey, 1980).

Studies designed to assess the health behaviour of adolescents need to consider the particular issues relevant to this stage of life. Adolescence is a stage of life in which young persons seek greater autonomy from their parents. Conflict with parents is often perceived to be greatest at this stage of development (Coupey & Cohen, 1984;

Eiser & Havermans, 1992; Honess & Lintern, 1990; Ingersoll, et al. 1986; Montemayor & Hanson, 1985; EC Perrin & Gerrity, 1984; JM Perrin, 1991; Ryan & Lynch, 1989; Steinberg, 1990; Steinberg & Silverberg, 1986; Varni & Wallander, 1984; Wysocki, 1993). The occurrence of a chronic illness during adolescence has implications for the development of the young person (Litt & Cuskey, 1980). Many studies investigating the adherence of adolescents to medical recommendations have not accounted for issues such as these (IM Friedman, et al. 1986).

This section reviews current knowledge in three key areas of research examining issues in adolescent medicine. These areas are: (1) chronic illnesses in adolescence; (2) adolescent autonomy; and (3) parent-adolescent conflict. In each area the current status of research is reviewed, and approaches needed for the further development of adherence research are identified.

1.3.1 Chronic Illness.

Chronic illnesses attract an increasing proportion of the practice of health professionals. This is due to two trends. First, advances in medical practice have ensured that acute and infectious conditions are more effectively prevented or treated than in the past (Blum, 1992; Coupey & Cohen, 1984; Garrison & McQuiston, 1989; Varni, 1983). Second, the management of chronic illnesses has advanced, so that many conditions which previously were rapidly fatal are now associated with longer survival (Bicknell & Parks, 1989; Coupey & Cohen, 1984; Gaut & Keickhefer, 1988; German, 1988; Newacheck & Taylor, 1992).

The shifting emphasis of practice onto chronic conditions adds to the importance of behavioural medicine, as many of the risk factors associated with the prevention or management of chronic illnesses are a function of health behaviours (Brown, 1980; Haggerty, 1977; Varni, 1983; Williams, Carter, Arnold, & Wynder, 1979). Further, adolescents with chronic conditions are more likely to be made responsible for the management of their illnesses than adolescents with acute conditions - because of the greater importance of behavioural aspects in the management of chronic conditions (Varni, 1983; Varni & Wallander, 1984). With the onus for the management of illnesses more heavily placed on the adolescent, chronic illnesses are more vulnerable to the impact of poor regimen adherence (Amir, Rabin, & Galatzer, 1990).

An adolescent's chronic illness can have a disruptive influence on the family. The behavioural restrictions of a chronic illness, such as dietary limitations, exercise requirements, and the use of medications or other treatments, are likely to impact upon the rest of the family. The involvement of parents in meal planning, and the coordination of other regimen activities, can place considerable burden on the family as a whole (Howe, Feinstein, Reiss, Molock, & Berger, 1993; Newacheck, McManus, & Fox, 1991; Stein & Jessop, 1984a; Varni & Wallander, 1984). Successful management of a child's chronic illness may force parents to redistribute responsibilities, reorganise daily routines and renegotiate family rules (Hauser, DiPlacido, Jacobson, Willett, & Cole, 1993).

It has been argued that the burdens and stresses associated with a child or an adolescent having a chronic illness are common to a variety of different illnesses

(Coupey & Cohen, 1984; Eiser & Havermans, 1992; Jessop & Stein, 1985; Stein & Jessop, 1982a, 1982b, 1984a, 1984b; Stein, Westbrook, & Bauman, 1997). An advantage of this 'noncategorical' view is that it focuses on the common processes of adaptation to chronic illnesses that are required of children and families with chronic illnesses (Garrison & McQuiston, 1989). This is not to say, however, that there are not unique features of each chronic illness, such as the individual components of the therapeutic regimens, which vary in their impact upon the ill individual and their family (Garrison & McQuiston, 1989).

This section addresses the developmental and psychosocial impact of the experience of a chronic illness on adolescents, as well as the impact of the chronic illness on the family.

1.3.1.1 The Impact of Chronic Illness on the Adolescent.

The experience of a chronic illness during adolescence can impact upon the development of the young person. During adolescence, the young person develops more autonomous ways of behaving (Hill & Holmbeck, 1986; Ryan & Lynch, 1989; D Shapiro, 1981). The development of autonomy is a salient issue for adolescents and its accomplishment is often seen as a central task of this developmental stage (SS Feldman & Rosenthal, 1991; Pardeck & Pardeck, 1990). This process involves moving away from dependency on parents toward independence in decision making, values, emotional attachment, and behaviour (Small, Eastman, & Cornelius, 1988; Steinberg, 1985). Early adolescence is a common time for experimentation in new

behaviours (Turner, Irwin, Tschann, & Millstein, 1993). Conflict with parents, particularly in relation to autonomy issues, typically becomes more common during mid-adolescence. Opportunities for self-determination and exercise of choice tend to become more important to the young person. (Hofmann & Gabriel, 1989).

Adolescents not experiencing chronic illness engage in a struggle to define their emerging identity, and to gain increasing independence (EC Perrin & Gerrity, 1984). At the same time, these adolescents continue to rely heavily on their parents, causing tension in their relationships with their parents (EC Perrin & Gerrity, 1984). The addition of a chronic illness to the adolescents' experiences during this period of tension and confusion adds to the difficulties that need to be addressed (Blum, et al. 1993). The social and psychological functioning of the adolescent may be negatively influenced, as may the family dynamics. These impacts in turn can negatively influence health behaviour, including the management of the chronic illness (Jessop & Stein, 1985).

Previous studies have found that the experience of a chronic illness during adolescence is associated with an increased risk of social, academic, and behavioural difficulties (Eiser, 1990; Eiser & Havermans, 1992). The development of autonomy may be inhibited by the need for dependence on others, particularly parents, for assistance in the management of the chronic condition. This may lead to frustration and resentment (EC Perrin & Gerrity, 1984).

The development of autonomy from parental control also may be described in terms of the increasing influence of peers on the behaviour of adolescents (Armsden &

Greenberg, 1987; Blum, 1992; Hauser, et al. 1993). SB Johnson (1984) noted that the presence of a chronic illness is likely to impede the adolescent's ability to conform with the behaviour of peers. The necessity of, for example, daily insulin injections and dietary restrictions (avoiding unplanned 'junk' food) for adolescents with insulin dependent diabetes, may limit the chronically ill adolescent's sense of belonging within their peer group (Garrison & McQuiston, 1989; Wolfish & McLean, 1974). This sense of isolation may in turn lead to frustration and resentment directed at the chronic illness itself.

It has been suggested that feelings of resentment associated with restrictions imposed on the autonomy of chronically ill adolescents, and on their conformity with peer behaviour, may lead some chronically ill adolescents to refuse to adhere to their treatment regimen (Garrison & McQuiston, 1989; EC Perrin & Gerrity, 1984). Adolescent noncompliance with parental requests is often viewed as a 'normal' behaviour (Garrison & McQuiston, 1989). Health practitioners often assume that adolescents also are poorly adherent to medical recommendations (Blum, 1984). Empirical studies have shown adolescents to be less adherent to medical regimens than younger children or adults (Dunbar, 1983; La Greca, 1982, 1990a; Litt & Cuskey, 1980).

1.3.1.2 The Impact of Chronic Illness on the Family.

The experience of a chronic illness during adolescence can also impact upon the functioning of the family, both as a system and as individuals. The influence of the

illness on the family is reciprocated by the influence of family characteristics on the progress and management of the illness (Bloch, Hafner, Harari, & Szmukler, 1994; Burlew, Evans, & Oler, 1989; Burr, 1985; Fiese, 1997; Hauser, et al. 1993; Kazak, 1997; Marteau, et al. 1987; J Shapiro, 1983). Previous research has primarily focused on the impact of the child's chronic illness on the family, however a body of research does exist which has examined the effect of the child's family on the child's adjustment to the illness.

When examining the literature exploring the relationships between children's chronic illness and family functioning, a caveat that needs to be considered is what is meant by the term 'family'. Increasingly, single-parent families and households containing unrelated adults are included in this definition, while the prevalence of the traditional nuclear family declines. Many studies examining family aspects of health behaviours have not defined what is considered to be a family, and what is excluded. While this issue is beyond the focus of this chapter, for the purpose of this review the approach adopted by Baranowski and Nader (1985) will be followed, so that "a family will ... be defined as two or more individuals who reside in the same household, who can identify some common emotional bond, and who are interrelated by performing some social tasks in common" (Baranowski & Nader, 1985, p 54).

A child, whether a young child or an adolescent child, experiencing a chronic illness presents a stressor for the entire family (JL Wallander, personal communication, 5 November, 1997). The chronic illness influences the relationships between the chronically ill child and the parents, the relationship between the parents, and the relationship between the parents and other children, as well as relationships between

family members and people outside the family (Burlew, et al. 1989; Burr, 1985; JM Perrin, Shayne, & Bloom, 1993). The lifestyle of the chronically ill child is affected, as is the lifestyle of other family members. Routines such as meal preparation, parents' work schedules and family transportation may be affected. For example, dietary restrictions for a child with Insulin-Dependent Diabetes may necessitate special meals being prepared for the ill child, and parents may have to alter work schedules to transport the ill child to treatment visits or to outpatient clinics in hospital (Kazak, 1989).

Childhood chronic illness is a potential source of tension and conflict. Conflict between chronically ill children and their parents, particularly primary care-givers, may be caused by the restriction of the children's autonomy, and the imposition of the requirements of illness treatments on parents (Burlew, et al. 1989). Conflict between parents and other children in these families may also result from a chronic illness, as extra attention and resources are dedicated to the care of the chronically ill children (Kazak, 1989; Rae-Grant, 1985). Stress caused by the occurrence of children's chronic illness also may cause tension and conflict between parents (Burlew, et al. 1989; Rae-Grant, 1985).

The influence of the characteristics of the family on the course of a child's chronic illness also needs to be considered. Baranowski and Nader (1985) reviewed the literature examining the relationship between family variables and adherence to children's chronic medical regimens. These authors found that family structure variables, such as the number of children, whether the family was a single-parent or dual-parent household, and parental education level, were not well related to regimen

adherence. Conversely, family process characteristics, such as the level of family cohesiveness, and the ability of the family to adapt to changes in routine, were more likely to be associated with regimen adherence. These authors noted that negative aspects of family process were more often related to adherence than positive aspects. For example, a common finding in the literature is that marital conflict, or the interference in the social roles of parents caused by the child's chronic illness, was likely to be associated with poor adherence. Findings relating positive aspects of family interaction, such as cohesiveness, with adherence levels, were rare (Baranowski & Nader, 1985). The reviewers concluded that regimen adherence does not occupy a high priority in the family, and that although no aspects of family life serve to maximise adherence, many aspects play an inhibitory role (Baranowski & Nader, 1985). A review of more recent publications suggests that the pattern of findings reported by these authors has not changed markedly since their review was conducted.

The ways in which family functioning influences children's regimen adherence is clear. Parents are responsible for forming many behaviour patterns in children and young adolescents, including health behaviour (Baranowski & Nader, 1985; Gochman, 1985; Sallis & Nader, 1988). Further, the parent usually plays the role of intermediary contact between the ill child and health care providers. For parents, having a child with a chronic illness involves a number of additional challenges. First, the illness itself needs to be managed, and the child gradually taught to assume responsibility for that management. Second, the psychological adjustment of the child needs to be considered, and normal development encouraged. Third, family routines

must be adapted to deal with disruptions imposed by the illness regimen, and family functioning must be normalised (SB Johnson, 1985).

It can be seen that the presence of the child's chronic illness impacts upon the functioning of the child and the child's family. It also can be seen that the functioning of the child and of the child's family in turn influences the management of the chronic illness, and therefore the health outcomes of the child (Jessop & Stein, 1985). Previous research has noted that family functioning is associated with disease control, and with the adjustment of the child (BJ Anderson & Auslander, 1980; Burr, 1985; Pless, 1984).

Most studies of family functioning in relation to chronic illness have addressed parents and chronically ill children, to the exclusion of other family members. More often than not, this has involved only the mothers, so that in most research the role of, and impact upon, fathers and siblings of the ill child has been ignored (Sabbeth, 1984). This is in part due to the difficulty involved in recruiting fathers into such studies. Mothers remain the primary care-givers in the majority of families, and attendance at, for example, outpatient clinics by fathers is typically less frequent than that of mothers (Bailey, 1991; Turner-Henson, Holaday, & Swan, 1992). A few recent studies have investigated the impact of a child's chronic illness on siblings. Siblings of children with chronic, life-threatening illnesses have been found to report more negative relations with their fathers, and more distal relations with their mothers, than children with no chronically ill siblings (DA Stewart, Stein, Forrest & Clark, 1992).

Several studies have examined the relationship between family functioning or family relations and metabolic control for children and adolescents with IDDM. Hanson, Henggeler, and colleagues (1989) examined family relations of 94 families with an adolescent child diagnosed with IDDM. Family members completed a series of questionnaires assessing relations, and adolescents' metabolic control was assessed by HbA_{1c} assay. This study revealed significant associations between high marital satisfaction and good metabolic control, and between family flexibility and good metabolic control. Family cohesion was marginally associated with good metabolic control. These effects were moderated by the duration of time since the child's diagnosis with IDDM, such that the link between family relations and metabolic control was strongest when the diagnosis of IDDM was recent, but that this link attenuated as the duration of IDDM increased. Marteau and colleagues (1987) examined the metabolic control of children and adolescents with IDDM in relation to their (1) family structure and family functioning, (2) parents' management of the children's IDDM, and (3) children's psychological adjustment. The findings of this study suggested that the psychological functioning of a family is related to their child's diabetic control. Families characterised by cohesion, emotional expressiveness, lack of conflict, and marital satisfaction had children with better metabolic control than families without these characteristics (Marteau, et al. 1987).

A small body of research has investigated the relationship between adolescent autonomy and regimen adherence. The following section, **Section 1.3.2**, reviews the literature relating to adolescent autonomy, and particularly its relationship with adolescents' adherence to chronic medical regimens and health outcomes with chronic illness.

The subsequent section, **Section 1.3.3**, reviews the literature relating to parent-adolescent conflict, and its association with adolescents' regimen adherence.

1.3.2 Adolescent Autonomy.

The literature addressing adolescent and family functioning is vast. A considerable portion of this literature is focused on the development of autonomy in adolescents. The development of autonomy by adolescents is widely conceived as a feature of normal development (Chassin, Presson, Sherman, & McConnell, 1995; SS Feldman & Quatman, 1988; SS Feldman & Rosenthal, 1991; Honess & Lintern, 1990; Ryan & Lynch, 1989; Sigafoos, Feinstein, Damond, & Reiss, 1988; Steinberg, 1990; Steinberg & Silverberg, 1986; Turner, et al. 1993).

This section reviews the literature exploring issues related to the development of adolescents' autonomy. First, the nature of adolescents' striving for autonomy is addressed, including consideration of the impact of this striving on the management of chronic illnesses, and the reciprocal influence of the illness on the development of autonomy. Second, the role of parents and peers in the development of autonomy is discussed, including the influence of chronic illness. Third, theoretical perspectives on the link between adolescents' adherence to chronic illness regimens and their desire for autonomy are considered. The final part of this section discusses future directions for research examining the link between adolescent autonomy and regimen adherence.

1.3.2.1 The Impact of Adolescents' Autonomy Seeking.

Adolescence is a stage in life characterised by transitions (Papini & Roggman, 1992; Yee & Flanagan, 1985). The adolescent seeks greater independence, experiences changing relationships with parents and with peers, and experiments with new behaviours (Honess & Lintern, 1990; EC Perrin & Gerrity, 1984; Turner, et al. 1993).

Research interest in adolescence has focused on the nature of these transitions. Recent authors have noted the development in adolescents of an interest in increasing independence. At the same time these adolescents maintain emotional attachments with parents (Chassin, et al. 1995; Honess & Lintern, 1990; EC Perrin & Gerrity, 1984; Steinberg, 1990; Turner, et al. 1993). Grotevant and Cooper (1986) have described this process as the renegotiation of adolescent-parent relations, that is, a disengagement of the parents' control over the adolescents' behaviour without the severance of the emotional bond. Steinberg and Silverberg (1986) described this transition in terms of the adolescent relinquishing childish dependencies on, and conceptualisations of, parents, rather than detachment from them. The development of more autonomous forms of behaviour by adolescents also has been described in terms of experimentation with new behaviours (Turner, et al. 1993).

It should be noted that in this section, and throughout this thesis, the term autonomy is used to refer to behavioural autonomy. A number of authors have identified several distinct forms of autonomy. Although the nomenclature has varied, essentially these

authors have identified emotional, behavioural, and moral domains of autonomy (Douvan and Adelson, 1966; SS Feldman & Rosenthal, 1991; Pardeck & Pardeck, 1990; Peterson, 1986; Steinberg, 1985; Steinberg & Silverberg, 1986). Behavioural autonomy, or functional autonomy, refers to the adolescents' independence of actions - their freedom to behave in the manner they choose. This form of autonomy includes their freedom to perform illness regimen activities for themselves, or to choose not to perform them. Ryan and Lynch (1989) described autonomy as "self-governance and self-regulation" (p 340). The use of the term autonomy in this thesis is consistent with this definition.

The development of autonomy by adolescents is likely to be impeded by the presence of a chronic illness. The restrictions of the illness regimen and the impact of illness on the health of the adolescent tend to force the adolescent into a dependent and passive role, preventing them from behaving autonomously (Blum, et al. 1993; IM Friedman, et al. 1986; Hoare, 1984; EC Perrin & Gerrity, 1984). For example, Hoare (1984) found that adolescents with chronic epilepsy were significantly more dependent on their parents than adolescents in the general population.

One way in which chronically ill adolescents can achieve a sense of autonomy is by adopting the responsibility for the management of the chronic illness (Coupey & Cohen, 1984). The transferral of responsibility for the performance of regimen activities is an important development for the chronically ill adolescent. The successful transferral of responsibility allows adolescents autonomy in their routine health care (Gaut & Kieckhefer, 1988). However, the adolescent's need for autonomy may clash with the restrictions imposed by the regimen. The adolescent may respond

by refusing to comply with the regimen (SB Johnson, et al. 1992; EC Perrin & Gerrity, 1984). Some authors have suggested that during periods of transition in adolescent roles, the sub-optimal management of the illness may be less harmful than delaying the development of autonomous behaviour patterns (Coupey & Cohen, 1984).

As noted in **Section 1.2.1.1**, the adherence of adolescents to medical regimens has been found to be worse than that both of younger children and of adults. A common explanation for this finding, which has received little empirical testing, is that the poor adherence observed in adolescents is the result of the autonomy seeking of the young person (La Greca, 1982, 1988b, 1990a). For example, La Greca (1982) found that adolescents with IDDM who were given more responsibility for the performance of regimen activities were in poorer metabolic control than other adolescents. However, although this finding is consistent with the assumption that autonomy seeking impedes adherence to illness regimens, this association has not been assessed directly in the literature (La Greca, 1990a).

Other authors have hypothesised that parents who are overprotective of their chronically ill adolescents, and who place unnecessary restrictions on their behaviour may cause feelings of resentment in the adolescents because of the interference with their autonomous development, and that this in turn may prompt the adolescents to be less adherent to their medication regimens (IM Friedman, et al. 1986; Hazzard, Hutchinson, & Krawiecki, 1990).

Another hypothesis relating autonomy with (poor) adherence is that put forward by Conrad and others (Conrad, 1985, 1987; Greenfield, Kaplan, & Ware, 1985; McCrea, Ranelli, Boyce, & Erwin, 1993; Warner, 1981; Zeltzer, 1980). These authors suggest that patients may choose not to adhere to medical recommendations as a means of maintaining control over their health care - patients may choose not to perform regimen activities that restrict their lifestyle, believing that their quality of life is better maintained by not allowing their illness to control their lives, even though this decision may place their long-term health at risk (McCrea, et al. 1993). It has been suggested that adolescents are especially likely to choose not to perform regimen activities which inhibit their lifestyle. The passive role of the patient clashes with the adolescent's need for autonomy (Blum, et al. 1993; IM Friedman, et al. 1986; Hoare, 1984).

Further, adolescents' seeking of autonomy has been characterised as shifting dependency away from parents and onto peers (Armsden & Greenberg, 1987; Greenberg, Siegel, & Leitch, 1983; Hill & Holmbeck, 1986; Steinberg & Silverberg, 1986). Adolescents' desires to conform with peers may influence them to choose to ignore aspects of their illness regimens which prevent them from behaving in the manner of their peers (Garrison & McQuiston, 1989; Hanson, et al. 1987a; SB Johnson, 1984).

1.3.2.2 The Impact of Adolescents' Autonomy on the Family.

The adolescents' movement toward greater autonomy necessarily involves the family in several ways. As adolescents become more autonomous, parents must learn to accept diminished involvement in many aspects of their adolescents' daily lives. Parents must concede control over much of their adolescent's behaviour (Eccles, et al. 1991; Holmbeck & O'Donnell, 1991; Small, et al. 1988). Adolescents' establishment of increased autonomy also requires the adoption of personal and social responsibilities, for the management of their daily lives (Greenberger, 1984).

For adolescents with chronic illnesses, the acquisition of increasing autonomy includes the adoption of responsibility for the daily management of the illness. The health care of younger children is likely to be the responsibility of the parents, but as the child develops, this responsibility must be transferred over to the child. However, as Gaut and Kieckhefer (1988) explain: "Because adolescents with chronic health problems are as concerned with establishing an independent lifestyle as they are with improving or maintaining their health status, the process of establishing self-reliance may interfere with the adolescent's willingness to follow prescribed therapy" (p 56).

In addition to the ordinary demands of rearing adolescents, parents of chronically ill adolescents need to understand the nature of the illness and its management, to determine which aspects of the management should become the adolescents' responsibility, and when, and to teach their adolescents to manage these tasks appropriately (SB Johnson, 1985). The transfer of responsibility for illness management is frequently a source of confusion between parents and adolescents

(Allen, et al. 1983). A number of researchers have found that adolescents and parents hold differing notions about who is responsible for regimen activities (BJ Anderson, et al. 1990; La Greca, 1990a; Tebbi, 1993; Tebbi, et al. 1986).

Confusion over the responsibility for regimen activities has been identified as a possible cause of the poor adherence observed amongst adolescents compared with other age groups (La Greca, 1990a; Tebbi, 1993; Tebbi, et al. 1986; Tebbi, Zevon, Richards, & Cummings, 1989; Wysocki, Meinhold, et al. 1992). For example, Ingersoll and colleagues (1986), found that parents of adolescents with IDDM decreased their involvement and ultimately discontinued managing their adolescent's illness, but the adolescents did not assume the management of the illness as expected. In contrast, the successful transfer of responsibility, when both adolescent and parent agree on who is responsible for regimen activities, promotes adherence to the regimen (Tebbi, 1993; Tebbi, Richards, Cummings, Zevon, & Mallon, 1988).

Adolescents cannot achieve autonomy without the co-operation of parents. Unless parents reduce their control over adolescents' activities, autonomy is restricted (Small, et al. 1988). Refusal by parents to release control, or expectations by the adolescent for greater levels of freedom than parents are willing to grant, is likely to be a source of conflict between adolescents and parents (Eccles, et al. 1991; Holmbeck & O'Donnell, 1991). The management of an adolescent's chronic illness may require the co-operation of the parent in allowing the ill adolescent freedom to manage their illness. Restriction of adolescents' autonomy in relation to illness management may result in poor adherence or rebellion from the regimen (IM Friedman, et al. 1986; Hauser, et al. 1993; Hazzard, et al. 1990).

1.3.2.3 Empirical Studies of the Link Between Adolescents' Adherence and their Autonomy.

There have been few empirical studies of adolescents' adherence to chronic medical regimens which have directly addressed the issue of adolescents' autonomy. While some studies have examined broader psychosocial issues relating to adolescence, a paucity of studies exist which provide detailed examinations of the link between adherence and autonomy. The absence of research in this area is perhaps due to the lack of appropriate measures. For example, some studies which have been intended to examine this relationship have employed general measures of personality to assess autonomy, rather than measures designed to assess the specific domain of interest.

Allen and coworkers (1983) examined the perceptions of adolescents and parents about responsibility for the adolescents' IDDM regimen activities. Responses from adolescent-parent dyads indicating that neither member of the dyad was taking responsibility for the regimen were negatively associated with health providers' estimates of adherence.

Litt, Cuskey and Rosenberg (1982) examined the regimen adherence of a group of 38 adolescents with Rheumatoid Arthritis, in relation to their autonomy. In this study, adherence was assessed on the basis of serum salicylate assay levels. Autonomy was assessed using a modified 5-item scale based on Eysenk's (1975) previous work. Adolescents reporting greater autonomy were rated as more adherent than adolescents

reporting lower levels of autonomy. The authors interpreted this finding as consistent with Hill's (1980) framework of adolescent autonomy, which posits that autonomy is associated with smooth relations with parents, rather than rebellion (e.g., Hill and Holmbeck, 1986). Unfortunately, this study employed a biological assay as the measure of adherence. As discussed in **Section 1.1.2.1**, assays are physiological rather than behavioural measures, and as such are poor measures of adherence. Further, the reliability and validity of the measure of autonomy used by Litt and colleagues in this study was not reported.

Another study examining the association between adolescents' adherence and their autonomy was conducted by IM Friedman and colleagues (1986). This study demonstrated significant associations between medication compliance and perceived autonomy in a group of adolescents with epilepsy. Adherence was assessed by interview, while autonomy was determined using the "Personal Freedom (Teen)" scale of the California Test of Personality (Thorpe, Clark, & Tiegs, 1953). Parents completed a scale devised by Friedman and colleagues to assess parents' perceptions of their adolescents' autonomy. This scale was intended to verify the data collected from the adolescents. This study represented a methodological improvement on the previous study, by its use of a behavioural assessment of adherence. However, this study did not employ a specific measure of autonomy, using instead a generic personality test.

BJ Anderson and coworkers (1990) examined the family sharing of responsibility for adolescents' IDDM management. The Diabetes Family Responsibility Questionnaire, completed separately by adolescents and parents, was developed to assess which

family member was responsible for each component of the regimen. Metabolic control was assessed by HbA_{1c} assays. Responses indicating that adolescents and parents each thought the other to be responsible for the management were associated with poor metabolic control. While this study does not directly assess autonomy, these results suggest that the development of increasing autonomy in the adolescent may be linked to increased confusion about adolescents' and parents' roles in the management of the adolescents' chronic illness.

1.3.2.4 Current Status of Investigations of the Link Between Adolescents' Adherence and their Autonomy.

At present, research examining the link between adolescents' adherence to chronic medical regimens and their experience of autonomy is limited. The few studies which have been conducted in this area have assessed these issues indirectly. The assessment of adherence in these studies has not been methodologically advanced, and the adolescents' autonomy has been measured using broadly conceived measures in which autonomy information is collected indirectly.

The lack of research in this area is surprising, as the issue of adolescent autonomy is frequently cited as a cause of adolescents' poor adherence or poor illness management. Hill and Holmbeck (1986) noted that autonomy has been connotatively associated with a variety of other variables, but that research in this area has for the most part been atheoretical and noncumulative.

Further investigation of the link between adolescents' autonomy and their adherence is warranted. The use of a more specific assessment of adolescents' autonomy would add to the understanding of this link. Further, the use of a measure of autonomy designed to be completed by both adolescents and parents would facilitate the examination of the perceptions of both groups of respondents. This would allow the examination of the relationship between adolescents' and parents' views, and determine whether agreement between adolescents and parents about autonomy and responsibility issues is associated with regimen adherence. Future studies also should incorporate multiple measures of adherence, with an emphasis on methodologically sophisticated assessments of adherence, as discussed in **Section 1.1.2** of this thesis. Previous studies have been limited by their use of less reliable assessments of adherence.

One of the few measures specifically designed to assess adolescents' autonomy was developed by Sigafoos and colleagues (1988). The Autonomous Functioning Checklist (AFC) was developed to study adolescents' transition from reliance on parents for caretaking to self-reliance. Subscales reflecting autonomous functioning in several specific domains of daily life, including self-care, avocations, communication, money handling, and initiative in social interaction are included (Howe, et al. 1993). This measure has demonstrated reasonable interrater reliability and scores show predicted developmental changes over time (Howe, et al. 1993; Sigafoos, et al. 1988).

Howe and colleagues (1993) assessed the autonomy of adolescents with a range of chronic medical conditions, using parent and adolescent responses on the AFC.

Adolescents with neurological conditions reported significantly less autonomy than adolescents without chronic conditions, while those with chronic conditions not relating to neurological functioning reported levels of autonomy between the two groups. This study suggests that the presence of a chronic illness does impede the development of autonomy in adolescents. The significant associations found in this study suggests that this line of investigation may be fruitful. Further studies are required to determine the relationship between autonomous functioning and regimen adherence.

1.3.3 Parent-Adolescent Conflict.

Another aspect of adolescent and family functioning that has generated considerable interest in the research literature is conflict between adolescents and parents. Studies of families have frequently included an examination of conflict between adolescents and their parents. The considerable research interest in this topic has included the development of a number of different, and at times contradictory, theories.

Before reviewing the literature relating to parent-adolescent conflict, and its relevance to regimen adherence and illness control during adolescence, it is necessary to understand what is meant by the term "conflict".

Definitions used in previous studies have varied. Hall (1987) wrote:

> Parent-adolescent conflict is more than just disagreement. Conflict connotes greater hostility, aggression, and emotion than does disagreement. In other words, a parent and teenager can have a disagreement that can be handled and solved calmly and without much effort. However, by definition, conflict between a parent and teenager means disagreement coupled with hostility. (p 768).

Hill and Holmbeck (1986), on the other hand, used a classical laboratory definition, that is, any interpersonal process that occurs when the actions of two people interfere with one another. This approach is clearly broader than that of Hall. Hill and Holmbeck (1986) suggest that their approach is more appropriate for research, because it does not involve an emotional component, thereby facilitating empirical measurement. The latter approach will, of course, produce higher estimates of conflict levels than the former. Paikoff and Brooks-Gunn (1991) noted that most studies have not explicitly defined conflict, and have relied on self-report measures to assess the level of conflict. This approach leaves the definition of conflict in the hands of the respondent. It is likely that different individual respondents will hold different personal definitions.

An often noted feature of conflict between parents and their children is that the level of this conflict increases as children enter adolescence (Flanagan, 1990; Paikoff & Brooks-Gunn, 1991; Papini, Clark, Barnett, & Savage, 1989; Steinberg, 1989, 1990). Robin and Foster (1989) suggested that conflict between adolescents and parents was a developmentally normal phenomenon, characteristic of the adolescents' emerging need for autonomy and the parents' need to maintain family stability.

Previous research has assessed the prevalence of conflict, and the prevalence of conflict in relation to different issues. For example, studies examining the nature of parent-adolescent conflict have typically observed that the topics of conflict are often mundane and everyday issues, such as curfew times, household chores, the use of spare time, and school work (Ellis-Schwabe & Thornburg, 1986; Hill & Holmbeck, 1987; Montemayor, 1983, 1986; Montemayor & Hanson, 1985; Paikoff & Brooks-Gunn, 1991; Papini & Sebby, 1988). This approach, however, has not determined whether these issues are organised around aspects or phases of the psychosocial development of the adolescent (Papini, et al. 1989).

The focus of parent-adolescent conflict around mundane issues has implications for the relationship between this form of conflict and adolescents' adherence to chronic medical regimens. If the issues most likely to be the subject of conflict are those which occur on a daily basis, and which relate to responsibility for behaviour and lifestyle, then the long-term regimen necessary for the management of a chronic illness such as IDDM is likely to become a subject of conflict. Daily insulin injections, blood glucose monitoring, and dietary restrictions fit well into the description of mundane issues which researchers have identified as the source of most frequent conflict. Conflict surrounding the adolescents' health behaviour could have a negative influence on the medical outcomes for the adolescent (Wysocki, 1993). This in turn could exacerbate the conflict between adolescents and parents about regimen activities.

1.3.3.1 Theoretical Links Between Adolescents' Adherence and their Conflict with Parents.

Several authors have addressed the theoretical links between parent-adolescent conflict and adolescent adherence to chronic medical regimens. Montemayor and Hanson (1985) reported that only around 15 % of conflicts between adolescents and parents were resolved through direct communication, and that the remainder were ended by withdrawal from the discussion or authoritarian decision. Wysocki (1993) suggested that if this pattern also held for conflicts relating to regimen activities in chronically ill adolescents, then the failure to resolve effectively the conflict could lead to confusion about who is responsible for regimen activities (i.e., the adolescent or the parent; cf. Ingersoll, et al. 1986; La Greca, Follansbee, & Skyler, 1990; Wysocki, Meinhold, et al. 1992).

Some researchers have used a Social Learning Theory perspective to conceptualise the relationship between adolescents' adherence and their conflict with parents. This perspective suggests that specific illness-related parental behaviour forms illness-specific support, which aids the management of the illness (Hanson, De Guire, et al. 1992). Empirical studies of this association have produced varied results (e.g, Schafer, et al. 1983, Schafer, et al. 1986).

Another theoretical standpoint that has been used to investigate the link between adolescents' adherence and their conflict with parents is a Systems Theory approach. This approach suggests that the adolescents' adaptation is influenced by their relationships with other family members, and by the relationships between other

family members. This view approaches the family as a system, rather than a group of individuals. Studies using this approach have used a systems view of family relations to predict adolescents' adherence to their regimens (e.g., Hanson, et al. 1987a, 1987b; Kazak, 1989).

1.3.3.2 Empirical Investigations of the Link Between Adolescents' Adherence and their Conflict with Parents.

A number of authors have explored the theoretical underpinnings of the association between adolescents' adherence to chronic medical regimens and their experienced level of conflict with parents. This section provides a brief review of studies empirically investigating the link between adolescents' adherence and the level of conflict they experience with their parents.

BJ Anderson, Miller, Auslander and Santiago (1981) compared the family environments of adolescents with IDMM in good, fair, or poor control. Fifty-eight adolescents, aged between 11 and 19 years, and their families participated in this study. The Moos Family Environment Scale (FES; Moos & Moos, 1981) was completed by adolescents and some of the parents. Diabetes control was assessed by HbA_{1c} assay; good control was defined as HbA_{1c} less than 10 %, fair control as HbA_{1c} between 10 % and 14 %, and poor control as HbA_{1c} above 14 %. Adolescents with well controlled diabetes reported more family cohesion and less family conflict than those with fair or poor control. Parents of adolescents with good IDDM control stated that their family members were encouraged to behave independently. A later

study by this research group examined risk factors to the health of children with IDDM (Auslander, et al. 1990). This study also used the FES to assess the social-environmental characteristics of the families, and HbA_{1c} assays to assess metabolic control. Unlike the previous study, this study found that neither family conflict nor the encouragement of independence differentiated children with good or poor metabolic control.

Another study using the Moos Family Environment Scale was conducted by Schafer and colleagues (1983), who examined 34 adolescents with IDDM, assessing regimen adherence and metabolic control in relation to family environment. A diabetes-specific measure of family interaction also was employed, the Diabetes Family Behavior Checklist (DFBC). Family conflict was significantly associated with regimen adherence (poor adherence was linked with high levels of conflict, good adherence with low levels of conflict). Negative interactions between adolescents and parents on the DFBC was associated with poor adherence. In another study by this group of researchers, Schafer and coworkers (1986) assessed the IDDM regimen adherence and metabolic control of adults and adolescents in relation to family interactions specific to the IDDM regimen. Adherence and metabolic control were assessed by the same measures as were used in the previous study. Negative family interactions were predictive of poor adherence amongst adults, but not adolescents, while positive interactions were not predictive of adherence amongst either group. This result is consistent with the conclusion drawn by Baranowski and Nader (1985), that positive aspects of family life do not maximise adherence, while negative aspects play an inhibitory role (see **Section 1.3.1.2**).

Klemp and La Greca (1987) examined the family cohesion and organisation of 50 adolescents with IDDM. Measures also assessed family conflict, and disruption due to diabetes. HbA_{1c} levels were used to assess metabolic control. Family cohesion and organisation were positively associated with good metabolic control, while conflict and family disruption were associated with poor metabolic control. Hauser and colleagues (1990) examined 52 children and adolescents with IDDM and their families. This study assessed adherence using a series of health provider ratings over four years. The family environment was rated using the Moos FES. Adolescents' and parents' reports of family conflict were associated with diminished concurrent adherence. Parents' perceptions of family cohesion were associated with good concurrent adherence. Longitudinal analyses revealed that adolescents' reports of family conflict were predictive of future poor adherence, and that their perceptions of family cohesion were predictive of good adherence.

Bobrow and coworkers (1985) explored the relationship between mother-daughter interactions and the daughters' adherence to IDDM regimens. Adherence was assessed by separate interviews of mothers and daughters, with regard to diet, insulin injection, glucose testing, exercise, and carrying glucose for emergency use. Measures of mother-daughter conflict, discussion of feelings, and concerns about diabetes also were collected. Poor adherence to IDDM self-care was associated with high levels of conflict, and particularly with confrontational and emotionally charged interactions between mothers and daughters.

Holden, Friend, and coworkers, (1991) examined the family functioning of 120 children attending diabetes summer camps, using the Family Adaptability and

Cohesion Evaluation Scales (FACES-III; Olson, 1986). Regimen adherence was assessed using observational measures of blood glucose monitoring and insulin injection, including the use of BGM records obtained from the electronic memory of blood glucose sensors. Family functioning prior to camp attendance was not associated with regimen adherence during camp, although children from poorly functioning families showed more improvement in diabetes control during camp than those from better functioning families. However, the children from poorly functioning families did not maintain their improved control after camp, while children from better functioning families maintained their control after camp experience. The authors suggest that these results indicate that camp experience is most beneficial for children with poorly functioning families, but that the maintenance of improvement in diabetes control achieved during camp is inhibited by the poor functioning of these families.

Hanson, Henggeler and Burghen (1987a) examined the association between global measures of adherence, metabolic control and family relations, using a series of measures to assess each domain. This study found the adherence to the IDDM regimen was 'marginally' associated with family relations. In a separate study the same authors reported that adolescents' perceptions of illness-specific parental support were associated with regimen adherence, but not illness control (Hanson, et al. 1987b). Hanson, and colleagues (1992) assessed family conflict surrounding a sample of 95 adolescents with IDDM, using parents' and adolescents' perceptions of conflict in the mother-adolescent, father-adolescent, and mother-father dyads. Adherence was assessed using a semi-structured interview. Illness-specific support

and family flexibility were predictive of adolescents' concurrent adherence, while high levels of conflict were associated with poor adherence.

Wysocki, Hough, and colleagues (1992) examined regimen adherence and parent-adolescent conflict experienced by adolescents with IDDM. Adherence was assessed using blood glucose monitoring data recorded on blood glucose sensors with electronic memories and by a behaviour checklist, while conflict was assessed by means of a standardised questionnaire (the Diabetes Responsibility and Conflict Scale; Rubin, Peyrot, & Young-Hyman, 1989). In this study, regimen adherence was significantly associated with parent-adolescent conflict, so that high levels of conflict were linked to poor adherence, and low levels of conflict to good adherence. Wysocki (1993) evaluated the relationship between parent-adolescent relations and metabolic control in a group of 115 adolescents with IDDM. Correlational analyses showed that better metabolic control was associated with more effective family communication skills and clear differentiation of family roles and boundaries. Further, "adolescents from families with conflictual parent-adolescent relations were more likely to exhibit poor diabetic control and IDDM-related maladjustment" (Wysocki, 1993, p 451).

1.3.3.3 Current Status of Investigations of the Link Between Adolescents' Adherence and their Conflict with Parents.

The previous section provided a brief review of studies examining the relationship between adolescents' adherence to their IDDM self-care regimens and their experience of conflict with parents. It should be noted, of course, that this review is

not exhaustive, but is an overview of some of the more prominent studies conducted to date, and is intended to be representative of other studies in this area. Nonetheless, when looking at these studies, a number of features typical of the published literature become apparent.

First, the majority of studies examining the relationship between parent-adolescent conflict or other aspects of family functioning and regimen adherence have employed general or global measures of family functioning. Most prominently, the Family Environment Scale (Moos & Moos, 1981) and the Family Adaptability and Cohesion Evaluation Scales (Olson, 1986) have been used. Although these measures benefit from having established psychometric properties, their design is intended for global assessments of the family environment. To examine the relationship between adherence and specific aspects of family functioning, such as parent-adolescent conflict, measures with more specific foci are appropriate (Drotar, 1997). For example, Hanson, Henggeler, and coworkers (1989) examined the metabolic control of adolescents' with IDDM in association with (1) marital relations, using the Marital Adjustment Scale, a scale designed to assess this specific relationship, and (2) the Family Adaptability and Cohesion Evaluation Scales to assess family relations. A specific measure of adolescent-parent relations was not employed, although the adolescents' metabolic control may be expected to be most influenced by the adolescents' relations with other family members.

Second, although a few of these studies had moderately large samples (e.g., 100 families), most involved only around fifty families. The use of small samples may limit the ability of researchers to determine the true extent of any associations between

adolescents' adherence and their conflict with their parents. That is, by restricting studies to small samples, the range of responses obtained on measures may also be restricted, which in turn limits the likelihood of detecting relationships between adherence and conflict.

Third, studies examining adolescents' adherence to IDDM regimens have not always employed the most methodologically sound assessments of adherence. Multiple assessments of adherence have been infrequent in this area of investigation, and the use of objective assessments, such as BGM data recorded in the memory of blood glucose sensors, has been limited. Hauser, et al. (1990), for example, used health provider ratings of adherence. As noted in **Section 1.1.2.1**, health provider estimates of adherence are liable to confound adherence with the health status of patients.

Further investigation of the relationship between parent-adolescent conflict and adolescent adherence is warranted. The use of measures specifically addressing the issue of parent-adolescent conflict would be of benefit. Future studies should also incorporate multiple measures of adherence, with an emphasis on methodologically sophisticated assessments of adherence, as discussed in **Section 1.1.2** of this thesis. Measures including the perspective of both adolescents and parents are important, and the combination of these with objective evaluations of adherence must be of value.

Robin and Foster (1984, 1989; Foster & Robin, 1988) have worked extensively in the area of parent-adolescent relations. These authors characterise parent-adolescent conflict as a function of (1) the adolescents' and parents' skill in problem solving communication and negotiation skills, (2) the adolescents' and parents' possession of

unreasonable beliefs and expectations about the other person, and (3) the functioning of paths of authority and influence within the family system. Robin and Foster have developed a series of assessment tools based upon this framework. These measures have been used to assess a variety of features of parent-adolescent relations. For example, the Issues Checklist is a self-report measure, completed separately by adolescents and parents, assessing the frequency and intensity with which specific issues are disputed between adolescents and their parents (Robin & Foster, 1988b). This measure has been used to examine reliably systematic variations in conflictual family issues during adolescence (Papini, et al. 1989). Similarly, the Conflict Behavior Questionnaire (CBQ) is a measure of perceived communication-conflict behaviour between adolescents and their parents. It provides an assessment of how much conflict and negative communication the family experiences. Parents and adolescents complete parallel versions (Robin & Foster, 1988a, 1989). The 20 item form of the CBQ has shown strong criterion-related and construct validity, and has a high level of internal consistency (Grace, Kelley, & McCain, 1993; Robin, 1980; Robin & Weiss, 1980; Schubiner & Robin, 1990)

Wysocki (1993) suggested that investigations of regimen adherence amongst adolescents with IDDM, based upon Robin and Foster's model of adolescent-parent relations, would provide an important development in research of the association between adolescent-parent relations and regimen adherence and metabolic control. This author used the Parent-Adolescent Relationships Questionnaire, (PARQ; Robin, Koepke, Moye, 1990) to examine the relationship between adolescents relations with their parents and their metabolic control. This study found that better metabolic control was associated with more effective family communication skills and clear

differentiation of family roles (Wysocki, 1993). The PARQ is a multidimensional scale assessing multiple components of adolescent-parent relations. Studies using measures addressing specific aspects of these relationships will further elucidate the link between adolescent-parent relations and adolescents regimen adherence and metabolic control.

1.4 Summary.

This chapter reviewed the published literature relating to this thesis. The topics addressed in this review relate to four major topics. The first section of this chapter examined issues relevant to the assessment of patient adherence. The definition of patient adherence was discussed. Strategies to measure patient adherence were reviewed. The relationship between adherence and health outcomes in previous research was discussed, and future directions for work in this area were identified. Issues relating to adherence assessment including the variation in adherence between regimens and between individual regimen characteristics were identified, as was the importance of multiple assessments of adherence. The benefits of longitudinal studies of adherence were identified. Also, theoretical models of health behaviour were reviewed, including the applicability of these models to patient adherence research. The use of these models in future studies also was addressed.

Second, factors reported to influence patient adherence were discussed. Current knowledge about factors relating to patient adherence to medical regimens was reviewed. Empirical studies and theories relating patient attributes such as age,

knowledge of the disease and health motivation with patient adherence were discussed. Characteristics of the regimen, including its complexity and duration, were addressed in association with patient adherence. The nature of the relationship between health practitioners and their patients, and the interaction between health practitioners, paediatric patients and their parents, were discussed in relation to adherence. The communication, openness, and warmth in these relationships have been associated with patient adherence. Methodological limitations in research published to date were reviewed. These include the use of cross-sectional research designs and the failure to examine children's reports of adherence. Opportunities to extend current knowledge of patient adherence were addressed, and areas deserving greater research attention identified.

Third, issues in adolescent medicine were explored. The impact of chronic illness on adolescents and their families was discussed, as well as the influence of family functioning on the progress of the chronic illness. The few studies which have examined the relationship between adolescents' autonomy and their illness management were reviewed, in light of the theoretical associations between these domains. Prospects for further investigation were identified. The literature examining family conflict, and specifically parent-adolescent conflict, was examined, including the link between this form of conflict and adolescents' adherence to medical regimens. Again, the current status of research was reviewed, including gaps in the literature.

CHAPTER TWO.

THE AIMS AND HYPOTHESES OF THIS THESIS.

The previous chapter, in reviewing the published literature, has identified a number of issues worthy of further investigation. This chapter summarises these issues, and describes the major aims of this thesis. The hypotheses under examination are then detailed.

2 THE AIMS AND HYPOTHESES OF THIS THESIS.

2.0 Introduction.

First, the review of the adherence literature identified a number of issues in the assessment of adherence that deserve consideration in further investigation.

The examination of both parents' and adolescent's perceptions of adherence should be assessed. Many studies have been limited by examining only the views of parents. Future studies are needed to investigate the health related behaviour and beliefs of both parents and children. The use of multiple measures of adherence is an important consideration in the design of future studies. There are several reasons why the use of multiple measures of adherence is important. First, adherence to one aspect of a complex regimen is typically independent of adherence to other aspects of the regimen; multiple measures of adherence allow the examination of adherence to diverse regimen activities. Further, each form of adherence measure has inherent limitations. The use of complementary forms of adherence measure can overcome the limitations of individual methods.

A limitation of research reported in the literature to date that should be addressed in future studies is the tendency to depict adherence as univariate. This tendency masks differences in adherence levels to various regimen activities. Further, the use of a uniform approach to the measurement of patient adherence would improve the accumulation of results from different studies.

The measurement of the relationship between adherence and health status should be considered. As the literature review identified, measures of these constructs should be temporally congruent. That is, to assess the relationship between adherence and health status properly, the measures used to examine these constructs must examine the same time frame.

Most studies have focused on patient variables such as regimen knowledge and health beliefs. Studies employing measures of more than one such variable permit a more comprehensive view of health behaviour, and facilitate the development of multivariate models to explain patient adherence.

The review of the literature also identified a number of issues relating to adolescent medicine.

Research examining the link between adolescents' adherence to chronic medical regimens and their experience of autonomy is limited; further investigation is warranted. The use of a specific assessment of adolescents' autonomy, designed to be completed by both adolescents and parents would add to the understanding of this link.

The relationship between parent-adolescent conflict and adolescent adherence also deserves further investigation. To examine the relationship between adherence and parent-adolescent conflict, measures with a specific focus on parent-adolescent relations must be used. Measures including the perspective of both adolescents and parents are important.

Finally, future investigations should be developed in a manner consistent with theoretical conceptions of adherence behaviour. This includes the use of models such as the Six-Factor Model of Adherence, as well as theories relating to adolescent development and adolescent medicine, such as the role of adolescents' autonomy and conflict with parents in their regimen adherence.

2.1 Aims of This Thesis.

The principal aim of this thesis is to examine adherence to medical recommendations amongst adolescents with Insulin-Dependent Diabetes Mellitus (IDDM). In particular, the influence of two specific aspects of adolescent / family functioning will be studied. These are: (1) adolescent autonomy, and (2) parent-adolescent conflict.

This thesis will investigate several components of adolescents' adherence. Measures include (1) their adherence to a range of specific aspects of their medical recommendations, (2) their general tendency to adhere or not to adhere to medical recommendations, and (3) an objective assessment of their Blood Glucose Monitoring, an important component of their IDDM regimen.

Each of the measures of adherence, as well as the measures of adolescent autonomy and parent-adolescent conflict, will be completed by adolescents and the parent identified as their primary caregiver.

The relationship between adolescents' adherence and a range of factors related to adults' adherence in the Six-Factor Model of Adherence also will be examined, to determine the applicability of this model to adolescents' regimen adherence. Finally, adolescents' health status will be measured in a manner temporally congruent with the assessments of adherence, to test the association between these constructs in this study.

2.1.1 Thesis Hypotheses.

Two hypotheses will be tested in the study:

1. Adolescents for whom reports of greater levels of conflict with their parents are obtained will be less adherent to their diabetes treatment recommendations than adolescents for whom reports of lower levels of conflict with their parents are obtained.

2. Adolescents for whom reports of greater levels of autonomy are obtained will be more adherent to their diabetes treatment recommendations than adolescents for whom reports of lower levels of autonomy are obtained.

CHAPTER THREE.

SAMPLING AND METHODOLOGY.

This chapter describes the methods of the main study of this thesis. This chapter consists of four major sections. These sections address: (1) the sampling strategy; (2) the procedures used to collect data; (3) the measures employed; and (4) the fundamental statistical analyses to be used in the study.

3 SAMPLING AND METHODOLOGY.

3.1 Subjects.

The sampling frame for this study included all adolescents aged between 12 and 17 years, and their parents, attending the Women's and Children's Hospital (WCH) Diabetes Outpatient Clinic. Subjects were recruited into the study between June 1995 and June 1996. Additional entry criteria for the study were as follows:

- participating adolescents must have been diagnosed with Insulin Dependent Diabetes for a minimum of 12 months.

- participating adolescents needed to attend the Outpatient Clinics in the company of a parent or guardian.

- participating adolescents and their parents needed to have sufficient comprehension of written English to complete the questionnaires. This criterion was not formally assessed; potential participants were excluded from the study if they reported that they were unable to complete the questionnaires because of language or literacy difficulties.

Adolescents were approached at the time of their routine appointment at the Diabetes Outpatient Clinic. All adolescents were prescribed similar regimens for their IDDM management, including daily injections of a mixture of intermediate- and slow-acting insulins, two daily blood glucose tests (i.e., morning and evening), a dietary plan that

included three regular meals and one or two snacks, and exercise recommendations. Adolescents were routinely followed at approximately 3-monthly intervals for their medical care. The treatment recommendations of these adolescents were similar to those of other groups of adolescents with IDDM (e.g., Jacobson, et al. 1987; SB Johnson, et al. 1986; SB Johnson, et al. 1990; La Greca, Swales, et al. 1995; Weissberg-Benchell, et al. 1995).

The demographic characteristics of the obtained sample are described in **Chapter 4**.

3.2 Procedure.

Several forms of data collection were employed to obtain data for the study. These included: self-reports from adolescents and parent reports completed in clinic waiting areas; electronic monitoring of adherence to blood glucose monitoring; and HbA_{1c} assays. Details of the pilot testing are given in **Appendix A.1**.

The Diabetes Outpatient Clinic of the WCH involves three Endocrinologists and an Endocrinology Registrar. In addition, a Diabetes Nurse Educator and a Dietitian participate in the clinic. A Podiatrist and a Social Worker visit the clinic on a rotational basis. Approximately thirty children or adolescents attend each weekly clinic.

Participants were approached to participate in the study when they attended the Diabetes Outpatient Clinic. The investigator described the nature and purpose of the

study, and provided information brochures which included names and telephone numbers of investigators to cater for later enquiries. A copy of the Information Sheet is included in **Appendix A.2**. Informed consent was obtained from all participants — both adolescents and parents. The Consent Form is included in **Appendix A.3**. Verbal instructions were given about the completion of questionnaires. **Appendix A.4** details the verbatim instructions given to participants.

3.2.1 Questionnaire Administration.

Adolescent self-reports and parent reports were used in this study to collect data about adolescents' adherence to their IDDM regimen, as well as their autonomy and their conflict with parents. Additional measures assessed IDDM treatment knowledge and predicted antecedents of adherence. The questionnaire measures were completed independently by the adolescents and their parents in the main waiting area of the clinic.

3.2.2 Collection of Objective Blood Glucose Monitoring Adherence Data.

Prior to their participation in the study, 75 adolescents with poor metabolic control were provided with new Companion 2™ blood glucose sensors. Poor metabolic control was clinically defined as a mean annual HbA_{1c} of greater than 10 %. The sensors were provided four weeks prior to Clinic attendance. Data was then collected from the electronic memory of these sensors during Clinic attendance.

The blood glucose sensors were supplied by their manufacturer, MediSense Australia, for research purposes. The allocation of these sensors to adolescents with poor metabolic control was based upon two factors. First, these adolescents were considered to be in greater need of additional help in the management of their IDDM. It was believed that the use of these monitors would facilitate this process. Second, these sensors were intended for later use in an investigation of an intervention designed to improve the metabolic control of adolescents with poor metabolic control. This intervention was conducted after the collection of the data presented in this thesis (Taylor, Fotheringham, Couper, Sawyer, 1996, 1997).

The demographic characteristics of the adolescents supplied with new blood glucose sensors are compared with those of the remaining adolescents in **Chapter 4**.

The electronic recording of BGM was employed in this study as an objective measure of the adolescents' adherence. The MediSense Companion 2™ sensors were used to obtain this data. BGM data was retrieved from participants' monitors upon attendance at the Diabetes Outpatient Clinics at the Women's and Children's Hospital. Retrieval was performed by means of the MediSense SensorLink™ system (MediSense, 1995). The SensorLink™ system was connected to individual participants' Companion 2™ sensors by cable, and results uploaded. The data was stored on the SensorLink™ system, along with identification data. This data was then downloaded as a database onto an IBM-compatible personal computer for the purpose of statistical analysis.

A major advantage of these devices was that they automatically record and store the date and time at which tests were undertaken, along with the test results. Previously,

this information was only available from diaries maintained by adolescents. The electronic storage of this information greatly improves its accuracy and reliability (Dunbar-Jacob, et al. 1991).

The MediSense SensorLink™ system is capable of retrieving up to 125 Companion 2™ sensor test results. Records stored in the SensorLink™ system are downloaded to an IBM-compatible Personal Computer (PC). Each downloaded test result appears in the form of one line of ASCII text, with each field of information separated by a tab. This recording method provided the timing (date and time) of tests, as well as the test results (**Figure 3.1**). This standard format is readable to spreadsheet and statistical software packages (MediSense, 1995).

The implementation of this form of assessment was designed to facilitate the comparison of results from the objective assessment of adherence to BGM with the results obtained using the self-reports and parent reports of BGM adherence. The data collected through the electronic recordings were coded to determine the number of appropriate days of BGM achieved during the previous four weeks, that is, to examine the same time period as the questionnaire assessment of adherence to this component of the IDDM self-care regimen.

3.2.3 Collection of Metabolic Control Data.

The metabolic control of the adolescents was determined by venous haemoglobin A_{1c} (HbA_{1c}) assays. These assays are recorded as a routine procedure in the Diabetes Outpatient Clinics to provide a standardised index of clinical status for IDDM.

The haemoglobin A_{1c} assays were collected using two Bayer Diagnostics DCA 2000® Analysers. The DCA 2000® analyser measures the level of concentration of HbA_{1c} and the concentration of total haemoglobin, and displays the ratio of the two as % HbA_{1c}. HbA_{1c} is calculated using a method based on inhibition of latex agglutination. In this process, an agglutination reaction causes increased scattering of light which is measured as an increase in absorbtion at 531 nm. HbA_{1c} competes for antibody-latex binding sites causing an inhibition of agglutination and a decreased scattering of light. The HbA_{1c} concentration is then quantified using a standard calibration curve of absorbance versus HbA_{1c} concentration (Guthrie, et al. 1992; John, Edwards, Price, 1994; Pope, et al. 1993; Rumley, Kilpatrick, Dominiczak, Small, 1993; Thai, Ng, Lui, Cheah, 1993). The reagents needed for this process are contained in a reagent cartridge; with the addition of 1 µl of capillary blood the measurement of HbA_{1c} is completed in six minutes.

Uniform measurement of HbA_{1c} was ensured by the use of the same analysers to perform all of the assays. Only one technician was involved in the performance of these assays, which were all taken at the Diabetes Outpatient Clinic at the WCH.

3.3 Measures.

Three forms of measure were employed in this study. First, questionnaire measures, which were completed by participating adolescents and parents. Second, an objective measure of the adolescents' Blood Glucose Monitoring adherence, which was obtained from the electronic memories of blood glucose sensors. Third, the adolescents' metabolic control, assessed by Haemoglobin A_{1c} assay.

3.3.1 Questionnaire Measures.

The measures described in this section were administered to participating adolescents and parents. These measures are shown in **Appendices A.5** and **A.6** respectively. This section describes the purpose, nature, and psychometric properties of the questionnaire measures employed.

3.3.1.1 Adherence to Medical Regimens.

This study employed two questionnaire measures of adherence to medical recommendations; the Diabetes Specific Adherence Scale and the General Adherence Scale.

The Diabetes Specific Adherence Scale.

Adherence to specific aspects of IDDM self-care recommendations was assessed using the Diabetes Specific Adherence Scale (DSAS; DiMatteo, et al. 1992; Sherbourne, et al. 1992). The DSAS is a nine item measure of adherence to specific IDDM self-care recommendations. Respondents used a six-point Likert scale ranging from *None of the time* to *All of the time* (**Figure 3.2**). High scores indicate high levels of adherence to IDDM self-care recommendations. The items of the DSAS were structured to assess adherence over the previous four weeks.

The DSAS employed in this study was tailored to the specific treatment recommendations received by participants (DiMatteo, et al. 1992; Sherbourne, et al. 1992). Other disease-specific adherence scales have been employed in Medical Outcomes Study (MOS), in parallel with the General Adherence Scale (DiMatteo, et al. 1992; Sherbourne, et al. 1992).

Prior to the present study, a disease-specific adherence scale had not been developed for use with adolescents with IDDM. However, a scale for use with adults with diabetes had been employed in the Medical Outcomes Study (DiMatteo, et al. 1992). After communication with Professor DiMatteo and Dr Hays, the authors of this scale, items from the MOS adult diabetes scale were adapted for use with Australian adolescents. A number of the items included in the MOS scale were inapplicable to adolescents with IDDM in this country, and were removed. Similarly, several aspects of the medical recommendations typically received by the target group were not found in the MOS scale, and had to be added. A draft version of the new questionnaire was

devised by the investigator, before being examined by members of the Women's and Children's Hospital Diabetes Team; including the Diabetes Clinical Nurse Consultant, the Diabetes Educator, and physicians participating in Diabetes Clinics. Several revisions were made to the wording of individual items, and one item, pertaining to dietary "exchanges" was deleted because clinicians were no longer emphasising this procedure. The second draft of the scale was then circulated to the WCH Diabetes Team, who endorsed the revisions.

In the present study, internal reliability was tested using Chronbach's alpha. The adolescent and parent responses to the DSAS produced coefficients of 0.64 and 0.71, respectively. These ratings compare favourably with those of previous studies using disease-specific adherence scales designed by DiMatteo and colleagues (DiMatteo, et al. 1992; Sherbourne, et al. 1992). For example, measures of adherence to Non-Insulin Dependent Diabetes, Hypertension, and Heart Disease have produced Chronbach's alphas of 0.69 and 0.67, 0.50 and 0.50, and 0.53 and 0.47 (Sherbourne, et al. 1992).

The General Adherence Scale.

General tendencies to adherence to medical recommendations were assessed using the General Adherence Scale (GAS; DiMatteo, et al. 1992; Sherbourne, et al. 1992). The GAS is a five item measure of general adherence tendencies. Respondents used a six-point Likert scale ranging from *None of the time* to *All of the time* (**Figure 3.3**). High scores indicate tendencies to adhere closely to medical recommendations. The items of the GAS were structured to assess adherence over the previous four weeks.

The GAS has been employed in the large scale Medical Outcomes Study (MOS) in the United States, and has a reported internal consistency of $\alpha = 0.80$, along with a two-year test-retest correlation of 0.41 (DiMatteo, et al. 1992; Sherbourne, et al. 1992). In the present study, adolescent and parent responses to the GAS produced Chronbach's alphas of 0.79 and 0.81, respectively.

The GAS was employed to examine participants' overall intentions to adhere. Items in the GAS did not identify specific recommendations, but focused on the overall tendencies of participants to adhere to medical recommendations. This design allowed the direct comparison of participants' responses to identical questions without regard for the specific recommendations given.

The GAS was selected in light of developments in the adherence literature which point to the advantage of employing multiple forms of adherence assessment (Dunbar, 1983). More particularly, some authors have advocated the systematic use of both generalised and specific self-report measures of adherence, as each form of adherence measure provides unique information, their combined use therefore gives a more complete representation of patient adherence (RD Hays & DiMatteo, 1987).

3.3.1.2 Psychosocial Functioning.

This study employed two measures of specific aspects of psychosocial functioning; the Conflict Behavior Questionnaire and the Autonomous Functioning Checklist.

The Conflict Behavior Questionnaire.

Parent-adolescent conflict was assessed using the Conflict Behavior Questionnaire (CBQ; Robin & Foster, 1988a). The CBQ is a twenty item measure of conflict and communication between adolescents and parents. Respondents use a *true-false* format to indicate acceptance of statements describing interactions between adolescents and parents (**Figure 3.4**). Parents and adolescents completed parallel versions of the CBQ. High scores indicated high levels of conflict between adolescents and parents. Items ask about interactions over the previous two to three weeks. The CBQ has been designed for use with adolescents aged between 10 and 19 years, and their parents.

The Original version of the CBQ (Prinz, Foster, Kent, O'Leary, 1979) contained 75 items. A subsequent 20-item short form has been constructed through item analysis, retaining the items most strongly correlated with scale scores and best discriminating distressed and non-distressed families. The 20-item short form, used in the present study, yields a single summary score that correlates highly ($r = 0.96$) with scores on the original long form (Robin & Foster, 1988a). In the present study, adolescent and parent responses to the CBQ produced Chronbach's alphas of 0.80 and 0.91, respectively.

Evidence for the discriminant and criterion validity of the CBQ is available from three studies comparing the responses from members of families referred to family therapy clinics with responses from members of non-referred families (Prinz, et al. 1979; Robin & Foster, 1984; Robin & Weiss, 1980). Clinic referred mothers, fathers, and

adolescents reported significantly more negative appraisals of the dyadic relationship. Data from these studies were pooled with preassessment data from two treatment studies to product-aggregated normative data for 137 clinic-referred and 68 non-clinic families (Robin & Foster, 1984). The CBQ reports also showed significant decreases in parent and adolescent scores following both behavioural and nonbehavioural family interventions (Foster, Prinz & O'Leary, 1983; Robin, 1981). In addition, the CBQ correlates strongly (r = -0.52) with problem-solving communication behaviour coded from audiotaped interaction tasks, and with the Dissatisfaction with Childrearing Scale of the Marital Satisfaction Inventory, yielding evidence for construct validity (Robin & Foster, 1984, 1988a).

The Autonomous Functioning Checklist.

Adolescents' autonomy was assessed using the Autonomous Functioning Checklist (AFC; Sigafoos, et al. 1988), completed by adolescents and parents. The AFC is a 78 item measure which generates a total score as well as four subscale scores: Self- and Family-Care, Management Activity, Recreational Activity, and Social / Vocational Activity. Respondents used a five-point rating scale ranging from *Does not do* to *Does every time there is an opportunity* for each of the first three subscales (**Figure 3.5**). For the final subscale, respondents used a dichotomous *yes-no* response format, whereby the performance of specific activities is indicated. High scores on each of the subscales indicated high levels of autonomy experienced by the adolescent. The AFC is designed to measure the transition from reliance on parents for care-taking to self-reliance amongst twelve- to eighteen-year olds.

The first subscale, Self- and Family-Care, is a 22 item measure of the extent to which the adolescent performs activities related to self-care and daily maintenance activities for family members (e.g., medical care, meal preparation, household chores). Possible scores on this subscale range from 0 to 88.

The second subscale, Management Activity, is a 20 item measure of adolescents' use of resources within their environment, and the adoption of responsibility for obligations (e.g., using banking services, planning transportation to special activities). Possible scores range from 0 to 80.

The third subscale, Recreational Activity, is a 16 item measure of the ways in which adolescents spend free time. For example, spending time in shopping areas, listening to music, or engaging in extra-curricular learning activities. The possible range of scores for this subscale is 0 to 64.

The final subscale, Social and Vocational Activity, is a 20 item measure of involvement in social and potentially career-related activities. Items for this subscale were scored dichotomously. Examples of activities described include maintaining close friendships with teenagers of the opposite sex, performing volunteer work, and participating in extracurricular groups. The scoring range was 0 to 20.

The psychometric properties of the Autonomous Functioning Checklist were evaluated in a study of 349 families (Sigafoos, et al. 1988). The four subscales were reported to have internal consistencies of $\alpha = 0.82$, $\alpha = 0.86$, $\alpha = 0.79$, and $\alpha = 0.76$ respectively. Scores on each subscale were significantly correlated with adolescents'

age ($p < 0.05$), suggesting appropriate concurrent validity. In a subsample of 52 families, both parents completed the AFC, inter-rater reliabilities were statistically significant for all subscales ($p < 0.01$; Sigafoos, et al. 1988). The range of obtained scores in these studies was broad, suggesting acceptable discriminant validity (Sigafoos, et al. 1988).

In the present study, adolescent responses to the four subscales of the AFC produced Chronbach's alphas of 0.85, 0.84, 0.78 and 0.66, respectively. Parent responses to the four subscales of the AFC produced Chronbach's alphas of 0.84, 0.85, 0.69 and 0.75, respectively. Chronbach's alphas for the total AFC scales by adolescents and parents in this study were 0.90 and 0.91 respectively.

3.3.1.3 Antecedents of Adherence.

This study employed three measures of factors reported to be antecedents of adherence in adults. These measures were included to test the applicability of these factors to adolescents' adherence. These measures were: the Adherence Determinants Questionnaire, the Health Value Scale, and the Diabetes Knowledge Questionnaire. Demographic information was also collected. In addition, the Socially Desirable Response Set was included to determine whether measures employed in the study were influenced by socially desirable responding.

The Adherence Determinants Questionnaire.

A range of proposed antecedents of adherence were assessed using the Adherence Determinants Questionnaire (ADQ; DiMatteo, Hays, et al. 1993; Sherbourne, et al. 1992). The ADQ is a 38 item measure consisting of seven scales: (*a*) Interpersonal Aspects of Care, (*b*) Perceived Utility, (*c*) Perceived Severity, (*d*) Perceived Susceptibility, (*e*) Subjective Norms, (*f*) Intentions to Adhere, and (*g*) Supports / Barriers. Respondents use a five-point Likert scale ranging from *Strongly Agree* to *Strongly Disagree* (**Figure 3.6**).

A number of items in the ADQ (items 15, 17-24) are designed to be tailored to the specific regimen involved; for example, in a study of cancer patients performed by DiMatteo, Hays, and colleagues (1993), item 17 read: "There are many diseases more severe than the kind of cancer I have." The same item read "There are many diseases more severe than the kind of diabetes I have," in the present study of adolescents with IDDM.

Interpersonal Aspects of Care. The first scale of the ADQ is an eight item measure of rapport between patients and health professionals. Higher scores indicate greater rapport; the possible range of scores for this scale is 8 to 40.

Perceived Utility. The second scale of the ADQ is an eight item measure of respondents' perceptions of the usefulness of their medical treatment. This scale includes two sections, the first relating to the benefits and costs of treatment, the

second relating to the efficacy of treatment. High scores on this scale indicate greater perceived utility of prescribed treatment; the possible range of scores is 8 to 40.

Perceived Severity. The third scale of the ADQ is a four item measure of respondents' perceptions of the seriousness of their illness. Higher scores indicate greater perceived severity, scores for this scale have a possible range of 4 to 20.

Perceived Susceptibility. The fourth scale of the ADQ is a four item measure of respondents' beliefs about their vulnerability to illness. In the case of chronic illnesses, perceived susceptibility relates to respondents' beliefs about their vulnerability to relapses. Higher scores indicate greater perceived susceptibility; the possible scoring range for this scale is 4 to 20.

Subjective Norms. The fifth scale of the ADQ is a six item measure of respondents' beliefs about the expectations of their families and friends, as well as the importance of these expectations to the respondent. Following the recommendations of Ajzen and Fishbein (1980), the Subjective Norms section contains three pairs of statements, relating to the expectations of the respondents' immediate family, close friends, and relatives. The first statement in each pair (*Normative belief*) described the expectations of others, for example "My close friends think I should follow my treatment plan." The second statement (*Motivation*) described the importance of these expectations to the respondents, e.g., "I want to do what my close friends think I should do about my treatment plan." As recommended by Ajzen and Fishbein (1980), scores on the two statements were multiplied to form a score for each of three social norm sources: family, friends, and relatives. Responses were re-coded as follows:

Normative belief, Strongly agree = +2, Agree = +1, Neither agree nor disagree = 0, Disagree = -1, Strongly Disagree = -2); *Motivation*, Strongly agree = 3, Agree = 2, Neither agree not disagree = 1, Disagree = 0, Strongly Disagree = 0. High positive scores on this range indicate a positive social influences, high negative scores indicate negative social influences. The possible range of scores for this section is -18 to +18.

Intentions to Adhere. The sixth scale of the ADQ is a four 4 item measure of respondents' commitment to their treatment plans. High scores on this scale indicate strong intentions to adhere to treatment in the future; the possible range of scores for this scale is 4 to 20.

Supports / Barriers. The seventh scale of the ADQ is a four item measure of barriers preventing respondents from adhering to their treatment plans, and supports which assist their adherence. High scores indicate a supportive environment for regimen adherence; the possible scoring range is 4 to 20.

The psychometric properties of the Adherence Determinants Questionnaire were assessed in a series of studies employing this measure to examine groups with three different chronic illnesses (DiMatteo, Hays, et al. 1993). As shown in **Table 3.1**, these scales produced reasonable alpha reliability and homogeneity estimates. In the present study, the alpha reliabilities of these scales were similar to those reported by DiMatteo, Hays, and colleagues (**Table 3.2**).

The Health Value Scale.

Respondents' value of good health was assessed using the Health Value Scale (HVS; Lau, Hartman & Ware, 1986). The HVS is a four item measure of the importance attached to good health. Respondents use a five-point Likert scale ranging from *Strongly Agree* to *Strongly Disagree* (**Figure 3.6**). High scores indicate a high value attributed to maintaining good health.

A series of studies reported by Lau and coworkers (1986) examined the reliability of the HVS. Alpha reliabilities ranged from $\alpha = 0.63$ to $\alpha = 0.73$, and the test-retest reliability of the scale over an 18-month period was 0.86. In the present study, adolescent and parent responses to the HVS produced Chronbach's alphas of 0.69 and 0.72, respectively.

The Diabetes Knowledge Questionnaire.

Knowledge of IDDM treatment was assessed using the Diabetes Knowledge Questionnaire (DKQ). The DKQ is a 15 item measure assessing knowledge of diabetes treatment. Respondents identify correct answers to questions asking about aspects of IDDM management, using a multiple choice format. High scores indicate good knowledge of IDDM management.

The DKQ used in this study was a slightly modified version of the original Diabetes Knowledge (DKN) scale developed by Dunn and colleagues (1984). IDDM management practices have advanced since the DKN scale was first developed,

making some of the items redundant. Despite an extensive review of the literature, no more suitable diabetes knowledge assessment device was located. In light of this, the investigator made slight adaptations the DKN to suit current diabetes management techniques.

Items in the original questionnaire which related to aspects of self-management that are no longer practiced were deleted (e.g., insulin testing of urine). New items were added after consultation with the Diabetes Clinical Nurse Consultant at the Diabetes Outpatient Clinic at the WCH. These items were designed to reflect the current management practices most equivalent to those deleted from the original scale. Similarly, items relating to diet were updated to reflect current practice, after consultation with the Dietitian attached to the Diabetes Team at the Women's and Children's Hospital. As with the Diabetes Specific Adherence Scale, a draft version of the new knowledge assessment device was circulated to members of the WCH Diabetes Team.

These procedures resulted in the new Diabetes Knowledge Questionnaire (DKQ). The DKQ consists of the same number of items as the original scale. The internal reliability of the revised scale was assessed using Chronbach's alpha; adolescent and parent responses to the scale generated alpha reliabilities of 0.62 and 0.64, respectively.

Demographic Information.

To provide information about the demographic characteristics of the sample, parents completing the questionnaires were asked to provide information about participating adolescents and their families. The questions asked in this section of the questionnaire are shown in **Appendix A.6**.

The Socially Desirable Response Set.

The influence of socially desirable responding on the measures used in this study was assessed using the Socially Desirable Response Set (SDRS; RD Hays, Hayashi & Stewart, 1989). The Socially Desirable Response Set is a five item measure designed to estimate whether self-reports are associated with a tendency to portray an image of desirable behaviour. Respondents use a five-point Likert scale ranging from *Definitely True* to *Definitely False* (**Figure 3.7**). High correlations between scores on self-reports and the SDRS are indicative of socially desirable responding on the self-report measure.

RD Hays and colleagues (1989) reported the psychometric properties of the SDRS to be satisfactory; finding alpha reliabilities of 0.66 and 0.68 in two different samples, with a one-month test-retest reliability of 0.75.

3.3.2 Objective Measure of Blood Glucose Monitoring.

Self monitoring of blood glucose is an important aspect of IDDM self-care (Newton & Greene, 1995). Adolescents with IDDM are typically recommended to monitor blood glucose at least twice daily. The results obtained from self-monitoring are used to adjust insulin doses, and provide an indication of the current health status of the adolescent.

The data downloaded from the electronic memories of blood glucose sensors were coded to examine the tests performed in the four weeks prior to clinic attendance. This data reflected the same time period as the self-report and parent reports of adherence. The data were coded to assess BGM adherence in two ways: (1) the number of days in the previous four weeks in which two or more blood glucose tests were performed, and (2) the total number of blood glucose tests performed in the previous four weeks. The former system of data coding was intended to reflect the number of days on which the adolescents had adhered to their BGM recommendations (see **Section 3.1**).

3.3.3 Metabolic Control Measure.

Adolescents' level of metabolic control was determined by Glycosylated Haemoglobin A_{1c} (HbA_{1c}) assays. These assays are recorded as a part of routine clinical care in the hospital.

HbA_{1c} measurement provides a more stable indication of metabolic control than blood glucose monitoring, which may vary from day to day. The level of haemoglobin A_{1c} present in blood provides an indication of the mean blood glucose concentration of the preceding two or three months (Olson, 1988). HbA_{1c} is widely accepted as the most informative measure of metabolic control and health status amongst diabetic patients, and is predictive of long term health outcomes for diabetic patients (Diabetes Control and Complications Trial Research Group, 1995; Nathan, Singer, Hurxthal, Goodson, 1984). HbA_{1c} is present at increased levels in people with diabetes mellitus (Olson, 1988; Scobie & Sönksen, 1984).

Glycosylation is the chemical reaction between glucose and haemoglobin, whereby glucose and haemoglobin are joined together once the haemoglobin has been synthesised by the erythrocyte (or red blood cell). A single blood sample that measures glycosylated haemoglobin reflects the time-averaged blood glucose over the preceding four to six weeks - the average age of the erythrocyte (Brink, 1987). The erythrocyte is permeable to glucose, and within each erythrocyte glycosylated haemoglobin is continuously formed at a rate proportional to the levels of ambient glucose during its lifetime (Brink, 1987).

Glycosylation is a gradual process, and is irreversible. As a consequence, the results of glycosylated haemoglobin (HbA_{1c}) assays, unlike blood glucose levels, are not susceptible to fluctuations because of temporary changes in activity or food intake. A reduction in HbA_{1c} levels is interpreted as an indication of improved metabolic control. This is achieved by monitoring blood glucose levels and adjusting insulin dosage accordingly.

Haemoglobin A_{1c} typically comprises 3 to 6 per cent of the total haemoglobin in persons without diabetes, and in excess of 6 % in persons with diabetes (Koenig, et al. 1976). For adolescents with IDDM, 6 to 8 % HbA_{1c} is considered to indicate good control, 8 to 10 % to indicate moderate control, and over 10 % to signify poor control (Diabetes Control and Complications Trial Research Group, 1995). The measurement of HbA_{1c} was performed using Bayer Diagnostics DCA 2000® Analysers, which have a measurement range of 2.5 % to 14 %.

3.4 Statistical Analyses.

This section provides an overview of the data handling and statistical analyses employed in this study. The specific techniques used for analyses are described in greater detail in the text at the point at which they are utilised. A summary of the statistics employed is given in **Table 3.3**.

3.4.1 Data Entry.

The self-report, parent report, and HbA_{1c} data were all entered into a database using the FORMS data entry module for SIR database software version 3.2 (SIR, 1993). All data was entered and re-entered for verification purposes. Blood Glucose Monitoring data was downloaded from the sensors' memories and entered directly into the database. The data was then exported into SPSS for Windows, version 6.1 (SPSS, 1994).

3.4.2 Basic Statistics.

Means, standard deviations (*SD*s), maxima, minima, and 95% confidence intervals (CI) were calculated for measures of adherence, adolescent autonomy, parent-adolescent conflict, and other proposed antecedents of adherence. These are presented, along with statistics about the demographic characteristics of the sample, in **Chapter 4**. Where possible, demographic characteristics of the sample are compared with Australian population data.

3.4.3 Exploratory Analyses.

Exploratory analyses in this thesis examined four major issues.

The first set of analyses are presented in **Chapter 5** and discussed in **Chapter 6.** These analyses examine the relationships between the different adherence measures employed in this thesis. Correlations between adolescent self-reports, parent reports, and BGM adherence observations are described. Further, the variation in reported adherence according to demographic characteristics such as adolescents' age and gender is reported. Other analyses in this chapter examine the variation in observed adherence over time. These analyses are based upon the objective BGM adherence data obtained from the blood glucose sensors. A Repeated Measures Analysis of Variance (ANOVA) is employed to determine whether the observed BGM adherence level varied over the time leading up to clinic attendance. The level of association

between each of the adherence measures and HbA_{1c}, the measure of metabolic control, is examined.

The second set of analyses, which are presented in **Chapter 7** and discussed in **Chapter 8**, test the first hypothesis of this thesis. The levels of association between adolescents' and parents' reports of conflict and each of the measures of adherence are examined. Further, the associations between reports of parent-adolescent conflict and adolescents' metabolic control are examined, including multivariate analyses of the relationship between metabolic control, adherence, and parent-adolescent conflict.

The third set of exploratory analyses are presented in **Chapter 9** and discussed in **Chapter 10**. These analyses test the second hypothesis of this thesis. The levels of association between adolescents' and parents' reports of the adolescents' autonomy and each of the measures of adherence are examined. Further, the associations between reports of adolescent autonomy and adolescents' metabolic control are examined, including multivariate analyses of the relationship between metabolic control, adherence, and adolescent autonomy.

Finally, exploratory analyses examine the association between each of the measures of adherence and the proposed antecedents of adherence obtained from previous studies of adherence amongst adult populations. These analyses are presented in **Chapter 11** and discussed in **Chapter 12.** The purpose of these analyses is to determine the utility of these factors in predicting adherence in a sample of adolescents with a chronic illness. Previous research has identified each of these issues as predictive of adherence amongst adults with chronic illnesses.

In some instances, multiple comparisons were made between groups of respondents involved in the study. For example, the variation in parent-adolescent concordance on the Diabetes Specific Adherence Scale according to adolescents' age is examined in **Section 5.2.1**; this analysis involves a total of fifteen comparisons. Feild and Armenakis (1974) have pointed out that in such circumstances the probability of obtaining significant results (by making a Type I error) is increased. These authors argue against the use of multiple tests without taking this increase into account. One approach used to account for this is to proceed with the multiple significance tests, but to regard as significant only those differences that are significant at a level lower than the conventional 0.05 level. For example, the $\alpha = 0.01$ level may be used instead of the $\alpha = 0.05$ level. While this approach does have the disadvantage of increasing the probability of making a Type II error (failing to reject the null hypothesis when it is false), the benefit of the reduction in risk of Type I errors may be considered to be more important (cf. Snedecor & Cochran, 1980; Winer, 1971). The statistical tests for group differences become more conservative under this approach (Feild & Armenakis, 1974). This approach was generally used in the analyses presented in this thesis.

Similarly, where analyses of variance have detected significant variations between groups, post hoc analyses were conducted to determine the location of the group differences. In this thesis, Tukey's Honestly Significant Difference was used to examine pairs of means to determine where group differences were located. Although a range of other post hoc analyses are available, this approach has been recommended by several authors, because of its broad applicability, moderate conservatism, and

simplicity (Hatcher & Stepanski, 1994; WL Hays, 1988; Norman & Streiner, 1994; Winer, 1971).

3.4.4 Advanced Analyses.

More advanced analyses are also reported in each of the subsequent chapters. These analyses build on the exploratory analyses overviewed in **Section 3.4.3**. As such, these analyses are not described in detail here, but are detailed in the appropriate sections of the subsequent chapters.

Finally, a multivariate model of adherence prediction is developed in **Chapter 13** and discussed in **Chapter 14**, by examining variance in adherence explained by the combination of measures of psychosocial functioning and of proposed antecedents of adherence.

CHAPTER FOUR.

DEMOGRAPHIC AND PSYCHOSOCIAL CHARACTERISTICS OF THE SAMPLE.

This chapter describes the characteristics of the participants in the study. This chapter consists of two sections. First, the demographic characteristics of the sample are described. Second, descriptive statistics of the participants' responses to the measures used in the study are described.

4 DEMOGRAPHIC AND PSYCHOSOCIAL CHARACTERISTICS OF THE SAMPLE

4.1 Sample Characteristics.

Subject recruitment was conducted in the Diabetes Outpatient Clinic at the WCH for a period of twelve months, between June, 1995 and June 1996. During this time, every adolescent meeting the eligibility criteria described in **Chapter 3** was approached to participate in the study. In total, 135 adolescents and their parents agreed to participate. Only three eligible adolescents declined to participate, giving a response rate of 97.8 %.

Two caveats about the generalisability of this sample should be considered. First, four adolescents who met the age and IDDM duration entry criteria for inclusion were excluded from the sample due to intellectual (n = 3) or language (n = 1) difficulties. Second, the adolescents involved in this sample all attended the Outpatient Clinics; it is possible that other adolescents, who did not attend any Outpatient Clinics during the study period, may have differed from those involved in the study. Although no adolescents were known to have missed all of their Outpatient appointments during this interval, it is possible that some adolescents who receive IDDM care only through private medical practices may have differed from those involved in the sample. However, there are believed to be very few adolescents in South Australia fitting this category.

Table 4.1 provides descriptive statistics of the obtained sample, **Table 4.3** details the occupational prestige and educational attainment of the parents of sample adolescents.

Adolescents' Age and Gender Distributions.

The distribution of the sample across the target age range was even, with approximately equal groups of adolescents in each age strata (i.e., 12 year olds, 13 year olds, etc). A higher percentage of female than male adolescents were recruited into the study (**Table 4.1**). **Table 4.2** displays the adolescents' age by gender distributions. The sample included larger numbers of 12 and 15 year old females than males, although the gender distributions in the other age strata were approximately balanced.

IDDM Duration.

The adolescents' time since diagnosis with IDDM was reported by parents. Examination of a random selection of medical charts suggested that this information was reported accurately. The impact of IDDM diagnosis on the functioning of families, and on parents and adolescents, is thought to recede with time (Sheeran, et al. 1997). Adolescents diagnosed for less than one year were excluded from the study because of the variable nature of the illness during the first 6-12 months after diagnosis, when natural insulin may be sporadically produced (Burcelin, et al. 1993; Dorchy, 1995).

The mean duration of IDDM diagnosis is shown in **Table 4.1**. The distribution of IDDM duration is slightly positively skewed (skewness = 0.54). This finding is not surprising, as younger adolescents are unlikely to have been diagnosed for a long period.

Marital Status of Parents.

A high proportion of the adolescents involved in the study were from two-parent households, the majority of the remainder were living in single-mother households (**Table 4.1**). This pattern was similar to South Australian (dual parent = 79.6 %, single mother = 18.1 %, single father = 2.3 %) and Australian (dual parent = 81.0 %, single mother = 16.6 %, single father = 2.3 %) data for families with dependent children collected by the Australian Bureau of Statistics at the time of the study (Australian Bureau of Statistics, 1996).

Information about whether the parents involved in the study had entered second (or later) marriages, and if so whether these marriages had been formed before or after the adolescents' diagnosis with IDDM, was not collected. This could be an informative point for future investigations.

Family Size.

Families ranged in size from one to six children under the age of twenty. The average size of families was 2.39 children (*SD* = 1.04). Due to differences in the classification

system used by the Australian Bureau of Statistics, it was not possible to compare these data with general population figures.

Occupational Prestige and Educational Attainment of Parents.

The distribution of occupational prestige of parents was coded using Daniel's (1983) Australian Occupational Prestige Scale. Lower ratings on the scale equate with more prestigious occupations. A large proportion of mothers, and one father, identified "home duties" or "domestic duties" as their occupation. The Daniel Scale codes this response as a separate category. Parents identified as students, unemployed, retired or pensioners were grouped into a single category (**Table 4.3**).

The majority of fathers were identified in occupations of middle prestige, while most mothers were identified as performing home duties or occupations of middle prestige. Due to differences in the classification system used by the Australian Bureau of Statistics and the Daniel scale, it was not possible to make meaningful comparisons of this sample with the general population.

4.1.1 Comparison of Complete Thesis Sample and Sample Providing BGM Data.

As described in **Chapter 3**, BGM data were obtained on seventy-five adolescents. BGM data were only obtained from those participants using a MediSense™ blood glucose sensor. Because these sensors were supplied to adolescents with poor metabolic control (see **Chapter 3**), it was expected that the mean HbA_{1c} of these

adolescents would be higher than that of the remaining 60 adolescents. Further, it is possible that the adherence of the adolescents supplied with MediSense™ sensors may have differed from the other adolescents.

Student's *t* tests were performed to determine whether the adolescents from whom BGM data were collected differed from those adolescents from whom this data could not be collected.

Table 4.4 displays the means (± *SD*s) for each group, and the significance levels of the *t* tests. The adolescents from whom BGM data were collected did not differ significantly[1] from the rest of the sample in terms of age or gender distributions. Reports of diabetes-specific adherence (DSAS) obtained from the adolescents in each group and from their parents were similar.

However, the mean duration of diagnosis of IDDM was significantly greater for those adolescents from whom BGM data were collected than for those from whom this information could not be obtained. This suggests that poor metabolic control in these adolescents may be linked to the amount of time elapsed since diagnosis.

As expected, the mean HbA_{1c} result amongst the adolescents from whom BGM data were collected was significantly higher than that of the remaining adolescents. Interestingly, the reports of general adherence to medical treatment (GAS) obtained from the adolescents from whom BGM data were collected, as well as the reports from the parents of these adolescents, were significantly lower than the reports

obtained from the remaining adolescents and parents. It is possible that the lower level of adherence reported by the adolescents from whom BGM data were collected was responsible for their poorer metabolic control.

4.2 Descriptive Statistics of Sample Responses.

This section provides basic statistics for the data obtained in the study. Descriptive statistics (e.g., means and *SD*s) are provided for the various measures used in the study, initially in relation to the entire sample, and subsequently in relation to various demographic characteristics. Responses to each of the measures in the present study will be compared with responses obtained on these measures in previous research. Finally, the relationship between scores of Socially Desirable Responding with the various questionnaire-based measures will be presented.

4.2.1 Measures of Adherence to Medical Recommendations.

This study used two questionnaire measures of adherence to medical regimens, the General Adherence Scale (GAS), and the Diabetes Specific Adherence Scale (DSAS). A third measure of adherence, specific to blood glucose monitoring, was assessed by means of the electronic recording of BGM on blood glucose sensors designed with this capacity. In this section the descriptive statistics of responses to each of these measures by the study participants are presented.

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[1] Throughout this thesis, except where otherwise stated, $\alpha = 0.05$ significance levels are employed.

4.2.1.1 The General Adherence Scale.

The range of responses obtained on the GAS from adolescents and parents, and their mean scores (± *SD*s) are shown in **Table 4.5**. Responses on the GAS ranged widely, with mean scores falling above the scale centre-point.

Responses to the GAS were not associated with adolescents' gender or age. A summary of responses by adolescents and parents to the GAS according to the adolescents' gender and age is shown in **Table 4.5**.

The GAS has been used in several previous investigations in North America. First, the Medical Outcomes Study prospectively investigated the health of 2181 adults with chronic conditions (RD Hays, et al. 1994; AL Stewart, et al. 1989; AL Stewart & Ware, 1992; Tarlov, et al. 1989; Wells, et al. 1989). In this study, mean responses to the GAS according to age strata varied between 21.1 (*SD* = 5.8) for 18 - 44 year olds, and 25.4 (*SD* = 4.9) for those over 75 years of age (DiMatteo, et al. 1992). The mean responses and the degree of variation found in the present study were consistent with these results. The Medical Outcomes Study did not investigate 12 to 18 years olds, preventing direct comparison with the present study.

DiMatteo, Hays, and colleagues (1993) also examined the adherence of several groups of adult patients (total n = 465). The level and distribution of adherence reported in these samples were similar to those found in the present study. Although, the investigation by DiMatteo and colleagues examined adult patients with conditions other than IDDM, the similar spread of responses obtained, both from the adolescents

and parents in this study, suggests that this scale is acceptable for use with adolescent populations.

An Australian study has employed the GAS in an investigation of parents' adherence to their young children's asthma treatment (Jilbert, 1995). This study examined parents' adherence to asthma regimens prescribed for children between 5 and 12 years of age. In this study, parents' reported adherence levels were higher than in the previous investigations, with a mean GAS score of 27.2 (SD = 3.2). However, the sample in this study was small (n = 47). It is possible that the higher reported adherence in this study may reflect parents' greater concern for their child's health than for their own health.

The present study found that parents' and adolescents' reports of adherence were very similar, and that the level of adherence described was consistent with the previous studies by DiMatteo and colleagues (DiMatteo, Hays, et al. 1993; DiMatteo, et al. 1992). The very similar mean responses to the adherence measures suggests that these measures may be reliably completed by adolescents and parents. Adolescents and parents completed the measures independently.

4.2.1.2 The Diabetes Specific Adherence Scale.

As may be seen in **Table 4.6**, the range of responses obtained on the DSAS from adolescents and parents were similar. Mean responses were above the centre-point for

both groups of respondents, indicating that adherence had typically been reported for *A good bit of the time* on this questionnaire.

Table 4.6 displays a summary of responses by adolescents and parents to the DSAS according to adolescents' gender and age. There was no significant association between adolescents' gender and responses made on the DSAS, although male adolescents and their parents reported slightly higher levels of adherence than did female adolescents and their parents. Responses to the DSAS by adolescents and parents were also unrelated to the adolescents' age. The link between adolescents' demographic characteristics and adherence reporting is more closely examined in **Chapter 5**.

Because the DSAS was slightly modified to address current treatment of Insulin-Dependent Diabetes, it is not possible to compare the responses obtained from adolescents and parents on this scale with responses obtained in previous research.

4.2.1.3 Blood Glucose Monitoring.

Blood Glucose Monitoring data were coded in two forms: (1) the number of appropriate days of blood glucose monitoring in the previous four weeks; and (2) the total number of blood glucose tests performed in the previous four weeks. As described in **Chapter 3**, and following the recommendations given to the participating adolescents, appropriate days of blood glucose monitoring were clinically defined as a minimum of two blood glucose tests per day.

A summary of the obtained BGM data is presented in **Tables 4.7** and **4.8**. It should be noted that the maximum possible number of tests is shown as one hundred and twenty five, as this is the memory capacity of the Companion 2™ sensors. **Table 4.7** displays the BGM data as number of tests performed in the previous four weeks, while **Table 4.8** displays the data as appropriate days of BGM in the previous four weeks.

The observed level of adherence to BGM varied widely. These adolescents performed a mean of 37.1 blood glucose tests in the previous four weeks (*SD* = 28.5), representing a mean of 11.9 days of appropriate testing (*SD* = 10.3).

In contrast to the questionnaire based measures of adherence, observed BGM adherence was slightly higher amongst female adolescents than male adolescents. This difference was not large; a *t*-test analysis of these results did not reach statistical significance. Adherence to BGM was significantly related to adolescents' age; younger adolescents' displaying greater adherence to BGM than older adolescents ($F = 3.08$; $df = 5,69$; $p = 0.02$).

4.2.2 Measures of Psychosocial Functioning.

This study involved the use of two measures of psychosocial functioning, the Conflict Behavior Questionnaire (CBQ), and the Autonomous Functioning Checklist (AFC). In this section the descriptive statistics of responses to each of these measures by the study participants are presented.

4.2.2.1 The Conflict Behavior Questionnaire.

Summary statistics for responses to the CBQ are shown in **Table 4.9**. Obtained scores on the parent and adolescent forms of this measure varied widely. However, the mean scores produced by both groups of respondents were low - the mean score obtained from parents was 5.2, and from adolescents was 5.7 - from a possible scoring range of 0 - 20. Responses on the CBQ were not significantly related to adolescents gender or age. The CBQ also generates a combined score, by summing the responses of adolescents and parents. **Table 4.10** displays the scoring distributions of the combined CBQ scores.

Normative data for the CBQ, produced in the United States, are presented in **Table 4.11**. Normative data for this scale produced in Australia are not currently available. This data presents mean (± *SD*) scores for families rated as exhibiting clinically significant levels of distress and conflict, and for families without this level of conflict. Previous studies have found that the CBQ discriminates families with clinically significant levels of distress and conflict from families with less conflict (Prinz, et al. 1979; Robin & Foster, 1984; Robin & Weiss, 1980). Note that although the normative data distinguishes mother-adolescent and father-adolescent conflict, in the present study the number of participating fathers was small, so the data were merged to produce parent-adolescent data (see also **Chapter 7**).

The data obtained in the present study indicate that the level of conflict reported by adolescents and parents was lower than in the families deemed clinically distressed in the normative data. The present data also suggest that the level of conflict experienced by participants in this study was greater than that of the normative sample of families with subclinical levels of distress. This finding suggests that the families of adolescents with IDDM may experience more conflict than the general population of families with adolescents, but less conflict than those families requiring clinical intervention.

4.2.2.2 The Autonomous Functioning Checklist.

Summary statistics for responses to the Autonomous Functioning Checklist are displayed in **Table 4.12**. The scoring distributions and scoring ranges on the total scale of the AFC according to adolescents' gender and age are shown in **Table 4.13**. To determine whether adolescents' autonomy, as reported by adolescents and parents, was associated with the adolescents' age, a One-Way Analysis of Variance was performed. Adolescents' and parents' reports of adolescents' autonomy were both significantly associated with the adolescents' age, such that older adolescents were reported to behave more autonomously (Adolescents: $F = 5.13$; $df = 5,126$; $p < 0.0003$. Parents: $F = 7.99$; $df = 5,133$; $p < 0.001$). Similarly, to test the relationship between reports of autonomy and adolescents' gender, *t*-tests were performed. Adolescents' reports of autonomy were higher amongst female adolescents than male adolescents ($t = -2.38$, $df = 125$, $p = 0.02$); parents' of female and male adolescents did not provide significantly different reports of their adolescents' autonomy. The finding

that adolescents' reported autonomy was associated with their age was consistent with the findings reported by Sigafoos and colleagues (1988) in developing the scale. This finding also provides evidence for the concurrent validity of this measure in this population (Sigafoos, et al. 1988).

Mean scores on each of the four subscales were similar for adolescents and parents. The distributions of responses to the four AFC subscales in relation to adolescents' gender and age are displayed in **Tables 4.14** to **4.17**.

Table 4.14 displays summary statistics for the first subscale of the AFC, Self- and Family-Care. Responses on this autonomy subscale by both adolescents and parents were significantly related to adolescents' age, responses from older adolescents and their parents indicating greater autonomy than those of younger adolescents (Adolescents: $F = 2.43$; $df = 5,126$; $p = 0.04$. Parents: $F = 5.94$; $df = 5,128$; $p < 0.001$). No significant differences were found between responses from male adolescents and female adolescents, nor between their respective parents.

Summary statistics for the second subscale of the AFC, Management Activity, are displayed in **Table 4.15**. One-way analysis of variance of responses to this AFC subscale according to adolescents' age produced significant results, both from adolescents' and parents' responses, indicating greater autonomy in older adolescents than in younger adolescents (Adolescents: $F = 12.68$; $df = 5,125$; $p < 0.001$. Parents: $F = 9.06$; $df = 5,129$; $p < 0.001$). For this subscale, adolescent responses differed significantly between males and females, with female adolescents typically achieving

higher scores (t = -2.84, df = 129, p = 0.005). In contrast, parent responses for female and male adolescents did not significantly differ.

Table 4.16 presents the summary statistics for the third subscale of the AFC, Recreational Activity. Responses to this subscale, both from adolescents and from parents, were not significantly related to adolescents' gender or age.

Table 4.17 presents the summary statistics for responses to the final subscale of the AFC, Social and Vocational Activity. Adolescents' age was significantly related to the responses of both parents and adolescents, both groups of respondents indicating greater autonomy on this subscale for older adolescents than for younger adolescents (Adolescents: F = 3.62; df = 5,127; p = 0.004. Parents: F = 4.14; df = 5,129; p = 0.002). Adolescents' gender, however, did not significantly relate to responses on this subscale.

Table 4.18 displays the normative mean (± *SD*s) scores produced by parents in a sample of 349 families (Sigafoos, et al. 1988). The comparison of the mean results for each age strata in the present study with the normative data presented by Sigafoos and coworkers suggests that the adolescents in the present study experienced lower levels of autonomy than adolescents of the same age in the previous study. There are at least three possible explanations for this finding. First, the sample of adolescents involved in the Sigafoos study were not selected on the basis of chronic medical conditions. It is possible that the lower level of autonomy reported in the present study is the result of the limitations imposed by the chronic illness experienced by these adolescents. A second possible explanation is that the difference in mean scores

produced in these studies is the result of the different locations in which the studies were conducted. Sigafoos and colleagues collected their data in the United States, while the present study was conducted in Australia. It is possible that American adolescents experience, or are perceived to experience, greater autonomy than Australian adolescents. Further use of this measure with Australian samples will clarify this point. A third possible explanation for this finding is that the clinic setting in which the AFC was completed in the present study influenced the responses of participants. Sigafoos and colleagues recruited families from a variety of organisations. Unfortunately, these authors do not indicate whether the AFC was completed at home or in the institutions through which families were contacted.

Another study employing the AFC was conducted by Howe and colleagues (1993). This study involved families of 214 adolescents aged 12 to 18 years; 80 with chronic neurological conditions (cerebral palsy, epilepsy, hydrocephalus and spina bifida), 85 with non-neurological chronic conditions (vision impairment, cystic fibrosis, IDDM and arthritis), and 49 controls. Adolescents with chronic conditions showed significantly lower levels of autonomy than their peers. Unfortunately, Howe and colleagues used a different scoring system, preventing the direct comparison of results. However, the reduced autonomy shown by adolescents with chronic conditions in the study by Howe and colleagues suggests that the lower levels of autonomy reported for adolescents in the present study when compared with Sigafoos' normative data may be the result of the limiting influence of their IDDM.

4.2.3 Measures of Proposed Antecedents of Adherence.

As described in **Chapter 3**, this study utilised three measures of antecedents of adherence, which have been found to be predictive of adherence in samples of chronically ill adults. These were the Adherence Determinants Questionnaire (ADQ), the Health Value Scale (HVS), and the Diabetes Knowledge Questionnaire (DKQ). This section describes the distributions of scores produced by study participants on each of these measures.

4.2.3.1 The Adherence Determinants Questionnaire.

Mean (± *SD*) scores for each scale of the Adherence Determinants Questionnaire are displayed in **Table 4.19**. Parent and adolescent responses were largely similar, in terms of mean scores and scoring distributions. The ADQ consists of seven scales. The distributions of parents' and adolescents' responses to each of these scales, according to the adolescents' gender and age are displayed in **Tables 4.20** to **4.26**.

Table 4.20 displays summary statistics for the first scale of the ADQ, Interpersonal Aspects of Care. Scores obtained on this scale tended to be above the midpoint, indicating good reported rapport between health professionals and adolescents and their parents. Scores obtained on this scale by both adolescent and parent respondents were not related to adolescents' age. Similarly, scores obtained by both groups of respondents were not significantly related to adolescents' gender.

The second scale of the ADQ is Perceived Utility. Summary statistics from this scale are displayed in **Table 4.21**. Responses from both groups of informants indicated generally high levels of perceived utility. Adolescent age was not significantly related to scores on the Perceived Utility scale from either adolescents or parents. Similarly, adolescent gender was not significantly related to adolescent or parent scores on this scale.

The third scale of the ADQ is Perceived Severity. **Table 4.22** presents the summary statistics of results obtained from this measure. Adolescent respondents typically produced scores in the lower half of this scale, as did their parents. However, parents more frequently produced scores approaching the scale midpoint. This result suggests that adolescents in the study tended to consider diabetes to be a less severe disease than their parents. Scores on the Perceived Severity scale obtained by adolescent and parents were unrelated to the adolescents' age. Scores obtained by adolescents on this measure were unrelated to gender, although parent scores were significantly related to their adolescent's gender, the parents of male adolescents reporting higher levels of perceived severity than the parents of female adolescent ($t = 2.56$, $df = 130$, $p = 0.01$).

Perceived Susceptibility is the fourth scale of the ADQ. Summary statistics of the results obtained on this measure are shown in **Table 4.23**. Responses obtained from both adolescents and parents, were generally distributed within the upper half of the scoring range. This result suggests that both participating adolescents and their parents deem it likely that the adolescents will experience hyperglycaemia or hypoglycaemia in the future. Results on this measure were unrelated to adolescents' age or gender.

The fifth scale of the ADQ is Subjective Norms. The scoring of this scale differs from the other scales of the ADQ, as described in **Chapter 3.** Both adolescent and parent scores on this scale were narrowly distributed; mean scores produced from both groups of respondents were slightly below zero, the scale midpoint (**Table 4.24**). The most common score produced by both adolescents and parents was zero, a score which suggests minimal influence from respondents' social environment on adherence to medical recommendation to the diabetes regimen. The distributions of scores produced by adolescents and parents on this scale were not related to adolescents' age. Similarly, the distributions of scores produced by male and female adolescents and their parents were not significantly different.

The penultimate scale of the ADQ is Intentions to Adhere. **Table 4.25** displays the summary statistics of the results obtained using this scale. Scores on this scale were most frequently above the scale midpoint, suggesting that most informants did intend to adhere to their regimen in the future. Adolescent age was not significantly related to adolescent or parent scores on this scale. Similarly, adolescent gender did not relate to scores obtained on this scale.

The final scale of the ADQ is Supports / Barriers. Adolescent and parent responses on this scale are described in **Table 4.26**. Scores on this scale were generally above the midpoint, indicating the presence of supports to adherence and/or the absence of barriers to adherence. Adolescent age was not related to either adolescent or parent scores on this scale. Similarly, adolescent gender did not relate significantly to scores on this scale by either group of respondents.

Table 4.27 displays mean scores (± *SD*s) for the scales of the ADQ in a series of studies reported by DiMatteo and colleagues, in developing this measure (DiMatteo, Hays, et al. 1993). The ADQ was used in samples of patients with various chronic conditions. Normative data for this measure cannot be reported for these scales, as they are used in relation to specific regimens. However, by comparing the data reported in **Table 4.19** with the adult self-report data obtained by DiMatteo and coworkers (**Table 4.27**), it may be seen that the mean level and distributions of responses to the scales of the ADQ in the present study were generally consistent with those in the studies reported by DiMatteo and colleagues. Responses to the Interpersonal Aspects of Care, Perceived Utility, and Supports / Barriers scales were similar to those in the studies of DiMatteo and colleagues. Adolescents' reports of Perceived Severity were lower in the present study than the responses obtained by DiMatteo and colleagues, although parents' responses were similar to those in the previous work. Perceived Susceptibility, as reported by adolescents and parents in the present study, was higher than in the previous investigation, while Intentions to Adhere were reported to be lower amongst the adolescents in the present study than amongst the participants in the previous work. These differences may be a function of the differing nature of IDDM and its treatment from the conditions examined in the previous investigation, or may reflect the different perceptions and influences on adherence for adolescents and adults.

4.2.3.2 The Health Value Scale.

The Health Value Scale was employed in this study as a measure of the importance of health to participants. **Table 4.28** contains the summary statistics of the results obtained with this measure. Scores obtained from both adolescents and parents most frequently indicated a high value attributed to health. This result was unrelated to adolescent age or gender.

Table 4.29 displays the mean scores (± *SD*s) for the Health Value Scale in studies performed by Lau and colleagues (1986), and by DiMatteo, Hays, and coworkers (1993). The samples utilised by Lau and colleagues completed the four-item HVS, with scoring ranges of either 4 to 20 or 4 to 28 (see notes to **Table 4.29**). The samples utilised by DiMatteo and coworkers completed a longer six-item version, with a scoring range of 6 to 30. The present study employed the original four-item, 5-point Likert version, with the resulting scoring range of 4 to 20. The original version was used in this study because of the availability of more data relating to its reliability and validity.

An examination of the mean scores in each of the previous samples shows that mean responses on each version of the scale were close to the three-quarter point of the scale. The mean scores produced by parents and adolescents in the present study were also close to the scale's three-quarter point. This finding suggests that the health value of the adolescents and parents participating in this study was similar to that of

the previous samples examined by Lau, et al. (1986) and DiMatteo, Hays, et al. (1993).

4.2.3.3 The Diabetes Knowledge Questionnaire.

The final questionnaire addressing antecedents of adherence in this study was the Diabetes Knowledge Questionnaire. Summary statistics of the results obtained on this measure are shown in **Table 4.30**. Parent knowledge of diabetes was on average slightly higher than adolescent knowledge, as assessed by this measure.

Adolescent age did not significantly relate to the scores obtained by either adolescents or their parents. However, although the scores obtained by male and female adolescents did not significantly differ, the scores obtained by parents of male adolescents were significantly higher than those produced by the parents of female adolescents ($t = 2.91$, $df = 132$, $p = 0.004$).

These results could not be compared with any normative data, for two reasons. First, the original Diabetes Knowledge Scale produced by Dunn and colleagues (1984) was not published with normative results. Second, the knowledge questionnaire used in this study had been slightly modified to reflect current IDDM treatment practices (see **Chapter 3**).

4.2.4 Metabolic Control.

Adolescents' metabolic control was assessed in this study by venous Haemoglobin A_{1c}, assayed in Outpatient Clinics. Mean assay values, and distributions of assay levels, are displayed in **Table 4.31**. The mean HbA_{1c} for the study sample was 9.6 % (*SD* = 1.8). There was no significant relationship between adolescent age and HbA_{1c} results. Male adolescents produced a mean HbA_{1c} 0.5 percent higher than female adolescents; this difference was not statistically significant.

4.2.5 Socially Desirable Responding.

The Socially Desirable Response Set (SDRS) was included in this study as a measure of the extent to which participants gave socially desirable answers. Socially Desirable responding has been defined in terms of providing responses which project an image that one behaves in a socially approved manner or feels socially approved feelings (RD Hays, et al. 1989).

This measure is employed to estimate whether the various questionnaire measures involved in the study appear to be associated with socially desirable responding. The level of correlation between self-report measures and the SDRS is interpreted as an indication of the degree to which respondents are responding in a socially desirable manner on that measure.

This section presents the analyses of correlations between the SDRS and the questionnaire measures. The Pearson correlations between scores on the adolescent completed and parent completed questionnaires and scores on the SDRS are shown in **Table 4.32**.

Socially Desirable Responding in Measures of Adherence to Medical Recommendations.

As may be seen in **Table 4.32**, the questionnaire measures of adherence did not strongly correlate with the SDRS. Adolescent scores on the Diabetes Specific Adherence Scale correlated significantly with SDRS scores at the $p < 0.05$ level, but not at the $p < 0.01$ level. Adolescent scores on the General Adherence Scale, as well as parent scores on both the General Adherence Scale and the Diabetes Specific Adherence Scale, were not statistically significantly correlated with SDRS scores.

Socially Desirable Responding in Measures of Psychosocial Functioning.

The correlations between the SDRS and the psychosocial measures are shown in **Table 4.32**. Adolescent scores on the AFC were associated with the SDRS at statistically significant levels; the Management Activity and Social & Vocational Activity subscales were particularly closely related to the measure of socially desirable responding. Parent scores on the AFC were less closely associated with scores on the measure of socially desirable responding, although both the Management Activity and the Recreational Activity subscales were significantly correlated with SDRS scores.

Correlations between scores on the CBQ and the SDRS by both adolescents and parents did not reach the traditional cutoffs for statistical significance.

Socially Desirable Responding in Measures of Antecedents of Adherence.

As may be seen in **Table 4.32**, adolescent scores on several subscales of the ADQ were significantly correlated with scores on the SDRS. In particular, the Perceived Utility and Intentions to Adhere subscales, when completed by adolescents, were strongly associated with responses to the SDRS. In contrast, responses to the ADQ subscales obtained from parents were not associated with their responses to the SDRS at traditional statistically significant cutoff levels.

Similarly, adolescent responses to the Health Value Scale were strongly correlated with responses to the SDRS, while parent responses on the same scale were only weakly correlated with SDRS scores.

The Influence of Socially Desirable Responding in the Present Study.

In sum, the levels of association between responses on the SDRS and on the adolescent and parent report measures in this study were not large. Although some statistically significant associations were detected, this was not unexpected with the large number of associations being examined. Overall, these results suggest that socially desirable responding had a minor influence on the responses of participants, and that the responses of the parents were less likely to be influenced by socially desirable responding than those of the adolescents.

CHAPTER FIVE.

RESULTS: THE ASSESSMENT OF PATIENT ADHERENCE.

This chapter presents the results pertaining to the measurement of patient adherence. The first section of this chapter, ***Section 5.1****, describes the relationship between the scores obtained on each of the adherence measures employed in this study. The second section of the chapter,* ***Section 5.2****, describes the relationship between adherence and demographic characteristics of the sample. The third section,* ***Section 5.3****, examines the variation in adherence over time, using the observed BGM adherence data. The results presented in this chapter are discussed in* ***Chapter 6****.*

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5 RESULTS: THE ASSESSMENT OF PATIENT ADHERENCE.

5.1 The Relationship Between Different Measures of Adherence.

Pearson product-moment correlations were employed to examine the level of association between scores on the different measures of adherence. These analyses are presented to examine (1) the relationships between scores on the questionnaire measures of adherence, and (2) the relationships between scores on the questionnaire measures of adherence and observed blood glucose monitoring adherence. Distributions of scores on each of the measures of adherence are displayed in **Table 5.1.**

The relationships between questionnaire measures of adherence were grouped into three sections, (1) relations between adolescent reports of adherence, (2) relations between parent reports of adherence, and (3) relations between adolescent and parent reports of adherence. These relationships are examined in turn. The relationship between questionnaire measures of adherence and the observed BGM adherence is then examined.

5.1.1 The Relationship Between Adolescent Reports of Adherence.

The effect size[1] of the relationship between adolescent reports of diabetes-specific adherence (DSAS) and adolescent reports of general adherence (GAS) was large (**Table 5.2**). Possible interpretations of this association are discussed in **Chapter 6**.

To investigate the possibility that adolescents' responses to these measures were similarly influenced by social desirability biases, the variation in reported adherence level to the different regimen activities identified in the DSAS was examined. The mean responses (± *SD*s) for each of the items of the DSAS and to the items of the GAS are displayed in **Appendices B.1** and **B.2**. Mean scores obtained from adolescents for the items of the DSAS varied. The highest mean rating was found on the item asking about adherence to insulin administration (item 1). The lowest mean rating of adherence was found for the item asking about BGM before or after exercise (item 8). Correlations between adolescent responses to items of the DSAS and GAS are shown in **Appendices B.3 and B.4**.

To further explore the variations in adolescents' reports of adherence levels, a Wilcoxon Matched-Pairs Signed-Ranks tests was performed. This nonparametric statistic was developed for use with paired-sample data. It has the advantage of making few assumptions about the distributions of scores, and has been described as the nonparametric counterpart to the Student's *t* test (Gibbons & Chakraborti, 1992). The Wilcoxon test requires that the paired scores under investigation be on the same

[1] In this thesis, correlational effect sizes will be described according to the conventions recommended by Cohen (1988). These are: small, $r = 0.10$; medium, $r = 0.30$; large, $r = 0.50$.

scale. To facilitate the comparison of reports obtained on the different adherence measures, the scores obtained on each measure were transformed linearly onto a 0 - 100 scoring range. This methodology was employed by DiMatteo, Hays and colleagues (1993), the developers of the GAS and the original DSAS. The transformations ensure that each of the measures are on the same metric, without changing the underlying properties of the score distributions (central tendency and variability) (Nunnally & Bernstein, 1994). These transformations are of the form $X' = bX + a$, where X' is the transformed score, X is the original score, and b and a are the multiplicative and additive consonants of the equation. **Table 5.3** displays the scoring distributions of each of the measures of adherence, before and after linear transformation.

The Wilcoxon signed-ranks test compared the scores produced by adolescents on the DSAS and on the GAS. Ninety-seven participating adolescents produced higher scores on the General Adherence Scale than on the Diabetes Specific Adherence Scale (mean rank 72.1), while only 33 of the adolescents produced higher scores on the specific measure than on the general scale (mean rank 46.2). There was one case that produced equal scores on the two scales, while four cases had missing data making them ineligible for this analysis. These results indicate a significant difference between adherence levels indicated on the GAS and DSAS (z = -6.35, $p < 0.0001$, **Table 5.4**).

5.1.2 The Relationship Between Parent Reports of Adherence.

The effect size of the positive relationship between parent reports of diabetes-specific adherence (DSAS) and parent reports of general adherence (GAS) was large (**Table 5.2**).

The examination of the parents' responses to the individual regimen activities identified in the DSAS provides further information about this association. **Appendices B.1** and **B.2** displays the parents' mean responses (± *SD*s) to each of the items of the DSAS and to the items of the GAS.

Mean responses to these items, obtained from parents, were varied. As with the adolescent responses, the highest mean rating for an item by parents was found on the item addressing adherence to insulin administration (item 1). The lowest mean parent score was found on the item asking about adherence to BGM before or after exercise (item 8). Correlations between parent responses to items of the DSAS and GAS are shown in **Appendices B.5** and **B.6**.

To further explore the variations in parents' reports of adherence levels, a Wilcoxon Matched-Pairs Signed-Ranks test was performed. Ninety-six of the participating parents produced higher scores on the General Adherence Scale than on the Diabetes Specific Adherence Scale (mean rank 71.1), while 37 of the parents produced higher scores on the specific measure than on the general scale (mean rank 56.5). There were no cases that produced equal scores on the two scales. Two cases had missing data

making them ineligible for this analysis. These results indicate a significant difference between adherence levels indicated by parents on the GAS and DSAS (**Table 5.4**).

The consistency of the association between the DSAS and GAS amongst both adolescents and parents suggests that these groups of respondents answered the two measures of adherence in similar ways. **Section 5.1.3** presents the examination of the association between adolescent and parent reports of adherence.

5.1.3 The Relationship Between Adolescent and Parent Reports of Adherence.

The relationship between adolescent and parent reports on the GAS was examined using a Pearson correlation. The relationship between adolescent and parent reports on the DSAS was also examined in this manner (**Table 5.2**). The effect size of the association between adolescent and parent reports on the GAS was large, as was the effect size of the association between adolescent and parent reports on the DSAS. Similar patterns of responses were produced by adolescents and parents to each item of the DSAS. **Appendix B.7** displays the frequency of responses to each item of the DSAS by adolescents and parents. Correlations between adolescent and parent responses to items of the DSAS and GAS are shown in **Appendix B.8** and **B.9**.

The significance of differences between scores obtained from adolescents and parents was examined, using the Wilcoxon Matched-Pairs Signed-Ranks Test. These

analyses were performed separately for the General Adherence Scale and the Diabetes Specific Adherence Scale.

There were 55 adolescent-parent dyads in which the adolescent produced a lower GAS score than did their parent (mean rank 53.1), and 58 dyads in which the adolescent produced the higher score (mean rank 60.7). Seventeen dyads elicited equal scores from adolescents and parents, and there were five dyads in which scores could not be calculated for at least one member (4 cases of missing adolescent data; 1 case of missing parent data). These results did not indicate a significant pattern of differentiation between adolescents' and parents' ratings of adherence on the GAS (**Table 5.4**).

The results of the Wilcoxon test of adolescent and parent responses to the DSAS were similar to the analysis of responses obtained on the GAS. Again, adolescents produced neither consistently higher nor lower scores than their parents. There were 62 cases of adolescents scoring more highly on the DSAS than their parents (mean rank 57.1), while in 55 cases the adolescents produced lower scores than their parents (mean rank 61.2). Again, in 17 of the adolescent-parent dyads the scores produced by each participant were equal. The analysis was not performed on one dyad for which the parent score was missing. These results also did not indicate a significant pattern of differentiation between adolescents' and parents' ratings of adherence (**Table 5.4**).

5.1.4 The Relationship Between Questionnaire Measures of Adherence and the Observed BGM Adherence.

The next set of analyses performed were designed to examine the relationship between adolescents' and parents' responses to the DSAS and GAS and the BGM adherence information obtained from the electronic memory of blood glucose sensors. BGM adherence was coded in terms of the number of days of appropriate blood glucose monitoring during the prior four weeks. This process is described in **Chapter 3**. The initial analyses performed to explore these relationships were Pearson correlations.

The adolescent reported general adherence (GAS) was moderately correlated with the observed BGM adherence, while parent reports of general adherence were slightly more closely associated with observed BGM adherence (**Table 5.5**). The correlations between both adolescent reported diabetes-specific adherence (DSAS) and observed BGM, and between parent reported diabetes-specific adherence and observed BGM adherence data, were large (**Table 5.5**).

5.2 The Variation in Reported Adherence According to Demographic Characteristics.

This section presents a series of analyses which were performed to determine whether the level of reported adherence varied in relation to demographic characteristics of the sample, such as adolescents' age or gender. These analyses included Pearson

correlations, Analyses of Variance, and Student's *t*-tests. Where significant associations were detected, further analyses were employed to explore these associations.

The analyses presented in this section address (1) the variation of reported adherence according to adolescent age, (2) the variation of reported adherence according to adolescent gender, (3) the variation of reported adherence according to adolescent HbA_{1c} level, (4) the variation in reported adherence according to the combination of adolescents' demographic characteristics, and (5) the variation of reported adherence according to parental work status, that is, whether parents were primarily in the home (home duties, pensioners, or working from home) or working outside the home environment.

5.2.1 The Variation in Reported Adherence According to Adolescent Age.

The first demographic characteristic of the sample to be considered in this section is adolescents' age. The variation in reported adherence according to adolescent age will be addressed in four ways: First, the variation in adolescents' reports of adherence according to their age. Second, the variation in parents' reports of adherence according to their adolescents' age. Third, the variation in the level of agreement between adolescent and parent reports of adherence according to the adolescents' age. Fourth, the variation in observed Blood Glucose Monitoring adherence according to the adolescents' age.

Table 5.6 displays the correlations between each measure of adherence and the adolescents' age.

Adolescent Reports.

A summary of responses by adolescents to the GAS according to the adolescents' age is shown in **Table 5.7**. Adolescents' responses to the GAS were not associated with adolescents' age. A one-way Analysis of Variance (ANOVA) was performed using adolescent responses to the GAS as the dependent variable and adolescent age level (12 year old, 13 year old, 14 year old, 15 year old, 16 year old, and 17 year old) as the independent factor. The result of this analysis was not statistically significant.

Table 5.8 displays a summary of responses by adolescents and parents to the DSAS according to adolescents' age. Responses to the DSAS by adolescents were not strongly associated with adolescents' age. One-way ANOVA of adolescent responses to the DSAS as the dependent variable and adolescent age level as the independent factor was not statistically significant.

Parent Reports.

A summary of responses by parents to the GAS according to the adolescents' age is shown in **Table 5.7**. Parents' responses to the GAS were not strongly associated with adolescents' age. One-way ANOVA of parent responses to the GAS and adolescent age was not significant. **Table 5.8** displays a summary of responses by parents to the DSAS according to adolescents' age. Parent scores on the DSAS were not

significantly correlated with adolescents' age. One-way ANOVA of parent responses to the DSAS and adolescent age level was not significant.

The Level of Agreement Between Adolescent and Parent Reports.

The next analyses were designed to determine whether the level of agreement between adolescent and parent reports of adherence differed according to the age of the adolescent[2]. Adolescent age data were stratified into year levels (12 year olds, 13 year olds, 14 year olds, 15 year olds, 16 year olds and 17 year olds). A statistical test for differences between correlations of parent and adolescent scores across the six age levels was conducted for the GAS and for the DSAS (Snedecor & Cochran, 1980).

The first of these analyses examined the variation in parent-adolescent agreement on the GAS according to adolescent age. The details of this test are shown in **Table 5.9**.

Following the methodology outlined in Snedecor and Cochran (1980), the correlation coefficients were converted to z scores using the formula:

$$z = (1/2)\left[\log_e(1+r) - \log_e(1-r)\right]$$

Weights $w_i = (n - 3)$ values calculated. The test of significance is performed as a Chi-square analysis:

[2] The author is indebted to Professor David L. Streiner, McMaster University, Canada, for his advice and support on these analyses.

$$\chi^2 = \sum_{i=1}^{k} w_i \left(z_i - \bar{z}_w \right)^2$$

$$\chi^2 = \sum_{i=1}^{k} w_i z_i^2 - \frac{\left(\sum_{i=1}^{k} w_i z_i^2 \right)^2}{\sum_{i=1}^{k} w_i}$$

$$\chi^2 = \sum (n-3) z^2 - \frac{\left[\sum (n-3) z \right]^2}{\sum (n-3)}$$

$$\chi^2 = 34.253 - \frac{[59.878]^2}{117}$$

$$= 3.609$$

With 5 degrees of freedom, this result was not significant. This finding does not support the suggestion that parent-adolescent agreement on the GAS varied in relation to adolescent age.

The next analysis examined the variation in parent-adolescent agreement on the DSAS according to adolescent age. **Table 5.10** displays the details of this test. The results of this analysis were significant ($\chi^2 = 17.69$, $df = 5$, $p < 0.0001$). Therefore a significant variation in parent-adolescent agreement according to adolescent age was observed on the DSAS.

In order to further explore this association, additional tests were performed to determine the location of the differences between correlations. Ferguson and Takane (1989) give the formula for testing the significance of the difference between two correlation coefficients for independent samples as:

$$z = \frac{z_{r_1} - z_{r_2}}{\sqrt{\frac{1}{(n_1 - 3)} + \frac{1}{(n_2 - 3)}}}$$

To determine the location of the differences in parent-adolescent score correlations on the DSAS according to adolescent age, this test was applied between the correlations produced by each of the six age strata. Because of the use of multiple tests, the criterion value was set at $p < 0.01$ (see **Section 3.4.3**). The details of these analyses are provided in **Appendix B.10**. A summary the results of these analyses is provided in **Table 5.11**.

Observed Blood Glucose Monitoring Adherence.

Table 5.12 displays a summary of observed levels of BGM adherence recorded from the electronic memory of blood glucose sensors, according to adolescents' age. BGM adherence by adolescents was moderately inversely associated with adolescents' age (**Table 5.7**). One-way ANOVA was performed using BGM adherence as the dependent variable and adolescent age level as the independent factor. The results of this ANOVA were statistically significant (F (5,74) = 3.077, p = 0.02). Post hoc comparisons were performed, using Tukey's Honestly Significant Differences. These comparisons revealed significant differences in observed BGM adherence between the 12 year olds and the 16 year olds, and between the 12 year olds and the 17 year olds.

To determine whether the association between BGM adherence and adolescents' age was indicated by the questionnaire responses addressing this specific regimen activity, additional analyses were performed on the adolescents' and parents' responses to the item of the DSAS specifically addressing this activity (item 2). This item was worded to address the behaviour in the same manner as it was coded - performing at least two blood glucose tests each day. Adolescent responses to the BGM item of the DSAS were weakly, and not significantly, associated with the adolescents' age (r = -0.15, p = 0.07). Parent responses to this item were not associated with the adolescents' age (r = -0.04, p = 0.6). Similarly, one-way ANOVAs examining responses to the BGM item of the DSAS (dependent variable) and adolescent age (independent variable), did not produce significant relationships (Adolescent: F (5,134) = 1.279, p = 0.3. Parent: F (5,134) = 0.617, p = 0.7).

In order to determine whether the adolescent and parent reports of BGM adherence in the DSAS failed to reveal a true relationship with the adolescents' age as the result of socially desirable responding, further analyses were employed. The associations between the measure of socially desirable responding (SDRS) and adolescent and parent reports of adherence were assessed according to adolescent age strata. The level of association between these measures was determined separately for young adolescents (aged 12 - 13 years), middle adolescents (aged 14 - 15 years) and older adolescents (aged 16 - 17 years).

While this stratification was somewhat arbitrary, these age groups appeared to cluster naturally in terms of adherence to BGM (**Figure 5.1**). That is, the distribution of the number of observed days of BGM adherence for adolescents aged 16 and 17 was

narrow, with the majority of these adolescents adhering to their BGM recommendations on average less than seven of the previous 28 days. The distribution of BGM adherence by the 14 and 15 year old adolescents was very wide, spanning the entire 28 day assessment period. The 12 and 13 year olds adolescents produced a narrower distribution of BGM adherence, and typically adhered to their BGM recommendations on more days during the previous four weeks than the older groups of adolescents.

The associations between each of the questionnaire measures of adherence and the observed BGM adherence according to this age stratification are reported in **Table 5.13**. As may be seen from this table, the level of association between measures of socially desirable responding and adolescent and parent reports of adherence was not large amongst the young adolescents and middle adolescents. The responses to the adherence measures by older adolescents were, however, more closely associated with the measure of socially desirable responding.

Further analyses were performed to test the possibility that the adolescents from whom BGM data as well as questionnaire measures were collected may have differed from the adolescents from whom only questionnaire data was collected. The associations between adolescents' age and adolescent and parent reports of adherence were again examined, selecting only those study participants for whom BGM data had been collected. These analyses are detailed in **Appendices B.11** and **B.12**. The level of association between adolescents' age and adolescents' and parents' reports of adherence was greater amongst this subsample than in the wider sample, with adolescents' responses on the DSAS significantly inversely related to their age (r =

-0.26, $p = 0.02$). However, the other questionnaire measures of adherence were not significantly associated with the adolescents' age in this subsample. One-way ANOVAs between each of the questionnaire measures of adherence (as dependent variables) and adolescents' age (as the independent variable) produced results amongst this subsample that were comparable with the results examining the wider sample.

5.2.2 The Variation in Reported Adherence According to Adolescent Gender.

The second demographic characteristic of the sample to be considered in this section is adolescent gender. The variation in reported adherence according to adolescent gender will be addressed in four ways: First, the variation in adolescents' reports of adherence according to their gender. Second, the variation in parents' reports of adherence according to their adolescents' gender. Third, the variation in the level of agreement between adolescent and parent reports of adherence according to the adolescents' gender. Fourth, the variation in observed Blood Glucose Monitoring adherence according to the adolescents' gender.

Adolescent Reports.

A summary of responses by adolescents to the GAS according to the adolescents' gender is shown in **Table 5.14**. To determine whether responses on the GAS differed between male and female adolescents, a Student's t test was performed. The results of this test were not significant (t (129) = 1.17, $p = 0.3$), indicating that adolescents'

responses to the GAS did not significantly vary according to the gender of the adolescent.

A summary of responses by adolescents to the DSAS according to the adolescents' gender is shown in **Table 5.15**. Differences between male adolescent and female adolescent responses to the DSAS were examined using a Student's *t* test. The results of this test indicate that adolescent responses on this scale were not associated with the adolescents' gender (t (133) = 0.82, p = 0.4).

Parent Reports.

A summary of responses by parents to the GAS according to the adolescents' gender is shown in **Table 5.14**. To determine whether parent responses on the GAS differed between the parents of male and female adolescents, a Student's *t* test was performed. Again, the results of this test were not significant (t (132) = 0.39, p = 0.7), indicating that parents' responses to the GAS were not significantly associated with adolescents' gender.

A summary of responses by parents to the DSAS according to the adolescents' gender is shown in **Table 5.15**. Differences between reports obtained from parents of male adolescents and parents of female adolescents on the DSAS were examined using a Student's *t* test. The results of this test indicate that parent responses on this scale were not associated with the adolescents' gender (t (132) = 0.67, p = 0.5).

The Level of Agreement Between Adolescent and Parent Reports.

The next series of analyses were designed to determine whether the level of agreement between adolescent and parent reports of adherence differed according to the gender of the adolescent. A test for differences in correlations of parent and adolescent scores between male and female adolescent samples was also performed on the GAS and DSAS (Snedecor & Cochran, 1980).

The first of these analyses examined the difference in parent-adolescent agreement on the GAS between the female and male adolescent samples. The details of this test are shown in **Table 5.16**. As outlined in Snedecor and Cochran (1980), the test of significance between two correlation coefficients differs from the test examining several correlations, employed in **Section 5.2.1**. Again, the correlation coefficients are converted to z scores, and weights ($w_i = n - 3$) calculated. The variance of the difference (D) between the z scores is the sum of their individual variances. Hence

$$t = D / \sigma_D$$

$$t = 0.170 / \sqrt{0.032}$$

$$= 0.950$$

This result is not significant, suggesting that parent-adolescent agreement on the GAS is not varied according to the gender of the adolescent.

The next analysis examined the difference in parent-adolescent agreement on the DSAS between the female and male adolescent samples. The details of this test are shown in **Table 5.17**. The result of this analysis was not significant (t = 1.46), suggesting that parent-adolescent agreement on the DSAS is not varied according to the gender of the adolescent.

Observed Blood Glucose Monitoring Adherence.

Table 5.18 displays a summary of observed levels of BGM adherence recorded from the electronic memory of blood glucose sensors, according to adolescents' gender. A Student's t test was performed to determine whether BGM adherence differed between male and female adolescents. It should be acknowledged that these data were slightly skewed. However, the t test has previously been found to be highly robust to violations of normality and homogeneity of variance (Boneau, 1960; WL Hays, 1988; Pagano, 1986). The results of the t test examining BGM adherence by male and female adolescents indicate that BGM adherence did not significantly differ between male and female adolescents (t (73) = -0.88, p = 0.4).

5.2.3 The Relationship Between Measures of Adherence and the Measure of Metabolic Control (HbA_{1c}).

This section presents the analysis of the relationship between the measures of adherence to medical recommendations and the measure of the metabolic control of participating adolescents, their HbA_{1c} assay levels.

Pearson correlations were employed to examine the level of association between these measures. Separate analyses examined the associations between adolescent responses on each of the measures and parent responses on the measures. These analyses are presented separately for each of the measures of adherence to medical recommendations; the General Adherence Scale, the Diabetes Specific Adherence Scale, and the observed Blood Glucose Monitoring adherence.

Adolescent Reports.

The level of correlation between adolescents' HbA_{1c} levels and the adolescent completed General Adherence Scale are shown in **Table 5.19**. The negative correlation indicates that greater levels of adherence were associated with lower HbA_{1c} levels, that is, with better metabolic control. This correlation was small, and failed to reach statistical significance at the 0.05 level.

However, to determine whether a curvilinear or complex relationship existed between adolescents' scores on the GAS and their HbA_{1c} levels, a one-way ANOVA was also performed. The one-way ANOVA was performed using adolescents' reports of general adherence (GAS) as the dependent variable and their metabolic control (HbA_{1c}) as the independent variable. HbA_{1c} assay level data were reduced from one decimal point into integers, for use in this analysis (value range 6 to 14). Although this process reduces the amount of information provided by the data, the process is necessary for the calculation of the ANOVA. The results of this analysis were statistically significant, F (8,127) = 2.98 (p = 0.01). A scatterplot illustrating the

distribution of scores on the GAS according to HbA_{1c} assay results (as integers) is shown in **Figure 5.2**. Post hoc comparisons were performed, using Tukey's Honestly Significant Differences. These comparisons revealed significant differences in GAS scores between adolescents with HbA_{1c} assays of 7 % and adolescents with HbA_{1c} assays of 10 or 11 % (those with lower HbA_{1c} assays reported higher levels of adherence on the GAS).

The level of correlation between adolescents' scores on the DSAS and their recorded HbA_{1c} levels are shown in **Table 5.19**. Again, the negative correlation indicates that greater adherence was associated with lower levels of HbA_{1c}, that is, with better metabolic control. This correlation was small, and did not reach statistical significance. A one-way ANOVA was performed to more closely examine the association between adolescents' reports of diabetes-specific adherence (DSAS; the dependent variable) and their metabolic control (the independent variable). The results of this analysis were not statistically significant, F (7,133) = 0.64 (p = 0.7).

Parent Reports.

The correlation between parents' scores on the GAS and their adolescents' HbA_{1c} levels is shown in **Table 5.19**. These variables showed a moderate negative association. This correlation was greater than the correlation between adolescents' scores on the GAS and their HbA_{1c} levels. One-way ANOVA was performed to more closely examine this association. The results of this analysis did not reach the $p < 0.05$ significance threshold (F (7,132) = 1.94, p = 0.07).

The level of correlation between parents' scores on the DSAS and their adolescents' HbA_{1c} levels are shown in **Table 5.19**. This correlation was moderately small, although larger than the correlation between adolescents' DSAS scores and their HbA_{1c} levels. The association between parents' reports of diabetes-specific adherence and adolescents' metabolic control was statistically significant. Again, a one-way ANOVA was performed to more closely examine the association (dependent variable: parents' DSAS; independent variable: adolescents' HbA_{1c}). The results of this analysis were not statistically significant (F (7,132) = 1.39, p = 0.2).

Observed Blood Glucose Monitoring Adherence.

Table 5.19 displays the correlation between observed levels of BGM adherence recorded from the electronic memory of blood glucose sensors and adolescent HbA_{1c} levels. BGM adherence by adolescents was moderately inversely associated with their metabolic control. One-way ANOVA of BGM adherence and adolescent HbA_{1c} level did not produce a statistically significant result (F (6,73) = 2.02, p = 0.08).

5.2.4 The Combined Effect of Adolescents' Demographic Characteristics on Reported Adherence.

The next set of analyses reported in this chapter were intended to examine the variation in reported adherence according to adolescents' demographic characteristics. The examination of a dependent variable (adherence) according to multiple independent variables (demographic variables) would usually be performed using

ANOVA methods. However, because multiple measures of adherence are being considered, a multivariate technique is appropriate.

The extension of analysis of variance to the case of multiple dependent variables is the multivariate analysis of variance (MANOVA). In MANOVA, a new dependent variable that maximises group differences is created from the set of dependent variables (Harris, 1985; Tabachnick & Fidell, 1989). Although ANOVA tests could be computed separately for each of the adherence measures, this approach ignores the interrelation among the adherence measures. This approach would suffer from the loss of substantial information when correlations between adherence variables were ignored. Further, although groups may not differ on individual measures of adherence, they may do so when a number of related individual adherence measures are examined jointly (cf. Bryman & Cramer, 1990).

MANOVA techniques represent an improvement on performing a series of ANOVAs for several reasons. First, they reduce the likelihood of making Type I errors (deciding there is a difference when there is none) when making a number of comparisons. A second advantage of MANOVA analyses over repeated ANOVAs is that by measuring several dependent variables instead of only one, the researcher improves the chance of discovering what it is that changes as a result of different treatments and their interactions (Tabachnick & Fidell, 1989).

The behavioural measure of adherence, Blood Glucose Monitoring, was not included in the MANOVA, because this information was only collected for 75 of the 135 participating adolescents, the inclusion of this variable in the multivariate analysis

would have introduced too great a proportion of missing data, thereby distorting the results of the analysis. Instead, a separate ANOVA was performed examining the relationship between this aspect of adherence and the demographic variables included in the MANOVA. The necessity of performing a separate analysis for this measure is unfortunate, as its introduction into the multivariate analysis would provide valuable information about the relationship between this measure and the questionnaire assessments of adherence.

Questionnaire Measures of Adherence.

A 6 x 2 between-subjects MANOVA was performed on four dependent variables: adolescent completed DSAS, adolescent completed GAS, parent completed DSAS and parent completed GAS. Independent variables were adolescent age (12 to 17) and adolescent gender. Entry of independent variables was ordered (1) adolescent age, then (2) adolescent gender. This analysis was performed on 129 subjects; 6 subjects had to be excluded from the analysis because of missing data.

To examine the Adolescent Age by Adolescent Gender interaction effect, Tabachnick and Fidell (1989) recommend the use of Wilk's lambda (λ) as the assessment criterion. In this analysis, Wilk's lambda produced an F ratio (20, 379.05) of 1.43. This result was not significant at the 0.05 level. Univariate tests of the dependent variables with adolescent age and gender were also not significant at the 0.05 level, with F ratios ranging from 0.94 to 2.07 (**Table 5.20**). While none of these univariate assessments reached the 0.05 level of significance, adolescent reports on the DSAS produced a strong F ratio, which approached this traditional statistical cut-off,

suggesting the possibility of a weak relationship between this aspect of adherence and adolescents' demographic characteristics.

Observed Blood Glucose Monitoring Adherence.

Because the Blood Glucose Monitoring data were only available for a subset of seventy-five adolescents, this data could not be included in the MANOVA. Instead, the BGM data were examined in a separate Two-Way Simple Factorial ANOVA, in relation to adolescents' age and gender. The results of this analysis are presented in **Table 5.21**.

Neither the main effects variations for adolescent age and adolescent gender, nor the two-way interaction effect were significant. Blood glucose monitoring behaviour was not systematically varied in relation to adolescents' age or gender.

5.2.5 The Variation in Reported Adherence According to Parental Work Status.

The next demographic characteristic of the sample to be considered in this section is parental work status. This term is used to indicate whether the parent completing the parent questionnaire measures in the study was primarily at home or primarily out of the home. The variation in reported adherence according to parental work status will be addressed in four ways: First, the variation in adolescents' reports of adherence according to parental work status. Second, the variation in parents' reports of adherence according to their work status. Third, the variation in the level of

agreement between adolescent and parent reports of adherence according to the parent's work status. Fourth, the variation in observed Blood Glucose Monitoring adherence according to the parent's work status.

Adolescent Reports.

A summary of responses by adolescents to the GAS according to parents' work status is shown in **Table 5.22**. To determine whether responses on the GAS differed between adolescents of parents primarily at home and adolescents of parents working primarily outside the home environment, a Student's *t* test was performed. The results of this test were not significant (t (128) = -0.29, p = 0.8), indicating that adolescents' responses to the GAS were not significantly associated with parental work status.

A summary of responses by adolescents to the DSAS according to parental work status is shown in **Table 5.23**. Differences between responses obtained on the DSAS from adolescents of parents primarily at home and adolescents of parents primarily out of the home were examined using a Student's *t* test. The results of this test indicate that adolescent responses on this scale were not significantly associated with parental work status (t (132) = 0.64, p = 0.5).

Parent Reports.

A summary of responses by parents to the GAS according to their work status is shown in **Table 5.22**. To determine whether responses on the GAS differed between parents primarily at home and parents primarily out of the home, a Student's *t* test was

performed. The results of this test were not significant (t (131) = -0.38, p = 0.7), indicating that parents' responses to the GAS were not significantly associated with their work status.

A summary of responses by parents to the DSAS according to their work status is shown in **Table 5.23**. Differences between responses obtained on the DSAS from parents primarily at home and parents primarily out of the home were examined using a Student's t test. The results of this test indicate that parents' responses on this scale were not significantly associated with their work status (t (131) = 0.58, p = 0.6).

The Level of Agreement Between Adolescent and Parent Reports.

The next analysis performed was designed to examine the variation in parent-adolescent agreement on the adherence measures according to whether parents were employed out of home or were at home. This analysis was performed to determine whether parents who were at home were more familiar with the adherence behaviour of their adolescents.

The analysis of parent-adolescent agreement on the GAS was performed to examine the relationship to parental work status. The details of this test are shown in **Table 5.24**. This result (t = 2.07) was not statistically significant at the 0.05 level.

The analysis of parent-adolescent agreement on the DSAS was also performed to examine the relationship to parental work status. The details of this test are shown in

Table 5.25. This result (t = 3.07) is significant at the $p < 0.05$ level, suggesting that parent-adolescent agreement about adherence to diabetes treatment recommendations is greater amongst parent-adolescent dyads where the parent works out of the home environment than in dyads where the parent is at home.

Observed Blood Glucose Monitoring Adherence.

Table 5.26 displays a summary of observed levels of BGM adherence recorded from the electronic memory of blood glucose sensors, according to parents' work status. A Student's t test was performed to determine whether BGM adherence differed between the adolescents of parents primarily in the home and the adolescents of parents primarily out of the home. The results of this t test (t (73) = 1.45, p = 0.2) indicate that BGM adherence did not significantly differ between these groups of adolescents.

5.3 The Variation in Adherence Over Time.

This section examines the variation in adherence over time. The analyses presented examine the data obtained from the electronic memory of the blood glucose sensors. These data represent an objective assessment of adherence to an important aspect of diabetes self-management. The analyses in this section will focus on the variation of adherence by adolescents in the sample over the 28 days prior to assessment.

The analyses fall into two broad categories. First, analyses are presented which examine the variation in the level of adherence to Blood Glucose Monitoring recommendations. Second, analyses are presented which examine the relations between adolescent and parent reports of adherence and assessment of Blood Glucose Monitoring adherence over different time spans.

5.3.1 Variation in Adherence Over Time.

The first analyses presented in this chapter examine the variation in the level of adherence to Blood Glucose Monitoring recommendations. The purpose of these analyses is to determine whether adherence to this aspects of diabetes management remains consistent over time. These analyses were performed on the electronically recorded BGM data obtained from the blood glucose sensors.

The first of these analyses employed a Repeated Measures ANOVA technique to determine whether a significant variation in the frequency of blood glucose testing is evident. The second analysis employed Trend Analysis techniques to examine the nature of the variation in BGM over time.

Variance in Blood Glucose Monitoring Frequency Over Time.

The analysis of the variance in blood glucose monitoring over time was performed on two sets of data. First, the BGM data were coded into seven consecutive four-day blocks. The analysis of these data provided information about the frequency of BGM

over short time periods. Second, the BGM data were coded into blocks of one week. This coding created four blocks. Although this smaller number of observational units provides a less detailed assessment, the week-long blocks account for possible variations between weekday and weekend activity. These analyses are presented separately.

Analysis of Four-Day Blocks of Blood Glucose Monitoring.

The BGM data obtained spanned the 28 days prior to assessment. In order to examine the variation in frequency of BGM within subjects over time, the days were grouped into blocks, each consisting of 4 days. The blocks were treated as the observational units. Hence the data were analysed as if there were 7 observations on each subject, an observation being the number of tests performed during a block of four consecutive days. **Figure 5.3** displays the distributions of the number of tests performed each day during the seven blocks. The adolescents were given recommendation to test their blood glucose at least twice each day.

As illustrated in **Figure 5.3**, the frequency of BGM was higher during the days immediately prior to assessment than earlier in the month before assessment. A Repeated Measures ANOVA was used to assess the variation in BGM frequency over time. This variation was statistically significant, the Repeated Measures ANOVA produced an F ratio (6,73) of 5.62 ($p < 0.001$; **Table 5.27**).

This significant result suggests a change in the frequency of BGM by participating adolescents. Inspection of **Figure 5.3** would suggest that this variation takes the form

of a systematic increase in BGM frequency as the assessment time approaches. An increase in mean BGM frequency is observed in the final blocks, and most notably in the final block.

Analysis of Seven-Day Blocks of Blood Glucose Monitoring.

To examine further the variation in BGM over time, the BGM data were re-coded into blocks of seven days. Again, these blocks were treated as observational units in a Repeated Measures ANOVA. Hence in this analysis there were 4 observations on each subject. **Figure 5.4** displays the mean number of tests performed each day during the four weeks blocks.

As illustrated in **Figure 5.4**, the frequency of BGM was higher during the week immediately prior to assessment than earlier in the month before assessment. The Repeated Measures ANOVA of this variation was significant, with an F ratio (3,73) of 9.00 ($p < 0.001$; **Table 5.28**).

This significant result again suggests a change in the frequency of BGM by participating adolescents. The pattern illustrated in **Figure 5.4**, consistent with that observed in **Figure 5.3**, suggests that the variation represents an increase in BGM frequency as the assessment time approaches, especially in the final week prior to assessment.

Trends in Blood Glucose Monitoring Variation Over Time.

In order to formally assess the form of the variation in BGM frequency, Trend Analyses were performed. These analyses were intended to determine the nature of the variation - that is, whether the change in BGM frequency over time was linear, or whether reversals in the trend were evident (i.e., quadratic or cubic trends).[3]

The analyses were performed on the BGM data obtained from seventy-four of the adolescents. The BGM data from 1 adolescent had to be discarded due to missing data - this adolescent had performed more tests during the previous 28 days than the memory of the sensor was able to record, as a result the data from the first few days were deleted as more recent tests were performed.

The Trend Analyses were performed following the methodology described by Winer (1971). Two sets of Trend Analysis were performed, the first utilising the four-day blocks of BGM data, the second using the seven-day blocks of BGM data. These are reported separately.

Trend Analysis of Four-Day Blocks of Blood Glucose Monitoring.

The mean squares corresponding to the linear and quadratic trends are computed in **Table 5.29**. The block totals for these experimental data are given near the top of **Table 5.29**. Each of these totals is the sum over 74 observations. Since there are

[3] The author is indebted to Professor David L. Streiner, McMaster University, Canada, for his advice and support on these analyses.

seven blocks, the coefficients corresponding to linear and quadratic trends are obtained from the set of coefficients for which $k = 7$ in Pearson and Hartley (1970; Table 47). Following the nomenclature employed by Winer (1971), the entries under the column headed Σc^2 represent the sums of squares of the coefficients in the corresponding rows. The entries under the column headed C represent the numerical value of the comparisons. For example, in the linear comparison, C is calculated as:

(-3)(344) + (-2)(358) + (-1)(373) + (0)(377) + (1)(395) + (2)(431) + (3)(495) = 621.

The mean square corresponding to the linear comparison is calculated as:

$$MS_{lin} = \frac{C_{lin}^2}{n\sum c^2}$$

$$MS_{lin} = \frac{(621)^2}{(74)(28)}$$

$$= 186.12$$

The test of significance for the linear trend is calculated by the F ratio

$$F = \frac{MS_{lin}}{MS_{res}}$$

$$F = \frac{186.12}{6.44}$$

$$= 28.90$$

The sampling distribution of this statistic (assuming no linear trend) may be approximated by an F distribution having (1,432) degrees of freedom. The linear trend is significant beyond the 0.01 level.

The analyses of the quadratic and higher order trends are presented in **Appendix B.13**. The quadratic and higher order trends did not add significant predictability to that of the linear trend. The conclusions drawn from these analyses, and their implications for the assessment of adherence, are discussed in **Chapter 6**.

Trend Analysis of Seven-Day Blocks of Blood Glucose Monitoring.

The Trend Analysis was then performed using the four 7-day blocks. The mean squares corresponding to the linear and quadratic trends are computed in **Table 5.30**. The block totals for these experimental data are given near the top of **Table 5.30**. Each of these totals is the sum over 74 observations. Since there are four blocks, the coefficients corresponding to linear and quadratic trends are obtained from the set of coefficients for which $k = 4$ in Pearson and Hartley (1970; Table 47). Again, following Winer's (1971) nomenclature, the entries under the column headed Σc^2 represent the sums of squares of the coefficients in the corresponding rows. The entries under the column headed C represent the numerical value of the comparisons. For example, in the linear comparison, C is calculated as

$$(-3)(605) + (-1)(664) + (1)(686) + (3)(824) = 679.$$

The mean square corresponding to the linear and higher trends are calculated in the same manner as in the previous analyses. These analyses are detailed in **Appendix B.14**. Again, the linear trend was the only trend relevant to the observed variation in BGM adherence. The conclusions drawn from these analyses, and their implications for the assessment of adherence, are discussed in **Chapter 6**.

5.3.2 Relations Between Adolescent and Parent Reports of Adherence and Measures of Blood Glucose Monitoring Adherence Over Different Time Periods.

This section presents a series of analyses designed to examine the relationship between the reports of adherence (GAS and DSAS) obtained from adolescents and parents, and the BGM adherence data. Each of these measures were framed to assess adherence over the past four weeks. The analyses presented in this section were intended to assess whether the adolescents' and parents' reports of adherence were more representative of adherence levels over a shorter time-frame. To assess this, the level of association between these reports and the observed level of BGM over various time-frames is examined.

These analyses were conducted on the basis of the finding that the observed level of blood glucose monitoring adherence varied over time, and was significantly higher immediately before assessment.

Previous authors have suggested that responses to measures which address behaviour over long time frames may suffer from biases such that the respondents' recall reflects

their behaviour over only the previous few days, extrapolated to represent the entire time frame addressed (Streiner & Norman, 1995; Foddy, 1993; Meany, et al. 1989). That is, the adherence reported by adolescents and parents may reflect the increased level of BGM adherence observed in the final few days before clinic attendance.

The second item of the DSAS directly addresses BGM adherence. As identified in **Section 5.2.1**, this item was worded to address the behaviour in the same manner as it was coded - performing at least two blood glucose tests each day. Responses to this item were used to determine the relationship between adolescents' and parents' reports of BGM adherence in the previous four weeks, and the observed BGM adherence over the previous four weeks.

In order to test the possibility that responses to this item were biased by behaviour over the previous few days, BGM adherence data were reanalysed to examine the following time frames:

- twenty-eight days prior to assessment (all seven sequential four-day blocks identified in **Section 5.3.1**);

- twenty days prior to assessment (the final five blocks);

- twelve days prior to assessment (the final three blocks);

- eight days prior to assessment (the final two blocks); and

- four days prior to assessment (the final block).

Pearson correlations were utilised to examine the level of association between adolescent and parent reports of adherence and the measures of BGM adherence over different time spans. The results of these correlations are shown in **Table 5.31**.

The associations between adolescent and parent reports of BGM adherence and the observed BGM adherence over the different time frames do not provide strong support for the suggestion that these reports were biased by the most recent adherence behaviour.

Adolescent reports of BGM adherence on the DSAS (Item 2) were highly correlated with observed BGM adherence in each of the time frames considered, with Pearson *r* values ranging from 0.54 (the last 4 days) to 0.66 (the last 28 days). The pattern of correlations produced between these variables did not support the suggestion that adolescents' responses to this item were biased by their most recent adherence behaviour; the adolescents' responses were most closely associated with observed BGM adherence over the 28-day time frame originally addressed by the questionnaire.

Parent responses to this item also showed large associations with observed BGM adherence. Again, these associations were greater over the larger time frames than over the last few days before assessment. The implications of these results are discussed in **Chapter 6**.

As a further test of the relationship between observed BGM adherence and adolescents' and parents' reports of adherence to this aspect of IDDM management, the responses of adolescents and parents were re-coded as a dichotomous variable. That is, responses of *1* (none of the time) to *3* (some of the time) were coded as Low BGM adherence, and responses of *4* (a good bit of the time) to *6* (all of the time) were coded as High BGM adherence. The mean number of days of observed BGM adherence in each of the time intervals was calculated for adolescents rated with Low or High BGM adherence, according to the adolescent and parent responses (**Tables 5.32** and **5.33** respectively).

The mean number of days of observed BGM adherence in each time frame was lower amongst the adolescents who reported Low BGM adherence than amongst those who reported High BGM adherence. These relationships were tested using Student's *t*-tests, and were significant in each time frame (**Table 5.32**).

Similarly, the mean number of days of observed BGM adherence in each time frame was lower amongst the adolescents for whom parents reported Low BGM adherence than amongst those for whom parents reported High BGM adherence. Again, these relationships were tested, and were significant in each time frame (**Table 5.33**).

This pattern was further analysed by the re-coding of responses on the DSAS item assessing BGM adherence (item 2), into trichotomous responses. That is, responses of *1* (none of the time) or *2* (a little of the time) were rated as Low BGM adherence; Responses of *3* (some of the time) or *4* (a good bit of the time) were rated as Moderate BGM adherence; and responses of *5* (most of the time) and *6* (all of the time) were

rated as High BGM adherence. The mean number of days of observed BGM adherence in each of the time intervals was calculated for adolescents rated with Low, Moderate or High BGM adherence, according to the adolescent and parent responses (**Tables 5.34** and **5.35** respectively).

As shown on **Table 5.34**, the variation in mean observed days of BGM adherence in relation to adolescents' reports of Low, Moderate, or High levels of BGM adherence was significant in each assessed time frame. Post hoc comparisons were performed, using Tukey's Honestly Significant Differences. These comparisons revealed significant differences in observed BGM adherence over each of the time frames between the adolescents who reported Low BGM adherence and those who reported High BGM adherence, as well as between those reporting Moderate BGM adherence and those reporting High BGM adherence. There were no significant differences in the mean number of observed days of BGM adherence over any time frames by the adolescents reporting Low and Moderate BGM adherence.

Similarly, **Table 5.35** indicates that the variations in observed BGM adherence in relation to parents' reports of Low, Moderate or High levels of BGM adherence were significant over each time frame assessed. Post hoc comparisons were performed, using Tukey's Honestly Significant Differences. These comparisons revealed significant differences in observed BGM adherence over the 28 day and 20 day time frames between the adolescents whose parents reported Moderate BGM adherence levels and the adolescents of parents who reported High BGM adherence levels. Significant differences in observed BGM were revealed between the adolescents of

parents reporting Low BGM adherence and High BGM adherence for all of the time frames assessed.

Patterns of variation in BGM by each adolescent were assessed as a final examination of the data of BGM variation over the four weeks prior to assessment. Adolescents' adherence to BGM in each of the four weeks was rated as high (appropriate BGM on four or more days of the week) or low (appropriate BGM on three or fewer days of the week). The adolescents were then grouped as:

- (A) Consistently high BGM adherence (i.e., four or more days of appropriate BGM in all four weeks),

- (B) Consistently low BGM adherence (i.e., three or fewer days of appropriate BGM in all four weeks),

- (C) Rising BGM adherence (i.e., initially low BGM adherence, but high BGM adherence by the final week before assessment),

- (D) Other (i.e., BGM adherence not consistent with the above patterns).

Twenty-two adolescents were coded as Consistently high, 33 as Consistently low, 12 as Rising, and 8 as Other. **Figures 5.5** to **5.8** display the mean number of days of appropriate BGM each week over the four weeks prior to assessment, for the adolescents in each of these groups.

A Repeated Measures ANOVA contrasting the variation in BGM over time was performed involving the adolescents rated with (a) Consistently High, (b) Consistently Low, or (c) Rising BGM adherence. The results of this analysis are reported in **Table 5.36**; significant variation in BGM adherence over time was detected, as well as a significant variation in BGM adherence between these groups. The interaction effect was also significant. These results suggest that these groups define significantly different patterns of blood glucose monitoring adherence.

The responses by adolescents and parents to the questionnaire measures of adherence were examined separately for the four groups. The distributions of scores on the GAS, DSAS and the BGM item of the DSAS (item 2) by adolescents and parents are reported for each group in **Table 5.37**.

The responses of adolescents and parents to the questionnaire measures of adherence were examined in relation to membership in these groups. ANOVAs were used to examine differences in responses to these measures amongst adolescents exhibiting Consistently High, Consistently Low and Rising BGM adherence. These analyses are summarised in **Tables 5.38** and **5.39**.

Post hoc comparisons were performed, using Tukey's Honestly Significant Differences. These comparisons revealed significant differences in reported adherence between the Consistently High and Consistently Low BGM adherence groups on all of the questionnaire adherence measures. Significant differences were also detected between the Consistently Low and Rising BGM adherence groups on the parent completed DSAS, and on adolescent and parent responses to the BGM item of

the DSAS. No significant differences in responses to the questionnaire measures were detected between the Consistently High and Rising groups.

5.3.3 The Relationship Between Measures of Blood Glucose Monitoring Adherence Over Different Time Periods and the Measure of Metabolic Control (HbA_{1c}).

The distributions of HbA_{1c} assay levels for each of the BGM adherence groups are reported in **Table 5.40**. The group categorised by Consistently High levels of BGM displayed a slightly lower median HbA_{1c} value than the Consistently Low, Rising, and Other BGM adherence groups. However, an ANOVA of HbA_{1c} results according to BGM adherence group found that this variation was not significant.

CHAPTER SIX.

DISCUSSION: THE ASSESSMENT OF PATIENT ADHERENCE.

This chapter discusses the results presented in ***Chapter 5****, describing the measurement of patient adherence in the present study. In parallel with* ***Chapter 5****, the sections of this chapter address: first, the relationship between each of the measures of adherence, second, the variation in reported adherence in relation to demographic characteristics, and third, the variation in adherence over time.*

Parts of this chapter were published in:

Fotheringham MJ, Couper JJ, Sawyer MG. (1997). Associations between adolescents' metabolic control, IDDM adherence and objective data of blood glucose monitoring. *Proceedings of the Australian Diabetes Society, 1997* A 93.

6 DISCUSSION: THE ASSESSMENT OF PATIENT ADHERENCE.

6.1 The Relationship Between Different Measures of Adherence.

This section discusses the results presented in **Section 5.1**, examining the associations between each of the measures of adherence.

Before interpreting these associations, a caveat should first be acknowledged. The General Adherence Scale is a measure of an individual's "tendency to adhere to medical recommendations" (DiMatteo, et al. 1992, p 52). In contrast, the Diabetes Specific Adherence Scale is a measure of adherence to a range of specific recommended activities. The measure of blood glucose monitoring adherence assessed adherence to only one of the recommended regimen activities. While each of these measures are not intended to assess the same actual behaviour, they are expected to each assess aspects of the same behavioural construct; adherence to medical recommendations. As such, the scales would not be expected to produce identical results. However, as each of these measures assess aspects of the same construct, it would be expected that the results obtained on each of these measures would be correlated. That is, adolescents with a general tendency to adhere well to medical recommendations (GAS) would be expected to adhere well to the specific regimen activities in the DSAS, and to adhere well to BGM recommendations. Adolescents with a tendency not to adhere closely to medical recommendations (assessed on the GAS) would be expected to rate poorly on the DSAS and in their BGM adherence. As an analogy, these measures might be expected to be associated in the same way that height and weight are associated - that is, the correlation between them is not

perfect, but people who are tall are often heavier than people who are shorter, and both height and weight can be seen as measures of a more general construct: people's size.

6.1.1 The Relationship Between Adolescent Reports of Adherence.

The large association detected between the different adolescent reports of adherence, the DSAS and the GAS, may be interpreted in several ways.

First, adolescents' perceptions of general adherence may be largely defined by their adherence to IDDM management activities. This interpretation seems reasonable in light of the considerable impact of diabetes management activities on the lifestyle of these adolescents, making these activities the most common activities performed in relation to medical advice. Nonetheless, it is important to recognise that the adolescents may have completed the GAS within a wider frame of reference. The general tendency to adhere to medical recommendations may obviously include adherence to medical recommendations received by the adolescents in relation to other illnesses. However, none of the adolescents involved in this study were experiencing other chronic conditions. Further, because the questionnaires were completed as part of a study of adolescents with IDDM, and were completed in the Diabetes Outpatients Clinics, participating adolescents are likely to have answered the General Adherence Scale only in relation to their IDDM treatment.

A second possible interpretation of this association is that the adolescents' responses to the DSAS and the GAS were similarly influenced by social desirability biases. However, this interpretation is made less likely by the finding, reported in **Chapter 3**, that these measures have only a small association with the measure of socially desirable responding, the Socially Desirable Response Set.

The finding that mean levels of reported adherence to individual items of the DSAS and GAS varied widely suggests that adolescents' reports were not uniformly biased by social desirability influences. Further, this finding provides support for the suggestion that adherence varies between regimen demands (Fotheringham & Sawyer, 1995; La Greca, 1990). The finding that the mean level of reported adherence to insulin administration was higher than the mean level of reported adherence for the other regimen activities is consistent with the findings of previous researchers, such as RE Glasgow and Anderson (1995) and SB Johnson (1990), who have reported that adherence to this aspect of IDDM management tends to be complete or near complete. The frequency of response options to this item are detailed in **Appendix C**. The vast majority of adolescents reported adhering to insulin administration all or most of the time.

A significant difference between adherence levels indicated on the GAS and DSAS was observed, with generally higher levels of reported adherence on the GAS. There are several possible interpretations of this result. However, it should again be recognised that the GAS and the DSAS do not assess the same activity, but are simply intended to tap the same general construct of adherence to medical recommendations. The level of adherence indicated on the two measures would not necessarily be

expected to be equal, but would be expected to be correlated. Nonetheless, possible meanings of the difference in levels of adherence rating obtained from these measures should be examined.

The first possible interpretation of this finding is that the adolescents may have perceived their overall adherence to be good, eliciting high scores on the General Adherence Scale, but at the same time perceived their adherence to the specific activities detailed on the DSAS to be poorer. This may reflect differing criteria held by the adolescents as to what behaviour is important to diabetes management. For example, the activities mentioned in the specific measure may be considered unimportant by the adolescents, who instead attributed importance to activities not included in the specific measure.

A second possible interpretation of this finding is that only a few of the activities mentioned in the DSAS were considered important criteria of adherence by participating adolescents. For instance, adherence to blood glucose monitoring or insulin administration may have been used as the basis of responses to the GAS, while the other seven activities listed in the DSAS may not have been considered in the GAS responses.

A third possible interpretation of this outcome is related to the nature of the two measures. It is possible that respondents were more inclined to respond in socially desirable manners to the general questions than to the questionnaire addressing specific aspects. However, as reported in **Chapter 4**, the associations between responses to the adherence measures and the measure of socially desirable responding

were not high. In fact, the only significant association between a measure of adherence and socially desirable responding was for the adolescent completed DSAS. These results therefore do not support the interpretation that the differences in scores between the general and the specific measure of adherence were the result of socially desirable responding.

It should also be noted that participants completed the Diabetes Specific Adherence Scale first, followed by the General Adherence Scale. It is possible that the ordering of the questionnaires influenced the pattern of responses provided. A randomised ordering of questions would determine the importance of this possibility, although this procedure was not performed in the present study. However, the trend to respond more favourably to the second of the adherence questionnaires would suggest that the ordering of the questionnaires was not influential.

The variation in reported levels of adherence on these measures is consistent with the finding, reported elsewhere, that adherence to one aspect of a regimen is not necessarily indicative of adherence to other aspects of the regimen (Fotheringham & Sawyer, 1995, La Greca, 1990).

6.1.2 The Relationship Between Parent Reports of Adherence.

The strong association detected between parent reports of adherence on the DSAS and on the GAS also may be interpreted in several ways.

First, parents' perceptions of their adolescents' general adherence levels may be dominated by their perceptions of the adolescent's adherence to diabetes-specific health behaviours. The same arguments that support this interpretation of the adolescent reports also apply to the parent reports.

A second possible interpretation of this result is that socially desirable responding influenced both the GAS and DSAS reports from parents. However, like the adolescent responses on these scales, the effect sizes of the associations between parents' responses to the adherence scales and the Socially Desirable Response Set were small. This suggests that the parents' responses on the DSAS and GAS were not biased by socially desirable responding.

A third interpretation of the close association between parents reports on the DSAS and the GAS is that because the parents' were less involved in the performance of regimen activities than the adolescents, their reports were based on only a general impression of the adherence of their adolescents. As such, parents' reports on the DSAS would be influenced by this general impression, along with the GAS responses.

The examination of the variation in parent reported adherence to individual regimen activities identified in the DSAS refutes the second and third interpretations described in this section of the close association between parents' reports of adherence on the DSAS and the GAS. That is, this variation suggests that these reports were not uniformly biased by socially desirable responding. Further, the variation in reported adherence levels to the different regimen activities suggests that parents' responses on the DSAS were not dictated by a general impression of adherence - parents were able

to distinguish activities which were closely adhered to and activities to which adherence was less strict. Like the results of the examination of adolescents' responses to items of the DSAS, these results are supportive of the suggestion that patients' level of adherence varies between regimen demands.

A caveat that should be considered when examining the variation between response trends to different items of the DSAS is that this scale was designed to produce a total score, and as such the psychometric properties of individual items may not be appropriate for these comparisons. A detailed examination of the psychometric properties of each item of the DSAS is beyond the scope of this thesis. However, it may be noted that the variation in responses to items of the DSAS by adolescent respondents was similar to the variation in responses to the DSAS items by parent respondents. **Appendix C** displays the frequency with which responses were selected for each DSAS item by the adolescent and parent respondents. The pattern of responses produced by the adolescents was very similar to that produced by the parents.

The results of the Wilcoxon Matched-Pairs Signed-Ranks test employed to compare the scores produced by parents on the DSAS and GAS were very similar to the results produced in the Wilcoxon test examining the adolescents' reports on these measures. Again, a significant difference between adherence levels indicated on the GAS and DSAS was observed, with generally higher levels of reported adherence on the GAS.

It should again be recognised that the GAS and the DSAS to not assess the same activity, but are simply intended to tap the same general construct of adherence to

medical recommendations. However the possible meanings of the difference in levels of reported adherence obtained from these measures should be considered.

First, it is possible that the parents perceived their adolescents' overall adherence to be good, therefore eliciting high scores on the General Adherence Scale, but perceived that their adolescents' adherence to the specific activities detailed on the DSAS was poorer. This may reflect differing criteria held by the parents as to what behaviour is important to diabetes management. For example, the activities mentioned in the specific measure may be considered unimportant by the parents, who instead attributed importance to activities not included in the specific measure.

A second possible interpretation of this result is that only a few of the activities mentioned in the DSAS were considered important criteria of adherence by participating parents; for instance adherence to blood glucose monitoring and to insulin administration may be deemed important, while the other seven activities listed in the measure may not have been considered when responding to the general measure.

A third possible interpretation of this outcome is related to the nature of the two measures. It is possible that respondents were more inclined to respond in socially desirable manners to the general questions than to the questionnaire addressing specific aspects. However, as reported in **Chapter 4**, the association between responses to the adherence measures and the measure of socially desirable responding were low, neither of the parent completed adherence measures were significantly associated with the measure of socially desirable responding. These results therefore

do not support the interpretation that the differences in scores between the general and the specific measure of adherence were the result of socially desirable responding.

Again it should also be noted that participants completed the Diabetes Specific Adherence Scale first, followed by the General Adherence Scale. It is possible that this ordering of the questionnaires influenced the pattern of responses provided.

6.1.3 The Relationship Between Adolescent and Parent Reports of Adherence.

A strong association was detected between adolescents' and parents' responses on the GAS. Similarly, a strong association was detected between adolescents' and parents' responses on the DSAS. The close associations between adolescents' and parents' responses on these measures provide support for their validity - the large association between adolescent and parent reports represents good cross-informant concordance on both of the questionnaire measures. This finding is supported by the patterns of responses elicited from adolescents and parents on each item of the DSAS, as illustrated in **Appendix C**.

The results of the Wilcoxon Matched-Pairs Signed-Ranks tests examining the differences between adolescents' and parents' responses on the adherence questionnaires suggest that the information obtained from each of these groups of respondents was not unique. This result may be interpreted as an indication that the views of parents and adolescents are not uniformly discrepant - parents do not rate adherence as consistently higher or lower than do adolescents. This is an important

result. The cross-informant concordance on both the GAS and the DSAS provides support for the convergent validity of the measures (AL Stewart, Hays, & Ware, 1992).

These results are consistent with the finding of a previous study, conducted by SB Johnson and colleagues (1986). In the previous study, high levels of parent-adolescent agreement were found on 24-hour recall measures of adherence assessing a range of IDDM management activities. The results of this previous study supported the use of 24-hour recall adolescent self-reports of adherence when used in conjunction with parent reports. The results of the current study extend on this finding, and supports the use of adolescent self-reports of adherence over longer time frames, when used in conjunction with parent reports.

6.1.4 The Relationship Between Questionnaire Measures of Adherence and the Observed BGM Adherence.

The moderate and strong correlations detected between observed BGM adherence and adolescent and parent ratings of adherence on the GAS and DSAS provide support for the criterion validity of the adolescent and parent completed measures of adherence.

It should again be acknowledged that the questionnaire measures of adherence are intended to measure general adherence tendencies (GAS) and adherence to a range of specific regimen activities (DSAS). The observed BGM adherence provides

information only about adherence to one aspect of the IDDM management recommendations.

However, one of the specific activities addressed in the DSAS is blood glucose monitoring. The relationships between adolescents' and parents' reports of BGM adherence and the observed BGM adherence, are reported in **Chapter 7**, and discussed in **Chapter 8**. Further analyses of the relationship between observed BGM adherence and GAS and DSAS responses by adolescents and parents are therefore not addressed in this chapter.

6.2 The Variation in Reported Adherence According to Demographic Characteristics.

This section discusses the findings of the analyses performed to determine whether adherence reports varied in relation to demographic characteristics. These findings were presented in **Section 5.2**.

The demographic characteristics of the sample considered in these findings are: first, the adolescents' age; second, the adolescents' gender; third, the combined influence of adolescents' age and gender; and fourth, participating parents' work status.

6.2.1 The Variation in Reported Adherence According to Adolescent Age.

The first demographic characteristic of the sample to be considered in this section was adolescents' age. Adolescents' and parents' reports of general adherence (GAS) were not associated with the adolescents' age. Similarly, the reports of adolescents and parents on the DSAS did not correlate with or vary according to the adolescents' age.

These results are surprising; previous studies have determined that rates of adherence to various regimens vary according to the age of adolescents (e.g., Dunbar, 1983; La Greca, 1982; Litt & Cuskey, 1980). For example, La Greca (1982) reported that adherence to IDDM treatment was poorer amongst older adolescents than amongst younger adolescents. The lack of association between adolescents' age and their reports of adherence in this study is therefore unexpected.

The lack of association between adolescents' age and their adherence cannot be traced to an imbalance in the age distribution in the sample; approximately equal numbers of adolescents at each age level were involved in the study. The previous studies in which adherence was found to vary with adolescents' age did not employ the GAS or DSAS as measures of adherence. La Greca (1982) did not report how adherence was assessed, so it cannot be determined whether this difference in findings is the result of the instruments employed.

In contrast, observed BGM adherence was found to vary significantly in relation to adolescents' age. Lower levels of BGM adherence were observed in the older adolescents than in the younger adolescents. An analysis of variance indicated that

this variation was significant. Post hoc comparisons of BGM adherence by adolescent age groups indicated that significant differences in BGM adherence were found between the 12 year old adolescents and the 16 and 17 year old adolescents. These findings are consistent with the results of previous studies, in which adherence was reported to be lower amongst older adolescents than amongst younger adolescents and children (Dunbar, 1983; La Greca, 1982; Litt & Cuskey, 1980; Weinberger, 1987). There are several possible explanations for the inconsistency of age-adherence relations observed between this result and the results obtained with the adolescent and parent reports of adherence.

First, it is important to recognise that the adolescent and parent reports of adherence were not focused on blood glucose monitoring alone, but addressed a range of diabetes regimen activities, either assessing adherence in general (GAS) or to a range of specific activities (DSAS). As such, it is possible that adherence to other diabetes care activities was not associated with adolescents' age - that this relationship only occurred with blood glucose monitoring. This interpretation is facilitated by the finding that adherence to one aspect of a complex treatment regimen is not necessarily associated with adherence to other aspects of the regimen (**Section 5.1.1**; Fotheringham & Sawyer, 1995).

As a further test of this interpretation, additional analyses were performed to determine whether the relationship between BGM adherence and adolescents' age was demonstrated in the adolescents' and parents' responses to the item of the DSAS that specifically addressed this activity. Pearson correlations and one-way ANOVAs did not detect significant relationships between adolescents' or parents' responses on this

item and the adolescents' age. These additional results do not provide support for the interpretation that BGM adherence is associated with adolescent age, while adherence to other aspects of the regimen are not. That is, a significant relationship between adolescents' age and responses on this item would have supported the finding from the observed BGM data that adherence to this regimen activity is associated with adolescents' age, and would have suggested that the lack of association between adolescents' age and scores on the GAS and DSAS indicate that adherence to other aspects of the IDDM management regimen are not associated with adolescents' age.

A second possible explanation for the reported inconsistency in age-adherence relations observed between different measures of adherence is that the adolescent and parent reports of adherence failed to reveal a true relationship between adherence and adolescents' age as a result of socially desirable responding. This interpretation is not supported, however, by the finding reported in **Chapter 4**, that these measures were not closely associated with measures of socially desirable responding.

Nonetheless, in order to more closely examine this possibility, associations between the measure of socially desirable responding (SDRS) and adolescent and parent reports of adherence were assessed according to adolescent age strata. The responses to the adherence measures by older adolescents (16 and 17 year olds) were more closely associated with the measure of socially desirable responding than the responses of the younger adolescents, suggesting that these older adolescents may have responded to the adherence questionnaires in socially desirable manners. This finding may explain some of the difference in age-adherence relations detected amongst the different adherence measures. However, it is noteworthy that the

responses of the parents of the older adolescents were not associated with the SDRS. This suggests that while socially desirable responding may have made some contribution to the variation in age-adherence relations, this type of responding does not fully account for the observed variation in results.

A third potential explanation for this contrast in results is that the significant association with age found in the BGM data was influenced by the smaller sample size involved in this analysis. The GAS and DSAS reports were collected from 135 adolescent-parent dyads, while the BGM data could only be collected from 75 of the adolescents' blood glucose monitors. The difference in sample size obtained from these measures may have influenced the results in two ways: (1) the reduced sample size available for the BGM data may have influenced the power of the association between age and adherence; (2) the adolescents from whom BGM data as well as questionnaire measures were collected may have differed from the adolescents from whom only questionnaire data was collected.

The former influence is unlikely to be relevant to the current sets of data, as the reduced sample size available for the BGM data would make a real association more difficult to detect than the larger sample available for the questionnaire data.

The latter influence also appears to be unlikely, as the subsample for whom BGM data were available was drawn from within the greater sample. However, to test this possibility, the associations between adolescents' age and adolescent and parent reports of adherence were again examined, selecting only those study participants for whom BGM data had been collected. The results of these analyses suggest that the

variation in age-adherence relations detected between the questionnaire measures of adherence and the BGM adherence data is not explained by the difference in sampling.

A fourth possible explanation for the differences in association with adolescents' age of the BGM adherence data and the questionnaire measures lies in the selection of adolescents for supply with the MediSense monitors. These monitors were supplied to a selection of adolescents with poor metabolic control. It is possible that the adolescents with poor metabolic control differed from the other adolescents in terms of the factors which influence their adherence. That is, adherence amongst adolescents with poor metabolic control may be influenced by age-associated factors, while adherence of adolescents with good metabolic control may not be influenced by such factors. Reasons for such a contrast in influences on adherence are unclear.

None of the explanations discussed here appear to properly account for the variation in results found in this study when examining the relations of different adherence measures with the adolescents' age. It is possible that some combination of the factors discussed here are responsible for the inconsistent findings, or that another factor, not considered here, would account for the inconsistency. Replication of these findings in future studies would offer the opportunity to more systematically explore this issue.

Further analysis of adolescents' and parents' adherence reports in relation to the adolescents' age determined that the level of agreement between adolescent and parent reports of adherence on the GAS did not differ according to the age of the

adolescent. However, the level of agreement between adolescent and parent reports on the DSAS did vary according to the adolescents' age. The level of agreement between adolescents and parents on this scale was greater amongst the sample of 17 year olds than amongst the younger adolescents, aged between 12 and 14 years.

These results are consistent with those of a study conducted by SB Johnson and colleagues (1986), in which parent-adolescent agreement on a range of IDDM adherence measures amongst adolescents aged between 12 and 17 was inconsistent. The results of this previous study suggest that parent-adolescent agreement was more consistent amongst a subsample of younger adolescents (age 12 to 15 years) than amongst the older (16 and 17 year old) adolescents.

The finding in the current study that parent-adolescent agreement was highest amongst the older adolescents was somewhat surprising. These adolescents would be expected to behave more independently than the younger adolescents, and their parents to therefore be less aware of their regimen adherence. This finding does not support this expectation. The association between adolescents' autonomy and their adherence will be examined in more detail in **Chapters 9** and **10**.

It is noteworthy that although adolescents' and parents' reports of adherence were not associated with adolescents' age, observed BGM adherence was. Older adolescents' BGM adherence was poorer than that of the younger and middle adolescents, and the level of agreement between adolescents' and parents' on adherence was greatest at this age. This combination of results suggests the possibility that parent-adolescent agreement on the GAS and DSAS was high because parents had assumed that

adolescents were taking responsibility for, and were adhering closely to, the regimen. Adolescents' responses to the DSAS and GAS were consistent with this view. However, the observed BGM suggested that the adherence of these older adolescents may have been poorer than the adolescents and parents reported. In contrast, the parents of younger adolescents were likely to have been more involved in the management of their adolescents' regimen. The responses of these parents to the GAS and DSAS were less closely associated with their adolescents' responses. These findings are consistent with the finding, reported in **Chapter 4**, that adolescents' responses on the GAS and DSAS were more closely associated with the measure of socially desirable responding than the responses of the parents.

These results are also consistent with the finding of previous researchers, that confusion over the responsibility for regimen activities is associated with poor adherence (e.g., BJ Anderson, et al. 1990; La Greca, 1990a; Tebbi, 1993; Tebbi, et al. 1986; Tebbi, et al. 1988; Tebbi, et al. 1989; Wysocki, Meinhold, et al. 1992). For example, Ingersoll and colleagues (1986) reported that parents of adolescents with IDDM decreased and ultimately discontinued their involvement in their adolescent's illness regimen, but the adolescents did not assume the illness management. The present study does not include an assessment of perceived responsibility for regimen activities between adolescents and parents. The collection of this information in further studies would be beneficial for the understanding of adolescents' adherence.

6.2.2 The Variation in Reported Adherence According to Adolescent Gender.

The second demographic characteristic of the sample to be considered in this section is adolescents' gender. Adolescent and parent responses on both the GAS and the DSAS were not differentiated according to the adolescents' gender. Similarly, the level of observed BGM adherence was not significantly different amongst the male adolescents when compared with the female adolescents.

Further analyses examined the level of agreement between adolescent and parent reports of adherence on the GAS and DSAS. The results of these analyses suggested that parent-adolescent agreement on these questionnaires was not varied according to the gender of the adolescent.

Previous studies have also reported no association between adolescents' adherence to medical recommendations and their gender (Brooks-Gunn, 1993; Iannotti & Bush, 1993; SB Johnson, et al. 1986). However, as RE Glasgow and Anderson (1995) point out, many previous studies have not involved large enough samples to stratify participants according to characteristics such as gender and perform meaningful subgroup analyses.

The findings in this study consistently demonstrated that adherence was not differentiated according to adolescents' gender. The uniformity of these results across all measures of adherence, and in the level of agreement between adolescent and parent reports of adherence, suggests that gender may be considered to have little influence on adolescents' adherence.

6.2.3 The Relationship Between Measures of Adherence and the Measure of Metabolic Control (HbA_{1c}).

The next set of findings examined the relationship between adolescents' adherence and their level of metabolic control. The purpose of examining this relationship was to test the assumption that adherence is associated with health outcomes, that is, that poor adherence is associated with poor health status, while high levels of adherence are associated with good health. For adolescents with IDDM, metabolic control (HbA_{1c}) is the most widely accepted measure of health status.

The first of these analyses examined the relationship between the adolescents' GAS reports and their HbA_{1c} levels. This correlation did not reach statistical significance. However, an Analysis of Variance was performed to examine the relationship further. This analysis showed a significant variation in metabolic control in relation to adolescent reported adherence on this measure.

The lack of significance of the correlation between HbA_{1c} and adolescent GAS scores, and the significance of the ANOVA of these variables, is explained by the scatterplot, shown in **Figure 5.2**. The distribution of scores by adolescents on the GAS was narrow for those adolescents with HbA_{1c} assay values of around 7 %; these adolescents all produced high scored on the GAS. The adolescents with HbA_{1c} assays around 10 % and 11 % produced a much wider distributions of scores on the GAS. Adolescents with HbA_{1c} assays of 12 % or higher produced a somewhat narrower

distribution of GAS scores, although the number of adolescents at this end of the HbA_{1c} range was limited. The variation in the spread of GAS scores along the range of HbA_{1c} values appears to explain the significance of the ANOVA, and the nonsignificance of the correlation. Post hoc analyses of the ANOVA results revealed this to be the case; significant differences were found in GAS scores between the adolescents who had HbA_{1c} assay results of 7 % and those with assays results of 10 % and 11 %.

Adolescents' scores on the DSAS were not significantly related to their HbA_{1c} assay levels. Parents' scores on the GAS and their adolescents' HbA_{1c} assay levels were moderately associated. That is, high scores on the GAS were moderately associated with low HbA1c levels - indicating good metabolic control. The association is in the expected direction, indicating that parents' perceptions of general adherence were moderately linked with good metabolic control by these adolescents. The relationship between parents' reports of diabetes-specific adherence and adolescents' metabolic control did reach significance, although the correlation coefficient was moderately small.

Similarly, recorded BGM adherence by adolescents was moderately inversely associated with their metabolic control. This result indicates that adherence to BGM recommendations was directly associated with the metabolic control of these adolescents.

The association between adolescents' metabolic control and the measures of adherence is an important one. Previous studies have produced inconsistent results

when relating health status or health outcomes with adherence. The importance of adherence assessment lies in the assumption that good adherence leads to good health, and that poor adherence leads to poor health. The findings in this study suggest that the measures used to assess adherence were generally associated with the adolescents' level of metabolic control. Had the adherence assessments in this study been unrelated to metabolic control, the importance of factors associated with adherence would have been diminished. The significant relationship between the various measures of adherence and metabolic control suggests that factors associated with adherence are likely to influence the metabolic control of these adolescents.

6.2.4 The Combined Effect of Adolescents' Demographic Characteristics on Reported Adherence.

The next set of findings examined the variation in reported adherence according to adolescents' demographic characteristics.

The variation in responses to the four questionnaire measures of adherence in relation to adolescents' age and gender was insignificant. Similarly, the variation in observed BGM adherence in relation to adolescents' age and gender, and the interaction effect between these factors, was not significant.

These findings are consistent with those discussed in **Sections 6.2.1** and **6.2.2**. These results indicate that the adherence of adolescents in this study was not predicted by their age or gender.

6.2.5 The Variation in Reported Adherence According to Parental Work Status.

The next demographic characteristic of the sample to be considered in this section is parental work status. This term is used to indicate whether the parent completing the parent questionnaire measures in the study was primarily at home (i.e., performing home duties, pensioner, or working from home) or primarily out of the home (i.e., working outside the home environment).

The purpose of these analyses was to determine whether parents who worked outside the home were able to report on their adolescents' adherence in the same manner as parents who were primarily based inside the home environment. These analyses are intended to determine whether parents' perceptions of their adolescents' behaviour, and their level of agreement with their adolescents on that behaviour, are influenced by their level of contact with the adolescents (JM Landgraf, personal communication, 20 August, 1996).

These analyses first examined adolescents' and parents' responses on the GAS and DSAS in relation to the work status of the parent-informant. There were no significant differences between the reports obtained from parents who were working outside the home and those who were primarily at home. There also were no differences between the reports obtained from adolescents whose participating parents worked outside the home or were primarily at home.

Similarly, an examination of the observed BGM adherence according to whether or not the parent-informant was primarily at home did not reveal significant differences in BGM adherence.

Also, the level of parent-adolescent agreement on the GAS and on the DSAS was not varied according to whether or not the responding parent was primarily at home or was working outside the home.

These results suggest that the level of contact parents experienced with their adolescents, as indicated by their work status, did not effect their reporting of their adolescents' adherence. The finding that the level of agreement between adolescents and parents was not differentiated by parental work status suggests that this factor does not influence adolescent-parent relations in terms of the adolescents' health care.

6.3 The Variation in Adherence Over Time.

This section discusses the results presented in **Section 5.3**, describing the variation of adolescents' adherence over time.

It should be recognised that the sample involved in these analyses was not the complete sample assessed using the questionnaire measures. BGM data were only obtained from the seventy-five participants who possessed a MediSense Companion 2™ blood glucose monitor. It is possible that this restriction creates a bias in the sample. These monitors were supplied to adolescents with poor metabolic

control (see **Chapter 3**). A comparison of the adolescents from whom BGM data were obtained and those who did not provide this data, is presented in **Chapter 4**.

6.3.1 Variation in Adherence Over Time.

The next findings examined the variation over time of the level of adherence to Blood Glucose Monitoring recommendations. The variation in BGM over time was examined in two ways. First, the BGM data were coded into seven consecutive four-day blocks. The analysis of this data provided information about the frequency of BGM over short time periods. The selection of four day blocks of data provides a workable dataset - the analysis of 28 separate days was considered inappropriate for two reasons: (1) the degree of variation of BGM on individual days was more likely to vary widely (e.g., a noise effect), and (2) the interpretation of a significant result of an analysis of 28 separate days would be difficult (DL Streiner, personal communication, 24 March, 1997). The division of this data into seven blocks of four days was designed to provide a sufficient number of observational units to detect a variation, while keeping the dataset to a manageable proportion.

A second coding of the original data also was performed. In this case, the BGM data were coded into four blocks of one week. Although this smaller number of observations units provides a less detailed assessment, the week-long blocks account for possible variations between weekday and weekend activity. These analyses are presented separately. This coding was performed because of the possibility that BGM adherence may be differentiated between weekdays and weekends. That is, adherence

may be poorer on weekends because of the less structured lifestyle experienced by adolescents on weekends. The coding of the BGM data into four blocks of seven days overcomes the possible distortion created by this cycle.

A significant variation in BGM adherence was detected using both sets of data. These significant results indicate that the frequency of BGM by participating adolescents changed over the 28 days prior to Outpatient Clinic attendance. The graphical representation of these datasets suggest that the variation takes the form of an increase in BGM frequency as assessment time approaches, especially in the final days before assessment (**Figures 5.3** and **5.4**).

In order to formally assess the form of this variation in BGM, Trend Analyses were performed. A linear trend was detected. This finding means that the variation in BGM was monotonic. The frequency of BGM increased with each consecutive block; there was no reversal of this trend.

The finding that blood glucose monitoring adherence varied over time, increasing linearly as clinic attendance approaches, suggests several possible interpretations. **Figures 6.1** and **6.2** illustrate five possible models describing the variation in adherence levels over time. These models are described in turn; factors supporting or contradicting each of the models are then considered. In these figures, BGM adherence variation over time is represented by a black line, travelling from left to right. The grey box in this model, and in each of the remaining models, represents the time frame of the BGM data collected in this study. In each of the models the level of

BGM adherence rises during the time frame of the study. The point of data collection (clinic attendance) is represented by the right edge of the grey box.

The first interpretation of the observed variation in BGM adherence is illustrated in Model A of **Figure 6.1**. This model posits that the adolescents' level of adherence steadily increases with time.

A second possible interpretation, related to the first, is illustrated as Model B in **Figure 6.1**. According to this interpretation, adolescents' adherence levels increase for a time, before reaching a plateau.

A third model of adherence variation over time is shown as Model C in **Figure 6.1**. Like Models A and B, in this model the adolescents' adherence increases for a time. However, instead of continuing to rise or reaching a plateau, in this model the adolescents' adherence level decreases at some point after the time frame of the study.

A fourth possible model of BGM adherence variation over time is illustrated as Model D in **Figure 6.2**. This interpretation is that adherence levels rise and fall in a cyclic fashion, in relation to the timing of outpatient clinics – for example, adherence increases before each clinic attendance, and declines again after attendance.

The fifth model of BGM adherence variation is illustrated as Model E in **Figure 6.2**. This model is similar to Model D, in that the adherence level rises and falls in a cyclic manner, based around the timing of clinic attendance. However, in this model the level of adherence remains high for a brief time after each clinic attendance.

It should be recognised that these models provide a simplified representation of patterns of variations in adherence levels over time. Of course, actual adherence levels are likely to fluctuate considerably, both between individuals, and within individuals on a day to day basis. Like most health behaviours, adherence to BGM is likely to be influenced by daily events in the adolescents' lives. Nonetheless, the consideration of trends such as those depicted in these four models provides an insight into adherence behaviour.

A number of considerations should be recognised in examining these models. For example, the first interpretation, Model A, is unlikely to be an accurate representation of adherence variation over time, as this trend would show strong associations between adherence and illness duration. Adolescents' BGM adherence was not strongly related to the length of time they had been diagnosed with IDDM (r = -0.04, p = 0.8).

It is possible that, rather than a straightforward practice effect based upon the duration of treatment, the increase shown in BGM adherence over time indicated a practice effect associated with the new MediSense Companion 2™ blood glucose sensors. The adolescents from whom the BGM adherence data were obtained had only recently acquired these new monitors. This practice effect is unlikely, however, as the behaviour involved in monitoring blood glucose with these monitors is the same as that involved in the use of other monitors. All of the adolescents involved in the study has been in possession of a blood glucose monitor for at least twelve months before the study commenced.

It may be suggested that the variation in BGM adherence seen in the four weeks prior to assessment indicates a novelty effect associated with the new blood glucose sensors. This effect is unlikely, for at least two reasons. First, as already stated, the behaviour involved in blood glucose testing with these monitors was essentially the same as that involved with other blood glucose sensors. Second, it is unlikely that the patterns shown in **Figures 5.3** and **5.4** are the result of a novelty effect; if the variation were due to novelty it is more plausible that a decrease would be evident over the four weeks, as depicted in **Figure 6.3**. That is, if novelty were responsible for the variation in BGM adherence, there would be an increase in adherence shortly after the adolescents' acquired the new monitors, followed by a gradual (or rapid) drop-off.

A more plausible explanation for the significant variation in BGM adherence level relates to the adolescents' attendance at the Diabetes Outpatient Clinics at the hospital. The data collected indicate that BGM frequency increased as the adolescents' clinic appointment approached. Two explanations relating the proximity of clinic appointments with adherence levels are suggested.

First, that the adherence increased prior to the clinic attendance during which data were collected, but that this pattern was not repeated prior to further clinic attendances (i.e., Models B and C in **Figure 6.1**). According to this explanation, the adolescents' adherence was influenced by clinic attendance only because of the prompt of receiving a new blood glucose monitor.

Second, that adherence increases prior to each clinic attendance, and decreases after the clinic visit. This explanation is depicted in Models D and E of **Figure 6.2**. This interpretation is consistent with the finding of a previous study by Cramer and colleagues (1990), who reported that adherence to antiepileptic medication declined between clinic visits.

A cyclic variation appears to be the most plausible interpretation of the observed variation in blood glucose monitoring adherence. To determine whether this pattern is repeated before each clinic attendance, a longitudinal study design would be required. A study of this nature would also be able to determine whether such a variation followed the pattern of Model D, Model E, or some other pattern. The design of the present study does not allow for a longitudinal assessment of this kind, however, the author is collaborating in an ongoing study of adolescents with IDDM, in which these data are being collected over a period of nineteen months (Taylor, Fotheringham, Couper, Sawyer, 1996, 1997). These adolescents are scheduled to attend outpatient clinics at three-monthly intervals, so the data collected in that study should provide an insight into the nature of the variation in BGM adherence between a number of clinic attendances.

6.3.2 Relations Between Adolescent and Parent Reports of Adherence and Measures of Blood Glucose Monitoring Adherence Over Different Time Periods.

This section discusses the series of findings relating the reports of adherence (General Adherence Scale and Diabetes Specific Adherence Scale) obtained from adolescents

and parents, and the BGM adherence data. Each of these measures were framed to assess adherence over the past four weeks. The findings discussed in this section, which were presented in **Section 5.3.2**, were intended to determine whether the adolescents' and parents' reports of adherence were more representative of adherence levels over a shorter time-frame. To assess this, the level of association between these reports and the observed level of BGM over various time-frames was examined. Adolescent and parent ratings of adherence to BGM were obtained as part of the DSAS. The second item of this scale asks how often in the past four weeks adolescents have "self monitored blood glucose at least twice a day."

The associations between adolescent and parent reports of adherence and the observed BGM adherence over the different time frames do not provide strong support for the suggestion that these reports were biased by the most recent adherence behaviour. That is, adolescent and parent reports were not more highly correlated with observed BGM adherence over the shorter time frames than over the complete time frame. The level of association between reports of BGM and observed BGM did not vary widely depending on the duration of BGM data examined. This finding does not provide support for the suggested response bias. However, a number of caveats should be considered when interpreting this finding.

First, as was identified in **Section 6.1**, the DSAS and GAS are measures of adherence to diabetes treatment activities and to medical treatment in general. These measures were not designed to assess adherence to blood glucose monitoring alone. As such, the differences shown between reported adherence levels on these measures and the observed level of adherence to BGM may reflect the variation in adherence to

different regimen activities. That is, the finding that the level of BGM adherence observed was lower than the reported levels of adherence on these measures may simply reflect that adherence to this activity was poorer than adherence to other regimen activities.

In order to explore this possibility, patterns of responses to Item 2 of the DSAS, which directly assesses adherence to blood glucose monitoring, were examined. This approach leads to the second caveat to be considered. That is, the BGM item of the DSAS was not designed to be used as a scale in isolation from the other items of the DSAS. The psychometric properties of this item as a stand-alone item are not known. While the findings relating this item to the observations of the same behaviour provide interesting additional information, they should be interpreted with caution.

Another consideration that should be noted when interpreting these findings is that the degree of variation in the correlations presented in **Table 5.28** is small. With the exception of responses to the GAS, the correlations of questionnaire measures with BGM measures of different duration did not vary in terms of significance levels. In light of this, the interpretations of these variations should be made with caution. This is an issue worthy of further investigation.

A final caveat to consider is that when examining the BGM adherence over shorter time frames, the degree of continuity of the data declines. For example, the BGM adherence assessment which spans only the last 4 days can only produce scores of 0 %, 25 %, 50 %, 75 % or 100 %. Given this lack of continuity, the level of

correlation between this measure and the adolescent and parent reports is likely to be reduced in comparison to more continuous assessments of BGM adherence.

This consideration should also be applied to the adolescent and parent ratings of BGM. The item asking about BGM in the DSAS was constructed with a six-point Likert answering format. This limited range of response options restricts the continuity of the adolescent and parent reported BGM information. This caution is related to the abovementioned absence of known psychometric properties for these reports of monitoring behaviour.

In light of this final caution, a further examination of the relationship between observed blood glucose monitoring and adolescents' and parents' reports of BGM was performed. The reports of BGM adherence from adolescents and from parents were each split according to the midpoint of the response options. That is, adolescents who responded using options 1, 2 or 3 on this item (None of the time, A little of the time, or Some of the time ["Low BGM Adherence"]) were separated from those who responded using options 4, 5 or 6 (A good bit of the time, Most of the time, or All of the time ["High BGM Adherence"]). This dichotomous categorisation was used to examine the level of observed BGM amongst the two groups in each of the assessed time frames. This analysis was repeated by examining the response of parents to the BGM item of the DSAS, again dividing the sample according to reports of Low or High BGM adherence.

The difference between the mean number of days of appropriate BGM in these groups was tested for each of the time frames employed in the previous analyses. In each

time frame, the difference in mean days of BGM adherence between those categorised as Low BGM adherence and those as High BGM adherence was significant; this pattern was evident for both adolescent and parent ratings.

A second approach used to examine this relationship was to categorise the adolescent and parent ratings of BGM adherence into "Low BGM Adherence" (responses of 1: None of the time, or 2: A little of the time), "Moderate BGM Adherence" (responses of 3: Some of the time, or 4: A good bit of the time), and "High BGM Adherence" (responses of 5: Most of the time, or 6: All of the time). This trichotomous categorisation was again used to examine the mean number of days of observed BGM adherence in each group for each of the time intervals. These analyses were completed separately for adolescent and parent responses.

Again, the differences in mean numbers of days of appropriate BGM amongst these groups were significant, according to both the adolescent and the parent ratings. Post hoc analyses revealed that the differences between groups were significant between the adolescent-rated High BGM Adherence group and the adolescent-rated Low and Moderate BGM Adherence groups, but were not significant between the adolescent-rated Low BGM adherence and Moderate BGM adherence groups. Post hoc analyses revealed similar variations in observed BGM adherence in relation to parents' ratings of BGM adherence. Significant differences in observed BGM were revealed between adolescents of parents reporting Low BGM adherence and High BGM adherence for all of the time frames assessed, and between those reporting Moderate BGM adherence and High BGM adherence over the 28 day and 20 day time frames.

These results suggest that the adolescents' and parents' responses to the BGM item of the DSAS were able to distinguish adolescents who were poorly adherent to this self-care recommendation from those who were more adherent. The significance of these tests, using both the dichotomous and trichotomous categorisation of responses, supports the accuracy of these ratings. Further, the significance of these differences when examining each of the time frames included (the last 28, 20, 12, 8 or 4 days) provides further evidence that responses to this item of the DSAS were not unduly biased by the behaviour of the final week before Outpatient Clinic attendance.

However, in interpreting these results, a number of considerations and limitations should be recognised. First, although the mean number of days of BGM adherence was significantly different between groups, the actual number of days of BGM adherence in the "High BGM Adherence" group in the dichotomous categorisation, or in the "Moderate BGM Adherence" and "High BGM Adherence" groups in the trichotomous categorisations, was quite low. For example, the mean number of days of BGM adherence in the High BGM Adherence in the dichotomous analyses, for adolescent and parent responses, were 16.4 (± 9.6) and 15.2 (± 10.0) respectively during the past 28 days (**Tables 5.32** and **5.33**). These mean figures represent only slightly greater than half of the days in the time frame.

This pattern is consistent with the findings of other studies, which have noted that reports of poor adherence are often more accurate than reports of high levels of adherence (e.g., Dunbar, 1980; Dunbar & Agras, 1980).

These analyses are also limited by the imbalanced distribution of respondents into the Low and High, or Low, Moderate and High, BGM adherence groups. For example, the adolescent responses produced groups of 27 participants in the Low BGM adherence group and 48 in the High BGM adherence group for the dichotomous analysis (**Table 5.32**), and groups of 16, 18 and 41 for Low, Moderate and High BGM adherence groups in the trichotomous assessment (**Table 5.34**). The sample sizes for these analyses may have distorted the significance of the differences in observed adherence between groups.

A further consideration with these analyses is that the BGM item of the DSAS was intended for use as part of a broader scale. The psychometric properties of this item when used in isolation have not been tested. Further, the response options for the item are not specific - including such options as "some of the time" and "a good bit of the time" rather than, for example "10-15 days" or "3 days per week."

Nonetheless, the consistently significant results obtained in these analyses in distinguishing levels of adherence to BGM provides strong support for the utility of these tests. The consistency of the relations between observed BGM adherence over a variety of time frames with both adolescent and parent responses, supports the previous finding that these responses were not biased by the participants' adherence in only the final days before assessment.

The final examination of the variation in BGM adherence over time involved the classification of the observed patterns of BGM adherence in the four weeks prior to assessment. Adolescents were categorised with Consistently High BGM adherence

(at least four days of appropriate BGM in each of the four weeks prior to assessment), Consistently Low BGM adherence (three or fewer days of appropriate BGM in each of the four weeks prior to assessment), Rising BGM adherence (three or fewer days of appropriate BGM per week at the beginning of the assessment period, increasing to four or more days of appropriate BGM adherence by the final week before assessment), or Other patterns of BGM adherence.

The variation in BGM adherence over time according to membership in the first three of these groups indicated that the groups were distinguished in terms of their BGM adherence patterns over time. Further analysis determined that responses from adolescents and their parents to the GAS, DSAS, and to the item of the DSAS specifically asking about blood glucose monitoring were differentiated between the Consistently High and Consistently Low BGM adherence groups, and between the Rising and Consistently Low groups. However, the Consistently High and the Rising groups were not differentiated on any of the questionnaire measures of adherence completed by adolescents or parents.

This finding suggests that the responses of the adolescents (and their parents) classified in the Rising BGM adherence group may have been based upon their adherence behaviour in the week or two before assessment, rather than on the entire four weeks or the early part of this assessment period.

The limited size of these groups should be noted. Although the Consistently Low group includes 33 cases, the Consistently High group has only 22 cases, and the Rising group includes only 12 of the adolescents (eight adolescents were coded as

"Other," and not included in the subsequent analyses). The small group sizes, particularly in the last of these groups, may limit the generalisability of these findings.

6.4 Summary.

This chapter discussed the results presented in **Chapter 5**. These results relate to the measurement of adolescents' adherence. The discussion presented in this chapter addressed the relationship between each of the measures of adherence employed in this study, and the relationship between these measures and demographic characteristics of the sample.

The measures of adherence employed in this thesis were: adolescent completed reports of adherence on the GAS and DSAS, parent completed reports on the GAS and DSAS, and observations of BGM adherence. Large correlations were detected between each of these measures, suggesting that these measures were assessing the same general construct: patient adherence. However, as has been reported in previous studies, the reported level of patient adherence varied between different regimen activities (Fotheringham & Sawyer, 1995).

In light of these findings, and the issues raised at the start of **Section 6.1**, each of the measures of patient adherence employed in this study will be analysed separately in subsequent analyses. A combined measure formed on the basis of each of the separate measures will not be created. The hypotheses of this thesis will be tested separately

using general adherence (GAS) and diabetes-specific adherence (DSAS) measures separately, by adolescents and parents, as well as the objective BGM adherence data.

The level of adherence reported by adolescents and parents was not associated with the adolescents' age. Further, the level of agreement between adolescents and parents on the adherence measures was only weakly associated with adolescents' age - agreement on the GAS was not associated with adolescents' age, while agreement on the DSAS showed greater agreement between the eldest adolescents and their parents than between young adolescents and their parents. The level of observed BGM adherence was varied according to adolescent age, with greater adherence observed in the younger adolescents than in the older adolescents.

The association between adherence reports and adolescent gender was more straightforward. The level of adherence reported by adolescents and parents was not varied according to the gender of the adolescent. Further, the level of agreement between adolescents and parents on the adherence measures was not influenced by the adolescents' gender. The observed level of BGM adherence was also not associated with adolescents' gender.

Reports of adherence obtained from adolescents were only weakly associated with the adolescents' HbA_{1c} levels, while reports obtained from parents, and observations of BGM adherence were moderately associated with the adolescents' HbA_{1c} levels.

Reports of adherence were not associated by the combined effect of adolescent age and gender. Reports of adherence from adolescents and parents, and observed BGM

adherence, were not varied according to whether the parent was primarily in the home or outside the home, however, the level of agreement between adolescent and parent reports of diabetes-specific adherence (DSAS) was greater when the parent was primarily outside the home than when the parent was primarily at home. This pattern was not repeated with the GAS.

In sum, reported and observed levels of adherence were generally not varied in relation to demographic characteristics of the sample. While some associations were detected, these associations were often weak. Further, by performing multiple tests among the five different measures of adherence and the various demographic criteria, the probability of finding at least one statistically significant association is increased (see **Section 3.4.3**). The lack of strong associations between demographic characteristics of the sample and their adherence ratings suggests that the analyses performed in the subsequent results chapters of this thesis do not need to be performed separately for each demographic group on the basis of their adherence ratings.

Blood glucose monitoring adherence levels varied over the 4 weeks prior to assessment, becoming increasingly high as clinic appointments approached. The variation in BGM adherence levels formed a linear trend. That is, the variation with time was consistently in the same direction - increasing, rather than increasing and then decreasing.

In light of this finding, subsequent analyses involving the BGM adherence information will be performed using data spanning a variety of time frames. That is, the data assessing BGM adherence will be used separately in analyses involving BGM

adherence in the 28 days, 20 days, 12 days, 8 days and 4 days prior to Outpatient Clinic attendance. The use of sets of BGM adherence data covering different time spans should provide a more detailed illustration of the association between this measure of adherence and the other variables assessed in this investigation.

Finally, patterns of BGM adherence over the four weeks prior to Outpatient Clinic attendance were coded as Consistently High, Consistently Low, Rising or Other. Responses to questionnaire measures of adherence were found to be differentiated by these groups. Therefore, analyses involving BGM adherence in subsequent chapters will also be performed separately for adolescents classified with Consistently High BGM adherence, Consistently Low BGM adherence, Rising BGM adherence and Other BGM adherence patterns.

CHAPTER SEVEN.

RESULTS: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND PARENT-ADOLESCENT CONFLICT.

This chapter examines the relationship between measures of adolescents' adherence to their diabetes treatment recommendations and reports of parent-adolescent conflict. These analyses were designed to test the first hypothesis of this thesis. This chapter consists of four sections. First, adolescents' and parents' reports of parent-adolescent conflict are presented in relation to sample characteristics. Second, analyses are presented that examine the association between reports of parent-adolescent conflict and reports of adherence. Third, analyses are presented reporting differences in the level of association between reports of parent-adolescent conflict and reports of adherence according to sample characteristics. Finally, the association between reports of parent-adolescent conflict and adolescents' metabolic control (HbA_{1c}) is examined.

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7 RESULTS: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND PARENT-ADOLESCENT CONFLICT.

7.1 The Reporting of Parent-Adolescent Conflict in Relation to Sample Characteristics.

This section examines obtained data from the measure of parent-adolescent conflict. The CBQ was completed by participating adolescents and parents; an aggregate score was generated by adding the adolescent and parent scores. **Table 7.1** displays distributions of scores on this measure by adolescents and parents, as well as aggregate scores. The scoring ranges for the adolescent completed and parent completed CBQs are 0 to 20, with higher scores indicating higher levels of conflict. The scoring range for the aggregate score is 0 to 40. As may be seen from this table, mean responses on this scale from adolescents and parents were in the lower half of the scale, indicating generally low levels of conflict. Further, the level of conflict reported by adolescents was similar to that reported by parents.

The scoring distributions of these measures are examined in relation to: (1) adolescents' age, (2) adolescents' gender, (3) parents' age, (4) parents' gender, (5) parents' work status, and (6) household structure (i.e., single or dual parent households).

7.1.1 The Reporting of Parent-Adolescent Conflict in Relation to Adolescents' Age.

The distributions of scores on the CBQ according to adolescents' age are reported in **Table 7.2**. Slightly lower levels of parent-adolescent conflict were reported amongst younger adolescents (i.e., 12 and 13 year olds) and their parents, than amongst older adolescents and their parents. One-way ANOVA of this variation revealed that these differences were not statistically significant. The correlations between the adolescent, parent, and combined CBQ forms and adolescents' age are shown in **Table 7.3**.

To explore further the association between reports of parent-adolescent conflict and adolescents' age, the level of agreement between adolescents' and parents' reports of conflict was examined in relation to this characteristic. These analyses are detailed in **Appendices D.1** and **D.2**. The level of agreement between adolescents and parents was particularly high amongst the 13 year old adolescents. This variation was significant.

7.1.2 The Reporting of Parent-Adolescent Conflict in Relation to Adolescents' Gender.

The distributions of scores on the CBQ by adolescents and parents according to adolescents' gender are reported in **Table 7.4**. Although female adolescents' mean scores on this scale were slightly higher than male adolescents' scores, this difference was not significant. Similarly, mean scores obtained from the parents of male and female adolescents were not significantly different; combined scores produced by

adolescents and parents were not significantly differentiated according to adolescent gender.

To explore further the association between reports of parent-adolescent conflict and adolescents' gender, the level of agreement between adolescents' and parents' reports of conflict was examined in relation to this characteristic. This analysis is detailed in **Appendix D.3**. Overall, adolescents' and parents' responses on the CBQ were highly correlated. The size of this correlation did not significantly vary according to adolescents' gender.

7.1.3 The Reporting of Parent-Adolescent Conflict in Relation to Parents' Age.

The distributions of scores on the CBQ by adolescents and parents according to parents' age are reported in **Table 7.5**. Parents' age was grouped into (a) those under 40 years old, (b) those aged 40 to 45 years old, and (c) those aged over 45 years old. This division meant that almost half of the sample were in the second group. However, the concentrated distribution of parents' age around the early 40s made this imbalance unavoidable.

A oneway ANOVA was used to examine the variation in adolescents' scores on the CBQ according to parents' age groups. The results of this analysis were not significant. Similarly, parents' scores on the CBQ were not significantly varied according to their age. Combined adolescent and parent CBQ scores were not significantly varied according to parents' age.

7.1.4 The Reporting of Parent-Adolescent Conflict in Relation to Parents' Gender.

The distribution of CBQ scores according to whether the parent-form was completed by the adolescents' mother or father is reported in **Table 7.6**. Similar levels of conflict were reported between adolescents and participating mothers, and adolescents and participating fathers. The distribution of CBQ scores according to adolescent gender and age depending on whether parent reports were obtained from mothers or fathers are reported in **Tables 7.7, 7.8** and **7.9**.

Item responses to individual items of the Conflict Behavior Questionnaire by adolescents completing the adolescent-mother conflict and adolescent-father conflict versions, as well as item responses by parents, are described in **Appendices D.4**, **D.5** and **D.6**. It should be noted that the number of fathers involved in this study was very limited. Because of these small sample sizes, formal analyses were not performed on this data.

7.1.5 The Reporting of Parent-Adolescent Conflict in Relation to Parents' Work Status.

The distributions of scores on the CBQ by adolescents and parents according to parents' work status are reported in **Table 7.10**. Parental work status was defined on the basis of whether the participating parent was working primarily in the home or outside the home environment (see also **Chapter 4**). Similar levels of parent-

adolescent conflict were reported by parents working inside and outside the home environment, and by their respective adolescents. Students' *t* test analyses revealed that mean scores on the adolescent, parent, and combined scales of the CBQ were not significantly different on the basis of parental work status.

To explore further the association between reports of parent-adolescent conflict and parents' work status, the level of agreement between adolescents' and parents' reports of conflict was examined in relation to this factor. These analyses are detailed in **Appendix D.7**. Interestingly, greater parent-adolescent agreement on the CBQ was observed amongst dyads in which the parent worked primarily outside the home environment than amongst dyads where the participating parent was primarily in the home.

The distribution of CBQ scores according to parent gender and work status is reported in **Table 7.11**. Again, similar levels of parent-adolescent conflict were reported in each of these groups. However, it should again be noted that the groups defined by fathers (father working at home and father working outside the home) contain very limited numbers of participants. Because of these small sample sizes, formal analyses were not performed on this data.

7.1.6 The Reporting of Parent-Adolescent Conflict in Relation to Household Structure.

The distributions of scores on the CBQ by adolescents and parents according to participants' household structure are reported in **Table 7.12**. Household structure was defined by the number of parents in the household. That is, these analyses compared the level of parent-adolescent conflict reported in single parent and dual parent households.

Adolescents reported very similar mean levels of conflict with parents in single and dual parent households. The mean level of parent-adolescent conflict reported by parents in single parent households was slightly higher than that reported by parents in dual parent households. This difference was not statistically significant.

7.2 The Level of Association Between Measures of Parent-Adolescent Conflict and Adherence.

The analyses presented in this section were designed to examine the association between the measures of parent-adolescent conflict and the measures of adherence to medical recommendations. Pearson correlations were employed to examine the level of association between these measures.

Separate analyses examined the associations between (1) adolescent reports of adherence and conflict, (2) parent reports of adherence and conflict, (3) adolescent and

parent reports of adherence and the combined measure of parent-adolescent conflict. Further analyses examined (4) cross-informant associations between reports of conflict and adherence (e.g., between adolescent reports of conflict and parent reports of adherence), and (5) associations between observed blood glucose monitoring adherence and reports of conflict between adolescents and parents.

7.2.1 Adolescent Reports of Parent-Adolescent Conflict and of Adherence.

The level of correlation between the adolescent completed measure of parent-adolescent conflict and the adolescent completed GAS is shown in **Table 7.13**. The effect size of the correlation between adolescents' GAS scores and their CBQ scores was moderately large and in the predicted direction.

The level of correlation between the adolescent completed measure of parent-adolescent conflict and the adolescent completed DSAS is shown in **Table 7.13**. The correlation between the adolescent completed DSAS and the adolescent completed CBQ was moderately strong, and in the direction predicted by the first hypothesis.

7.2.2 Parent Reports of Parent-Adolescent Conflict and of Adherence.

The correlation between parent scores on the CBQ and on the GAS is reported in **Table 7.13**. The association between these reports was moderate, and in the direction predicted by the first hypothesis.

The correlation between the parent completed DSAS and the parent completed CBQ was also moderately strong and in the predicted direction (**Table 7.13**).

7.2.3 Combined Reports of Parent-Adolescent Conflict and Reports of Adherence.

The correlations between combined parent and adolescent CBQ scores and adolescent scores on the GAS and DSAS are reported in **Table 7.13**. Correlations between these combined CBQ scores and parents' scores on the GAS and the DSAS are also reported in **Table 7.13**.

These associations were all moderately strong, and in the direction predicted by the first hypothesis. That is, higher levels of reported adherence were associated with lower levels of reported conflict between adolescents and parents. The levels of association between the adolescent and parent completed GAS and the combined CBQ were greater than the levels of associations of the adolescent and parent completed DSAS with the combined CBQ.

7.2.4 Cross-Informant Associations Between Reports of Parent-Adolescent Conflict and Adherence.

The next analyses examined the association between (1) adolescents' reports of conflict with their parents, and the parents' reports of the adolescents' adherence, and (2) adolescents' reports of adherence, and their parents' reports of conflict with the adolescents. These analyses were performed to examine from another angle the

association between reported conflict and adherence. The examination of cross-informant associations also reduces the vulnerability of the analyses to shared method variances (see **Chapter 8** for a discussion of this point).

Adolescent Reports of Conflict and Parent Reports of Adherence.

The levels of association between adolescent responses on the CBQ and parent scores on the GAS and DSAS are reported in **Table 7.13**. The effect sizes of these associations are consistent with the associations between adolescent responses on each of these measures, as well as between parent responses between these measures.

These results suggest that the associations detected in the previous analyses (**Sections 7.2.1, 7.2.2** and **7.2.3**) between scores on the CBQ and the GAS and DSAS were not the result of respondent biases. These findings provide further support for the first hypothesis of this thesis.

Parent Reports of Conflict and Adolescent Reports of Adherence.

The levels of association between parent responses on the CBQ and adolescent scores on the GAS and DSAS are reported in **Table 7.13**. The effect size of the association between the parent completed CBQ and adolescents' scores on the GAS was consistent with the association between these questionnaires as completed by the adolescents (**Section 7.2.1**) and by the parents (**Section 7.2.2**).

The level of association between the parent completed CBQ and adolescent scores on the DSAS was smaller than that reported in the within-informant analyses. This association was not significant at the 0.05 α level. This result was the only association between the reports of adherence and the reports of parent-adolescent conflict not to reach this level of significance.

7.2.5 Reports of Parent-Adolescent Conflict and Observed Blood Glucose Monitoring Adherence.

The next analyses examined the relationship between reports of parent-adolescent conflict and observed blood glucose monitoring adherence. These analyses took three forms. First, the relationship between scores on the CBQ and the observed BGM adherence was examined using the complete BGM adherence dataset. Second, relationships between CBQ scores and observed BGM adherence over the final 20, 12, 8, and 4 days before assessment were examined separately. Third, the relationship between CBQ scores and observed BGM adherence over the previous 28 days was examined separately for adolescents coded with Consistently High, Consistently Low, Rising, or Other patterns of BGM adherence over the assessment period.

The Relationship Between Reports of Parent-Adolescent Conflict and Observed Blood Glucose Monitoring Adherence.

The correlations between the objective recording of Blood Glucose Monitoring and the measures of parent-adolescent conflict are reported in **Table 7.14**. These

correlations were weaker than those found between the questionnaire measures of adherence and the conflict measures.

The effect size of the association between adolescent reports of parent-adolescent conflict and observed blood glucose monitoring was moderately small. The effect size of the association between parent reports of parent-adolescent conflict and observed blood glucose monitoring was smaller. The effect size of the association between the combined CBQ score and the observed blood glucose monitoring was slightly smaller than that of the adolescent reports. Of these associations, only the correlation between the adolescent reports of conflict and the observed BGM approached the 0.05 significance level.

However, these correlations were all in the direction consistent with the first hypothesis of this thesis. These results, when considered independently of the previous analyses, do not provide strong support for the hypothesised inverse relation between parent-adolescent conflict and adolescents' adherence to medical treatment. However, the consistent direction of effect that has been observed in these and the preceding results, is supportive of the hypothesis. The strong relationship observed between adolescents' and parents' reports of adherence and parent-adolescent conflict provides considerable support for the acceptance of the hypothesised inverse relationship between parent-adolescent conflict and adolescent adherence to medical treatment.

The Relationship Between Reports of Parent-Adolescent Conflict and Observed Blood Glucose Monitoring Adherence Over Different Time Frames.

The correlations between the BGM adherence data spanning different time frames and the measures of parent-adolescent conflict are reported in **Table 7.15**. These correlations are reported for the observed BGM adherence over the final 28, 20, 12, 8 and 4 days prior to assessment. These analyses were intended to examine the relationship between reports of conflict between adolescents and parents and adherence to BGM over different time frames. As reported in **Chapter 5**, observed BGM adherence varied significantly over the four weeks prior to assessment, increasing as attendance to the clinic approached.

The magnitude of the correlations between each of the measures of conflict and the observed BGM adherence did not vary greatly when the time frame examined by this data was adjusted.

The Relationship Between Reports of Parent-Adolescent Conflict and Blood Glucose Monitoring Adherence, According to Observed Patterns of Adherence Over Time.

Table 7.16 reports the distribution of scores on the adolescent, parent and combined scales of the CBQ for each blood glucose monitoring adherence group (Consistently High, Consistently Low, Rising, Other). The mean scores obtained on each of these scales of the conflict measure were highest amongst the group whose adolescents were categorised with Consistently Low BGM adherence. The mean scores obtained on

each of these scales of the conflict measure were lowest amongst the group whose adolescents were categorised with Consistently High BGM adherence. The mean reported levels of conflict obtained from the remaining adolescents (categorised with Rising or Other patterns of BGM adherence) and their parents were distributed between the Consistently High and Consistently Low BGM adherence groups' mean scores.

Oneway ANOVAs were performed for each of the conflict scales (as dependent variables) against the four BGM adherence groups (the independent variable). These analyses were use to determine whether the level of conflict reported between adolescents and parents varied between these groups. The results of these ANOVAs are reported in **Table 7.17**. Reported levels of parent-adolescent conflict, on the adolescent, parent, and combined scales of the CBQ, were not significantly varied according to the BGM adherence groups.

A second approach employed to analyse the possible variation in reported conflict according to the BGM adherence profiles was pursued. This approach involved the combination of the Rising and Other BGM adherence groups into a single group. The levels of conflict reported by these adolescents and their parents were compared with those reported amongst the Consistently High and Consistently Low BGM adherence groups using oneway ANOVAs. The results of these analyses are reported in **Table 7.18**. Although this process increased the *F* ratios produced in the analyses, reported levels of parent-adolescent conflict on each of the scales were again not significantly varied according to these BGM adherence groups.

7.3 Differences in Associations Between Parent-Adolescent Conflict and Adherence According to Sample Characteristics.

The analyses presented in this section were designed to examine the variation in the associations between the measures of parent-adolescent conflict and the measures of adherence according to demographic characteristics of the sample. These associations are examined in relation to: (1) adolescents' age, (2) adolescents' gender, (3) parents' age, (4) parents' gender, (5) parents' work status, and (6) household structure (i.e., single or dual parent households).

7.3.1 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Adolescents' Age.

The associations between reports of parent-adolescent conflict and regimen adherence, separated by adolescent age levels (12 year olds, 13 year olds, 14 year olds, 15 year olds, 16 year olds and 17 year olds) are reported in **Tables 7.19** and **7.20**. The levels of association between reports of conflict and reports of adherence were greatest amongst the 13 year olds and their parents.

However, the small sample sizes produced by this division of the sample limited the variation in scores obtained on each measure. To overcome this limitation, the sample was examined using broader age divisions. First, the sample was separated into 12 and 13 years olds, 14 and 15 year olds, and 16 and 17 year olds (**Table 7.21**). This division created three sub-samples of around 40 adolescents and parents. The greater

sample sizes produced by this division, and the greater variation in scores on the adherence and conflict measures, meant that the correlations produced for these groups more often reached statistical significance. The largest correlations were obtained amongst the youngest adolescents (aged 12 and 13) and their parents.

As a second examination of this pattern, the sample was divided into adolescents aged 12 to 14 years, and adolescents aged 15 to 17 years. The associations between the measures of adherence and the measures of conflict for these groups are reported in **Table 7.22**. In line with the results reported in **Tables 7.19**, **7.20** and **7.21**, the associations between reports of adherence and reports of parent-adolescent conflict were greater among the younger adolescents and their parents than among the sample of older adolescents and their parents.

7.3.2 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Adolescents' Gender.

The associations between reports of parent-adolescent conflict and regimen adherence are reported separately according to adolescent gender in **Table 7.23**. The levels of association between reports of conflict and reports of adherence were very similar amongst the samples of male and female adolescents and their parents. However, the levels of association between parent reports of diabetes-specific adherence and the reports of conflict were greater for the male adolescents than for the female adolescents.

7.3.3 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Parents' Age.

The associations between reports of parent-adolescent conflict and regimen adherence are reported separately according to parents' age in **Table 7.24**. Parents' age was grouped into (a) those under 40, (b) those aged 40 to 45, and (c) those aged over 45; in the same manner as that described in **Section 7.1.3**.

The levels of association between reports of conflict and reports of adherence were similar amongst the samples defined by parents' age. The level of significance of these correlations was greatest amongst the sample characterised by parents aged 40 to 45 years, because of the larger sample size for this group. However the levels of association generally were not larger in this group than in the groups defined by older or younger parents.

7.3.4 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Parents' Gender.

The associations between reports of parent-adolescent conflict and regimen adherence are reported separately according to parents' gender in **Table 7.25**. The levels of associations produced amongst the sample of mothers and their adolescents were greater and had more statistical significance than those produced by the participating fathers and their adolescents.

However, the number of fathers involved in the study was very limited. As such, the variation in obtained scores on the adherence and conflict scales by this sub-sample was limited.

7.3.5 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Parents' Work Status.

The associations between reports of parent-adolescent conflict and regimen adherence are reported separately according to parents' work status in **Table 7.26**. The levels of association between the conflict reported by adolescents and the adherence measures were slightly greater amongst the sample categorised by the parent working outside the home environment than amongst the sample categorised by parents who were primarily at home. The conflict reports obtained from parents were more closely associated with reports of general adherence amongst those parents who were primarily at home than amongst the parents working outside the home. The combined adolescent and parent reports of parent-adolescent conflict were more closely associated with the adolescents' and parents' reports of adherence amongst the sample defined by the participating parent working outside the home, than amongst the sample in which parents were primarily at home.

7.3.6. Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Household Structure.

The associations between reports of parent-adolescent conflict and regimen adherence are reported separately according to household structure in **Table 7.27**. Household structure was classified in terms of single parent (whether mother or father) versus dual parent households.

The levels of associations produced amongst the sample categorised by dual parent households were generally more statistically significance than those produced by the members of single parent households. However, the effect sizes of the associations between these measures were generally larger in the single parent group than in the dual parent group.

7.4 The Level of Association Between Measures of Parent-Adolescent Conflict and Adolescents' Metabolic Control.

The analyses presented in this section were designed to examine the association between the measures of parent-adolescent conflict and adolescents' HbA_{1c} assay levels - the measure of their metabolic control. These analyses were performed to examine further the hypothesised relationship between parent-adolescent conflict and adolescents' adherence.

Correlations of the adolescent completed, parent completed, and combined CBQ scores with adolescents' HbA_{1c} are displayed in **Table 7.28**. The correlations between both the adolescent completed CBQ and the combined adolescent-parent score with adolescents' HbA_{1c} levels were moderately small, but statistically significant. The parent completed CBQ was less strongly correlated with adolescents' HbA_{1c} levels. This association did not reach statistical significance.

The final analyses that were conducted examined whether the parent-adolescent conflict ratings accounted for unique variance in HbA_{1c} assay levels once the adherence reports were entered into regression equations first. Eight such hierarchical multiple regression analyses (HMRAs) were conducted, using adolescents' HbA_{1c} assay results as the dependent variable. These analyses are reported in **Table 7.29**. The first two of these HMRAs involving the adolescent form of the CBQ (*Step 2*), entered after the adolescent completed GAS (*Step 1* in the first regression equation), or the adolescent completed DSAS (*Step 1* in the second regression equation). Two further HMRAs were conducted, entering the parent responses to the CBQ (*Step 2*), after (1) the parent completed GAS (*Step 1*), and (2) the parent completed DSAS (*Step 1*). The final four HMRAs involved the combined score on the CBQ (*Step 2*), entered after (1) the adolescent completed GAS, (2) the adolescent completed DSAS, (3) the parent completed GAS, and (4) the parent completed DSAS (each as *Step 1* in separate regressions).

Adolescent Reports of Adherence and Conflict.

As reported in **Table 7.29**, adolescent reports of parent-adolescent conflict added a significant amount of the variance in *Step 2* after the adolescent reports of general adherence had been entered. The regression analyses involving adolescent responses to the DSAS were halted before the conflict measure was entered, because of the lack of predictive power of these adherence reports to the adolescents' metabolic control levels.

Parent Reports of Adherence and Conflict.

As reported in **Table 7.29**, parent reports of parent-adolescent conflict did not significantly predict adolescents' metabolic control, as assessed by HbA_{1c} assays.

Combined Adolescent and Parent Reports of Conflict and Reports of Adherence.

As reported in **Table 7.29**, combined adolescent and parent reports of parent-adolescent conflict added a significant amount of the variance to adolescents' metabolic control in *Step 2* after the adolescent reports of general adherence had been entered. The regression analyses involving adolescent responses to the DSAS were halted before the combined conflict measure was entered, because of the lack of predictive power of these adherence reports to the adolescents' metabolic control levels.

The combined adolescent and parent reports of conflict added a significant amount of the variance in *Step 2*, after the parent reports of diabetes-specific adherence (DSAS) had been entered. However, the combined adolescent and parent reports of conflict did not add a significant amount of the variance to adolescents' metabolic control in *Step 2*, after the parent reports of general adherence (GAS) had been entered.

CHAPTER EIGHT.

DISCUSSION: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND PARENT-ADOLESCENT CONFLICT.

This chapter discusses the results presented in ***Chapter*** *7, describing the relationship between the measures of patient adherence and parent-adolescent conflict in the present study. In parallel with* ***Chapter*** *7, the sections of this chapter address: (1) the reporting of parent-adolescent conflict in relation to sample characteristics; (2) the level of association between measures of parent-adolescent conflict and adherence; (3) differences in associations between parent adolescent conflict and adherence according to sample characteristics; and (4) the level of association between measures of parent-adolescent conflict and adolescents' metabolic control.*

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8 DISCUSSION: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND PARENT-ADOLESCENT CONFLICT.

8.1 The Reporting of Parent-Adolescent Conflict in Relation to Sample Characteristics.

This section discusses the results presented in **Section 7.1**, examining the reporting of parent-adolescent conflict by adolescents and parents in this study. These reports are examined in relation to respondents' demographic characteristics.

In examining the obtained reports of parent-adolescent conflict, it may be noted that that the mean score on the Combined form of the CBQ is not equal to the sum of the mean adolescent score and the mean parent score (**Table 7.1**). Similarly, the minimum score obtained by adolescents was 0, as was the minimum score obtained by parents, whereas the minimum score produced on the combined scale was 1. This occurred because, although the responses of adolescents and parents on this measure were highly correlated, the adolescent reporting the lowest CBQ score may not have belonged to the same dyad as the parent reporting the lowest CBQ score. Similarly, adolescents who reported a level of conflict equal to the obtained mean score may have been paired with parents who reported levels of conflict higher than or lower than the mean score on the parent form.

The scoring distributions of these measures are examined in relation to: (1) adolescents' age, (2) adolescents' gender, (3) parents' age, (4) parents' gender, (5)

parents' work status, and (6) household structure (i.e., single or dual parent households).

8.1.1 The Reporting of Parent-Adolescent Conflict in Relation to Adolescents' Age.

Previous studies have reported that conflict between adolescents and parents increases as adolescents enter middle adolescence (Montemayor, 1983; Paikoff & Brooks-Gunn, 1991; Papini, et al. 1989; Papini & Sebby, 1988). In the present study, slightly higher mean levels of parent-adolescent conflict were reported for the adolescents aged 14 years and above than for the 12 and 13 year old adolescents, although this variation was not significant.

There are several possible explanations for the absence of differences in parent-adolescent conflict according to age in this study. First, although the full sample was quite large, it is possible that the number of adolescents involved in the study at each age level was too small to detect a significant variation in conflict reporting. The largest age sample involved in the study included only 24 adolescents and parents. The smallest age sample included only 16 adolescents and parents. It is possible that larger samples would have revealed a significant variation. However, the effect sizes of the associations between reported conflict and reported adherence, were very small. As such, it is unlikely that the lack of significant differences in reported conflict according to adolescents' age is due to limited sample sizes.

Another possible explanation for the inconsistency in results between this study and previous research is that the age ranges included in this study and the previous studies varied. That is, some previous studies have examined younger age groups than were included in this study. Few studies have examined this issue in adolescents up to 17 years of age. A related explanation for the inconsistency in findings between this study and previous research is that some studies have based their age comparisons on pubertal status. That is, prepubertal and pubertal adolescents were compared in terms of conflict with parents. In the present study, pubertal status was not examined. The lack of variation in parent-adolescent conflict may reflect a uniformity in pubertal status amongst the adolescents involved in this study. However, it is very unlikely that the pubertal status of the adolescents involved in this study was uniform, given the age range of these adolescents.

The inconsistency in results may also be an artifact of the different methodologies used to assess parent-adolescent conflict. For example, previous studies have used (1) questionnaires completed only by adolescents, (2) interviews of adolescents, or (3) projective measures of conflict (Montemayor, 1983). The difference in results found in this study may be a product of the approach used to assess conflict. Future studies should be able to clarify this point.

One final interpretation for the difference in age-conflict relationships between this study and previous studies is the cultural base of each of the studies. The previously mentioned studies by Montemayor (1983), Paikoff & Brooks-Gunn (1991), and Papini and colleagues (Papini, et al. 1989; Papini & Sebby, 1988) were all conducted in North America, whereas the current study was conducted in Australia. It is possible

that parent-adolescent conflict is more dependent on adolescents' age in North American societies than in Australia. Some studies have examined differences in parent-adolescent conflict between western and eastern cultures (DeRosier & Kupersmidt, 1991; Zahn-Waxler, et al. 1996). However, comparisons of parent-adolescent conflict between American and Australian societies have not been reported in the literature.

The reasons for the differences in the level of agreement between adolescents and parents on the conflict measure according to the adolescents' age are unclear. If the level of parent-adolescent agreement had varied in a systematic manner, such as that agreement was higher amongst younger adolescents than amongst older adolescents, then the results may have been meaningfully interpreted. However, in this study the level of agreement was much higher amongst the 13 year old adolescent sample than any other age group. As reported in **Table D.2** of **Appendix D.2**, the correlation between the conflict reports of adolescents and parents amongst the 13 year old group was $r = 0.9$. This was the only correlation over 0.5. It appears that this extreme result is due to chance, rather than a systematic variation in relation to adolescents' age. Previous studies using the CBQ have not reported such a variation in parent-adolescent agreement in relation to adolescents' age.

8.1.2 The Reporting of Parent-Adolescent Conflict in Relation to Adolescents' Gender.

Previous studies have reported conflicting findings about the variation in parent-adolescent conflict in relation to adolescents' gender. For example, Papini and Sebby (1988) found that female adolescents experienced more conflict with parents than male adolescents. In contrast, Papini and colleagues (1989), using the same measures of conflict, reported that male adolescents experienced more conflict with parents than female adolescents. Other investigations of parent-adolescent conflict have not addressed gender differences in conflict levels, but have focused on different issues involved in adolescent males' conflict with their parents and adolescent females' conflict with their parents. These studies have typically reported similar overall levels of parent-adolescent conflict amongst male and female adolescents (e.g., Flanagan, 1990; Montemayor, 1983; Montemayor & Hanson, 1985).

In this study, the mean level of conflict reported amongst female adolescents and their parents was slightly, but not significantly, higher than the mean level of conflict reported amongst male adolescents and their parents. These results were consistent with the results of most previous investigations. The information collected in this study does not assess the nature or topic of conflict between adolescents and parents. This information would probably provide a more complete picture of variations in conflict between female and male adolescents and their parents.

8.1.3 The Reporting of Parent-Adolescent Conflict in Relation to Parents' Age.

Previous investigations have not reported variation in the level of conflict between adolescents and parents in relation to the parents' age. In this study, parents' age was grouped into (a) those under 40 years old, (b) those aged 40 to 45 years old, and (c) those aged over 45 years old. Conflict between adolescents and parents was not found to vary according to these parental age groups.

It is intuitively appealing to suggest that conflict may be greater between adolescents and older parents than between adolescents and young parents, because of the greater age gap between adolescent and older parents than between adolescents and younger parents. However, the results of this study do not support this suggestion. The measures used in this study did not determine whether the nature (i.e., topic, method of resolution) of parent-adolescent conflict varied according to parents' age.

8.1.4 The Reporting of Parent-Adolescent Conflict in Relation to Parents' Gender.

Previous authors have noted the difficulty of recruiting fathers into research investigating aspects of their children's health-care (e.g., Bailey, 1991; Turner-Henson, Holaday, & Swan, 1992). Only a small number of fathers participated in this study. As was identified in **Chapter 4**, the responses of participating fathers to the CBQ were similar to those of participating mothers. In light of these findings, obtained conflict reports from mothers and from fathers were treated as equivalent in this study, that is, these reports were treated as parent responses.

The finding of similar ratings of conflict between adolescents and fathers, and adolescents and mothers in this study differs from the findings reported by Montemayor and Hanson (1985). These authors reported higher levels of conflict between adolescents and mothers than between adolescents and fathers in a sample of 10th grade students and their families. There are at least three possible explanations for this difference in findings.

First, the methods used to obtain parent-adolescent conflict information in the two studies differed. In the present study, questionnaires were completed by participating adolescents and the parents accompanying the adolescents to the Diabetes Outpatient Clinics. In Montemayor and Hanson's study, conflict was assessed solely on the basis of telephone interviews with participating adolescents. It is possible that the difference in findings relating to adolescents' levels of conflict with mothers and fathers may be a result of these differing methods.

Second, the fathers around whom father-adolescent conflict information was obtained in this study were more likely to be those fathers who were more involved in their adolescents' health care, that is, these fathers were identified as the primary carer in the Outpatient Clinics. Further, two of these fathers were single parent fathers. In contrast; in the Montemayor and Hanson study, father-adolescent conflict information was obtained for all of the participating families. Participation in Montemayor and Hanson's investigation only involved the adolescents, who were interviewed by telephone. The level of contact or involvement of the fathers with their adolescents

was not determined in the Montemayor and Hanson study. Parents' reports of conflict were not obtained.

Third, there were differences in the family structures of the participants in the present study and the study by Montemayor and Hanson. In the study by Montemayor and Hanson, all of the participants were in dual parent households. In the present study, nearly one-in-five of the participants resided in single parent households. It is possible that this difference was responsible for the contrasting findings of these studies.

However, two caveats should be recognised when examining these contrasting findings. First, it should also be recognised that Montemayor and Hanson were able to compare the level of conflict between adolescents and their mothers and adolescents and their fathers, *in the same households.* In the present study, information was only collected about adolescents' conflict with one of their parents. It is possible that the adolescents in dual parent households in the present study would have reported different levels of conflict with the parent not involved in the study.

Second, the adolescents who participated in the present study who were from single parent households were reporting on conflict with their only household parent. Sole parent households were excluded from the Montemayor and Hanson study. It is possible that the nature or reporting of conflict with sole parents differs from that of dual parents. This issue is discussed further in **Section 8.1.6**.

8.1.5 The Reporting of Parent-Adolescent Conflict in Relation to Parents' Work Status.

The next demographic characteristic by which reports of parent-adolescent conflict were examined was parents' work status. Previously, Flanagan (1990) reported that conflict between adolescents is greater when parents are unemployed than when parents are employed. In the present study, parental work status was defined in terms of whether the participating parent was working primarily in the home or outside the home environment (this process is explained in **Chapter 4**).

The level of parent-adolescent conflict reported in this study amongst dyads with parents working inside the home environment was similar to that reported amongst dyads with parents working outside the home. This finding appears to contradict that of Flanagan (1990). However, it should be recognised that the parents in Flanagan's study who were unemployed had all been made redundant. In the present study, parents who were primarily at home included the unemployed, as well as students, pensioners, retirees, and those performing home duties. The nature of the work status definitions in this study and in the study conducted by Flanagan can therefore be seen to differ. It is likely that this difference in sampling approaches is the cause of the difference in findings.

Greater parent-adolescent agreement was observed on the CBQ amongst dyads in which the parent worked primarily outside the home environment than amongst dyads where the participating parent worked primarily in the home. There are at least two possible explanations for this finding. First, the level of contact or involvement

between adolescents and parents primarily at home is likely to be greater than that between adolescents and parents working outside the home. As such, parents who are primarily in the home environment may have a greater experience of harmonious relations with their adolescent children than parents who work outside the home. Information about the level of involvement of parents with their adolescents was not collected as a part of this investigation. This issue may be worthy of further investigation.

A second possible explanation for the variation in parent-adolescent agreement on the CBQ according to parents' work status relates to the amount of time parents spend in the home environment. Parents who work outside the home may be expected to spend less time in the home environment than parents who are primarily at home. As such, the occurrence of conflict between adolescent and parent is likely to represent a greater proportion of the time spent in the home by the parent. In contrast, for parents who work in the home environment, the occurrence of conflict with their adolescents is likely to represent a smaller proportion of time spent in the home. Adolescents, with school, extracurricular, and social commitments, are likely to spend less time in the home than home-based parents. The experience of parent-adolescent conflict by adolescents would likely occupy a similar proportion of time spent at home to that of parents working outside the home. This behavioural pattern may be responsible for the greater agreement between the conflict reports of adolescents with parents working outside the home than with parents primarily at home.

8.1.6 The Reporting of Parent-Adolescent Conflict in Relation to Household Structure.

The final demographic characteristic by which reports of parent-adolescent conflict were examined was household structure. In this study, household structure was defined in terms of single parent or dual parent households. Information about whether dual parents were remarried (i.e., step-parents), or were natural parents of participating adolescents, was not collected. Surprisingly little previous research has compared the level of parent-adolescent conflict in single parent and dual parent households. MK Stone and Hutchinson (1992) reported that college students of divorced parents retrospectively reported more family conflict than students from intact families. However, their study examined general family conflict, rather than adolescent-parent conflict. Family conflict may also include marital conflict, which may be expected to have been greater in marriages ending in divorce than in intact marriages.

In this study, reports of conflict were only collected to assess conflict between the participating adolescent and the participating parent, usually the mother. In dual parent households, which comprise over 80 % of the sample, conflict between the adolescent and the parent not involved in the study was not assessed. It may be argued that the parents who participated in the study, the parents who attended the Diabetes Outpatient Clinic with the adolescents, are likely to have been more involved in their adolescents' diabetes management and had greater contact with their adolescents than the parents who did not attend the clinic. It is possible that the level of conflict between the adolescents and these parents was different to that between the

adolescents and the parents not involved in the study. This view is consistent with the findings of Montemayor and Hanson (1985), who reported higher levels of conflict between adolescents and mothers than between adolescents and fathers in dual parent households. The vast majority of parents involved in the present study were mothers.

However, information about each parents' level of involvement in the adolescents' IDDM management, or about each parents' level of contact with the adolescents was not formally collected as part of this study. The results obtained on the conflict measure may have differed if the other parents (usually the fathers) had also been involved in the study. Previous authors have also noted the difficulty of recruiting fathers into research of this kind (Bailey, 1991; Turner-Henson, Holaday, & Swan, 1992).

Further, it is possible that the reports of parent-adolescent conflict obtained from study participants residing in single-parent households provides different information to that obtained from study participants residing in dual households. That is, the information obtained about parent-adolescent conflict in single parent households represents the conflict between the adolescent and the only parent in the household - there is no other conflict between these adolescents and other parents in the house. In contrast, the information obtained about parent-adolescent conflict in the dual parent households represents the conflict between the adolescent and only one of the two parents in the house.

Because of the possibility that these reports may be different in single parent households than in dual parent households, differences in reports of parent-adolescent

conflict according to household structure were examined. Household structure was defined by the number of parents in the household. Adolescents reported very similar mean levels of conflict with parents in single and dual parent households. The mean level of parent-adolescent conflict reported by parents in single parent households was slightly higher than that reported by parents in dual parent households. This difference was not statistically significant.

8.2 The Level of Association Between Measures of Parent-Adolescent Conflict and Adherence.

This section discusses the results presented in **Section 7.2**, examining the association between the measures of parent-adolescent conflict and the measures of adherence to medical recommendations. Adolescent, parent and combined reports are examined, as well as cross-informant comparisons.

The associations between (1) adolescent reports of adherence and conflict, (2) parent reports of adherence and conflict, (3) adolescent and parent reports of adherence and the combined measure of parent-adolescent conflict, (4) cross-informant associations between reports of conflict and adherence (e.g., between adolescent reports of conflict and parent reports of adherence), and (5) associations between observed blood glucose monitoring adherence and reports of conflict between adolescents and parents, are discussed.

8.2.1 Adolescent Reports of Parent-Adolescent Conflict and of Adherence.

The statistically significant associations between adolescents' scores on the CBQ and both the GAS and the DSAS may be interpreted in several ways.

First, these significant associations are consistent with the first hypothesis. That is, adolescents' reports of conflict and adherence were inversely associated. Adolescents' reports of high levels of adherence were associated with their reports of low levels of parent-adolescent conflict. The consistency of these associations adds further support for this finding. The adolescents' scores on the CBQ were correlated with their scores on the GAS and DSAS to very similar extents.

This consistency suggests that parent-adolescent conflict is related to both general tendencies to adhere to medical treatment and to adherence to specific aspects of the IDDM self-management regimen. However, the observed consistency in results also suggests an alternative interpretation of the moderate associations between adolescents' scores on the CBQ and the GAS and DSAS.

The second interpretation of these results is that the consistently significant correlations between adolescents reports of conflict and their reports of adherence may be the result of a shared method variance. Some adolescents may have responded in socially desirable manners to each of these measures. Alternatively, some adolescents may have responded according to a tendency to give positive responses, i.e., an acquiescence bias, or yea-saying (Streiner & Norman, 1995).

The likelihood that an acquiescence bias influenced these associations is reduced by the direction of the correlation; more high frequency responses on the adherence scale (i.e., greater reported adherence) were associated with fewer yes responses on the CBQ (i.e., reports of lower conflict levels - or more negative responses).

The likelihood that socially desirable responding influenced these associations is reduced by the finding, reported in **Chapter 4**, that adolescents' responses to the CBQ and to the GAS were not associated with the measure of socially desirable responding. However, in order to avoid the possibility of this type of bias, cross-informant comparisons were made between responses on the CBQ and the adherence measures. That is, adolescents' reports on the CBQ were examined in relation to parents' responses on the GAS and DSAS, and vice versa. These analyses were presented in **Section 7.2.4**, and are discussed in **Section 8.2.4** of this chapter.

The reports of conflict obtained in this study ask about conflict between adolescents and parents in general. These reports are not limited to conflict about diabetes management. Future investigations could determine whether the association between reports of IDDM-related conflict are more closely associated with adolescents' adherence to their IDDM regimens. Rubin, et al. (1989) have developed a Diabetes Responsibility and Conflict Scale. To date, investigations employing this measure have not collected adolescents' reports of IDDM adherence. This is an area worthy of further investigation.

8.2.2 Parent Reports of Parent-Adolescent Conflict and of Adherence.

Significant associations between parent scores on the CBQ and on the GAS and DSAS were also detected. The correlation between the GAS and the CBQ was slightly greater than the correlation between the DSAS and the CBQ. Again, these statistically significant associations may be interpreted in several ways.

First, like the associations between adolescent reports of adherence and conflict, these associations support the first hypothesis of this thesis. That is, parents' reports of conflict and adherence were inversely associated. Parents' reports of high levels of adherence were associated with reports of low levels of parent-adolescent conflict. The consistency of the associations between respondents' reports of conflict and of adherence adds further support for this finding.

However, parents' scores on the CBQ were correlated with their scores on the GAS to a greater extent than with their scores on the DSAS. This finding suggests that parents' perceptions of conflict with their adolescents were more closely related to their perceptions of their adolescents' general tendencies to adhere to treatment than to perceptions of the adolescents' adherence to specific IDDM management recommendations.

Again, these associations may be interpreted in terms of a possible shared method variance. However, parent responses to these measures were not related to the measure of socially desirable responding used in the study. As mentioned in the previous section, the use of cross-informant analyses avoids this potential bias.

Another approach that reduces this potential influence is the examination of combined adolescent and parent reports. The following section discusses the relationship between combined adolescent reports of conflict and reports of adherence obtained from both of these groups of participants.

8.2.3 Combined Reports of Parent-Adolescent Conflict and Reports of Adherence.

All of the associations between combined parent and adolescent reports of parent-adolescent conflict and each of the reports of adherence collected from these respondents were statistically significant.

Again, these associations were all in the direction predicted by the first hypothesis. The use of a combined parent and adolescent scale of the CBQ reduces the likelihood that these associations are the result of a shared method variance. These findings provide support for the first hypothesis of this thesis.

Like the associations between parent reports of conflict and adherence, the associations between the combined CBQ and adolescent and parent reports of adherence were greater for the General Adherence Scale than for the Diabetes Specific Adherence Scale. Again, this finding may be interpreted as an indication that parent-adolescent conflict was more closely related to the adolescents' general tendencies to adhere to treatment than to the adolescents' adherence to specific IDDM management recommendations.

Hanson, De Guire, et al. (1992) used combined adolescent and parent reports of relationships between adolescents and parents on the Family Relationship Questionnaire (Henggeler & Tavormina, 1980) in a study of the IDDM self-management of adolescents attending outpatient clinics. In this study, family relations were significantly associated with the adolescents' dietary adherence, as assessed by patient interviews. The findings of the present study are consistent with those of Hanson, De Guire, and colleagues, and extend on the previous study by examining a specific aspect of parent-adolescent relations; parent-adolescent conflict.

8.2.4 Cross-Informant Associations Between Reports of Parent-Adolescent Conflict and Adherence.

Cross-informant analyses further examined associations between reports of adherence and reports of conflict.

The associations between adolescents' reports of conflict and parents' reports of adherence are consistent with the associations obtained within informants. The consistency of these findings with the within-informant analyses suggests that the associations detected in the previous analyses between scores on the CBQ and the GAS and DSAS were not the result of shared method biases. These findings provide further support for the first hypothesis of this thesis.

Further, the association between parent reports of conflict and adolescent reports of general adherence was consistent with the association between these questionnaires as

completed by the adolescents and by the parents. Again, this finding suggests that the associations detected between measures of adherence and conflict within informants were not the result of shared method variances.

However, the association between parent reports of conflict and adolescent reports of IDDM-specific adherence was weaker, and was not significant. This association was the only one of the twelve associations considered between the measures of adherence and conflict that did not reach statistical significance. This inconsistent finding may be interpreted in two ways.

First, this result may indicate that shared method variances did contribute to the significant findings discussed in the previous sections. The significant cross-informant associations detected between the other measures suggests that this form of bias was not solely responsible for the significant within-informant associations. It is possible, however, that shared method biases added to the associations between adherence and conflict. Second, it may be noted from **Table 7.13** that the parents' conflict reports were less strongly associated with the other measures of adherence than the adolescent or combined measures of conflict. In particular, the parent report of conflict was not strongly associated with the parent report of IDDM-specific adherence - the association conceptually closest to the non-significant association.

In sum, the cross-informant analysis of associations between adolescents' and parents' reports of adherence and parent-adolescent conflict add considerable support for the first hypothesis of this thesis. Cross-informant analyses of parent-adolescent conflict and adolescents' IDDM regimen adherence have not been previously reported in the

literature. The findings obtained in this study support the use of these analyses to examine the relationship between adolescents' regimen adherence and their experience of conflict with their parents.

8.2.5 Reports of Parent-Adolescent Conflict and Observed Blood Glucose Monitoring Adherence.

Reports of parent-adolescent conflict were less closely related to observed blood glucose monitoring adherence than to the parent and adolescent reports of adherence. The associations between observed BGM and conflict reports were not statistically significant. Further, the effect sizes of the associations between each of the measures of adherence and the observed BGM adherence did not vary greatly when the time frame examined by this data was adjusted. Reported levels of parent-adolescent conflict were not significantly varied between groups of adolescents categorised by Consistently High, Consistently Low, Rising or Other BGM adherence patterns over the four weeks prior to assessment. These results may be interpreted in a number of ways.

First, these findings may indicate that the results obtained relating reports of adherence with reports of conflict were in part the result of shared method variances. However, the cross-informant relationships between these reports reduce the plausibility of this interpretation. Further, the relative strengths of these associations - involving the adolescent, parent, and combined conflict reports - reflect the same pattern as was found with the associations involving adolescents' and parents' reports

of adherence. That is, the parent CBQ scale was less closely related with the adherence measures than were the adolescent or combined CBQ scales. This consistency refutes the interpretation of the non-significant associations as an indication of shared method variances.

Second, the lower levels of association between reports of parent-adolescent conflict and observed BGM adherence than between these conflict reports and questionnaire measures of adherence may reflect the specific nature of this adherence measure. It may be seen that for all of the analyses examining adolescent and parent reports of adherence, presented in **Table 7.13**, the level of association with the conflict measures was greater for the GAS than for the DSAS. It is possible that parent-adolescent conflict is closely related to general tendencies to adhere to treatment, and less closely to adherence to a range of specific IDDM management activities. In turn, the observed BGM adherence measure, which is even more specific than the DSAS, may be expected to be less closely associated with reports of parent-adolescent conflict. It should again be noted that the conflict measure employed in this study assessed conflict in general, not specifically in relation to IDDM management. An examination of these associations using an IDDM-specific measure of conflict would further the understanding of these relationships.

Third, as has already been noted, the observed blood glucose monitoring adherence information only assesses adherence to one aspect of a multi-component regimen. While parent-adolescent conflict may be poorly related to adherence to this aspect of the IDDM management regimen, this form of conflict may be more closely linked with adherence to other aspects of the regimen. For example, parent-adolescent

conflict may be more closely linked with adherence to insulin administration recommendations or dietary recommendations.

A fourth interpretation of the lack of association between the observed BGM adherence and the measures of parent-adolescent conflict relates to the sample from which BGM data were obtained. These data were collected from a group of adolescents with poor metabolic control. It is possible that the weaker associations found using the BGM data may be the result of a sample bias. This possibility is supported by the finding that reports of parent-adolescent conflict were associated with metabolic control (**Section 7.4**). However, an examination of separate associations between the measures of adherence and the measures of conflict according to whether or not BGM data were available does not support this possibility. These associations are shown in **Appendix E**.

Finally, the associations reported in **Appendix E** suggest one other interpretation of the lack of associations between observed BGM adherence and reports of parent-adolescent conflict. When the adolescent and parent reports of adherence are examined separately according to whether or not the BGM data were available, the associations with reports of conflict were smaller, and less significant than when the sample was examined as a whole. It is possible that the non-significant findings involving BGM observations and reports of conflict were weakened by the smaller sample size involved in this analysis. This is an issue that could be resolved by further investigation.

Previously, Wysocki, Hough, and colleagues (1992) investigated the use of BGM data, in relation to aspects of family functioning. In this study, the Diabetes Conflict Scale (DCS; Rubin, et al. 1989) was completed by adolescents and parents. Scores on this scale were significantly related to BGM data use. Unfortunately, Wysocki and colleagues do not specify whether it was the adolescent or the parent form of the DCS that was associated with BGM use, or whether it was a combined DCS scale. Further, these authors reported on BGM data use, controlling for BGM frequency. In this context, BGM data use refers to the use of BGM information to adjust insulin administration. Therefore the findings of the present study extend on those of Wysocki, Hough and colleagues by determining that adolescents' frequency of blood glucose monitoring was not associated with their conflict with parents.

8.3 Differences in Associations Between Parent-Adolescent Conflict and Adherence According to Sample Characteristics.

This section discusses the results presented in **Section 7.3**, examining the differences in association levels between measures of parent-adolescent conflict and measures of medical adherence, in relation to the demographic characteristics of the sample. These associations are examined in relation to: (1) adolescents' age, (2) adolescents' gender, (3) parents' age, (4) parents' gender, (5) parents' work status, and (6) household structure (i.e., single or dual parent households).

8.3.1 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Adolescents' Age.

The associations between reports of parent-adolescent conflict and medical adherence, performed according to adolescents' age, revealed greater associations amongst the 13 year olds and their parents than any other age group. There are at least two possible meanings of this result.

First, the greater association between adherence and conflict amongst 13 year olds may reflect a transition point in adolescent development. Previous research has identified that parent-adolescent conflict increases dramatically during mid-adolescence (Montemayor, 1983; Paikoff & Brooks-Gunn, 1991; Papini, et al. 1989; Papini & Sebby, 1988). In the present study, the level of conflict reported by adolescents and parents was lower amongst the 12 and 13 year olds than amongst the 14 to 17 year old adolescents. This combination of findings leads to the suggestion that older adolescents, who experience more conflict with their parents, may be more immune to the impact of this conflict, and as a result may be less influenced in their adherence level by the conflict. Previous research has examined the impact of different forms of family conflict on adolescents' depressive symptoms (Amato & Keith, 1991). However, studies examining the psychological impact of parent-adolescent conflict on adolescents of different ages have not been reported in the literature to date.

This interpretation, however, does not account for the difference in associations between measures of adherence and conflict amongst the 12 and 13 year old

adolescents. These groups reported similar levels of parent-adolescent conflict, so an 'immunity' model would not account for the difference in association between the reported conflict experienced by these groups and their reported adherence.

A second interpretation of the greater levels of association detected with the 13 year old adolescents than with the other adolescents is that this result may simply be a chance finding, that is, this finding may be the result of random variation. The small sample sizes involved at each age level lend support to this possibility. Future investigation could further explore this issue. The replication of these finding using larger samples of adolescents of different ages could clarify this possible relationship.

8.3.2 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Adolescents' Gender.

The associations between reports of parent-adolescent conflict and medical adherence, performed according to adolescents' gender, revealed very similar levels of association amongst the samples of male and female adolescents and their parents. This finding suggests that the link between adolescents' adherence and their experience of conflict with parents is not gender dependent.

8.3.3 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Parents' Age.

The associations between reports of parent-adolescent conflict and medical adherence, performed according to parents' age, revealed no significant variations in association. This finding suggests that the relationship between adolescents' adherence and their experience of parent-adolescent conflict is not influenced by the age of their parents.

8.3.4 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Parents' Gender.

The associations between reports of parent-adolescent conflict and medical adherence, performed according to parents' gender, revealed greater associations amongst the participating mothers and their adolescents than amongst the participating fathers and their adolescents. This finding may be interpreted as an indication of mothers taking a more central role compared with fathers in the management of adolescents' IDDM regimens. It may be argued that mothers are more likely to engage in conflict with their adolescent children about their IDDM regimen than fathers, for the same reasons that it is difficult to recruit fathers into studies of their children's healthcare (see **Section 1.3.1.2:** *The Impact of Chronic Illness on the Family* for a further discussion of this point). As such, the greater association of adolescent-mother conflict with adolescents' IDDM adherence than adolescent-father conflict with this adherence, is plausible.

However, the number of fathers involved in the study was very limited. As such, the variation in obtained scores on the adherence and conflict scales by this sub-sample was also limited. It is possible that a larger sample of fathers and their adolescents would produce a greater association between their conflict and the adolescents' adherence than was obtained in the present study.

8.3.5 Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Parents' Work Status.

The associations between reports of parent-adolescent conflict and medical adherence, performed according to parents' work status, revealed mixed results. The levels of association between the conflict reported by adolescents and the adherence measures were slightly greater amongst the sample categorised by the parent working outside the home environment than amongst the sample categorised by parents who were primarily at home. The conflict reports obtained from parents were more closely associated with reports of adherence amongst those parents who were primarily at home than amongst the parents working outside the home. The combined adolescent and parent reports of parent-adolescent conflict were more closely associated with the adolescents' and parents' reports of adherence amongst the sample defined by the participating parent working outside the home, than amongst the sample in which parents were primarily at home.

The sample included approximately even numbers of participating parents who worked outside the home and who were primarily in the home, so the results cannot

be attributed to an imbalance in the sample sizes. The most plausible explanation for this mixture of results is that parental work status is not influential on the relationship between parent-adolescent conflict and adolescents' adherence to medical recommendations.

8.3.6. Variations in Associations Between Parent-Adolescent Conflict and Adherence in Relation to Household Structure.

The associations between reports of parent-adolescent conflict and medical adherence, performed according to household structure, also revealed a mixture of results.

The levels of associations produced amongst the sample categorised by dual parent households were generally more statistically significant than those produced by the members of single parent households. However, the effect sizes of the associations between these measures were generally larger in the single parent group than in the dual parent group.

Like the number of fathers involved in the study, the number of single parents involved was limited. Because of this limited sample size, the significance of small associations amongst these study participants were inflated. Further, the level of variation in scores produced by single parents was smaller than that of the dual parents, limiting the effect sizes of these associations.

The imbalance of sample sizes in the dual parent and single parent groups prevent the meaningful comparison of conflict-adherence relations in this study. This issue is worthy of further exploration. Future investigations should examine the differential influence of parent-adolescent conflict in single and dual parent households.

8.4 The Level of Association Between Measures of Parent-Adolescent Conflict and Adolescents' Metabolic Control.

This section discusses the results presented in **Section 7.4**, examining the relationship between reports of parent-adolescent conflict and adolescents' level of metabolic control.

In light of the conceptual link between regimen adherence and health outcomes, the association between metabolic control and parent-adolescent conflict was examined as an extension of the first hypothesis of this thesis. The importance of studying patient adherence lies in its association with the health outcomes of patients. The importance of the association between parent-adolescent conflict and adherence is reduced if this form of conflict is unrelated to patients' health outcomes. The hypothesised relationship between parent-adolescent conflict and health outcomes includes patient adherence as a mediating factor, nonetheless the direct association of parent-adolescent conflict with health outcome is pertinent to the understanding of the relationship between conflict and adherence. Adolescents' HbA_{1c} assay levels were treated as the measure of health outcome for these analyses.

The initial analyses performed to examine the relationship between parent-adolescent conflict and adolescents' metabolic control revealed statistically significant relations between these constructs. Interestingly, the adolescents' reports of conflict were more closely associated with their metabolic control than were their parents' reports of conflict. This finding is consistent with the suggestion that adolescents' illness control is linked to their perceptions of their family relations, that is, their perceptions of conflict are associated with their illness control. Earlier findings demonstrate that adolescents' and parents' perceptions of conflict are related to their illness management practices (i.e., adherence). This finding suggests that this influence extends to their experienced level of health (i.e., metabolic control). It is not surprising that parents' perceptions of conflict were less closely associated with adolescents' metabolic control than the adolescents' own perceptions. The parents' perceptions would not be expected to link directly to the adolescents' IDDM control.

While these results do not provide direct support for the first hypothesis of this thesis, they are consistent with its tenet. These results suggest that parent-adolescent conflict is weakly associated with decreased health status amongst the adolescents.

The final analyses that were conducted therefore examined whether the parent-adolescent conflict ratings accounted for unique variance in HbA_{1c} assay levels after the adherence reports had been entered into hierarchical regression equations.

Adolescents' reports of parent-adolescent conflict uniquely predicted their level of metabolic control, above that of the adolescents' reports of general adherence. In contrast, parents' reports of conflict did not account for any of the variance in

adolescents' level of metabolic control, above that of the parents' reports of adherence. In light of these findings, it is not surprising that the addition of combined adolescent and parent reports of conflict to the individual adolescent and parent reports of adherence produced mixed results. The combined conflict reports added unique prediction of the adolescents' metabolic control when added to their reports of general adherence. Further, the combined conflict score added unique prediction of the adolescents' metabolic control when added to parents' reports of diabetes-specific adherence. However, these conflict reports did not account for additional variance when added to the regression of parents' general adherence reports with adolescents' metabolic control.

The regression analyses which involved the entry of adolescents' reports of diabetes-specific adherence (DSAS) as the first step were not pursued, as this measure did not have significant predictive power for the adolescents' level of metabolic control (see Cliff (1987) for a discussion of the statistical implications of this point).

Before interpreting these findings, it should be recognised that reports of general adherence (GAS) accounted for greater proportions of variance in adolescents' metabolic control than reports of diabetes-specific adherence (DSAS). This pattern was evident in both the adolescent and parent reports. With this point in mind, it appears reasonable to suggest that reports of parent-adolescent conflict added to the predictability of adolescents' metabolic control established from the reports of adherence obtained from the adolescents and their parents. This finding again provides additional indirect support for the first hypothesis of this thesis.

However, an alternative interpretation of these findings must be considered. It is possible that parent-adolescent conflict is directly associated with metabolic control, that is, conflict could influence the metabolic functioning of the adolescents, or vice versa. This view would suggest that adherence, rather than being directly related to conflict, could be associated though a mediating effect of metabolic control (i.e., poor metabolic control leading to abandonment of the regimen, or poor adherence). There is, however, little support for this alternate view. The associations between conflict and metabolic control are weak. A direct effect of conflict on metabolic control has been proposed (Minuchin, et al. 1975). However, in the two decades since this effect was proposed, no empirical support for the effect has been reported, and the findings of a recent study suggest that no such effect exists (Miller-Johnson, et al. 1994).

Wysocki (1993) found that mothers' and adolescents' reports of conflictual parent-adolescent relations were associated with adolescents' metabolic control. This investigation involved 242 North American families of adolescents aged between 11 and 18 years, with insulin dependent diabetes. The results of the present study replicated these findings in an Australian sample, using a different measure of parent-adolescent conflict.

8.5 Summary and Future Directions: The Relationship Between Patient Adherence and Parent-Adolescent Conflict.

This section provides a synthesis of the findings discussed in this chapter, in light of the published literature. The implications of these findings to the wider literature and to future research are addressed.

8.5.1 The Relationship Between Patient Adherence and Parent-Adolescent Conflict.

The findings discussed in this chapter examined the first hypothesis of this thesis. This hypothesis states that higher levels of reported conflict will be associated with lower levels of reported adherence, that is, an inverse association between parent-adolescent conflict and adolescents' medical adherence.

In previous studies by Hauser and colleagues (1990), Hanson, De Guire, and colleagues (1992) and Miller-Johnson and colleagues (1994), various measures of family relations have been associated with measures of adolescents' adherence to IDDM management recommendations.

Hauser and colleagues (1990) used the Moos Family Environment Scale (Moos & Moos, 1981) to assess adolescents' and mothers' perceptions of family relations. Reports of adherence to three specific aspects of IDDM management recommendations, as well as a composite measure of adherence, were completed by

health care workers. Adolescents' reports of family conflict were associated with physicians' perceptions of poor adherence.

Hanson, De Guire, and colleagues (1992) assessed the family functioning of families of adolescents with IDDM using the Family Adaptability and Cohesion Scales (Olson, 1986), the Marital Adjustment Scale (Locke & Wallace, 1959), and the Family Relationship Questionnaire (FRQ; Henggeler & Tavormina, 1980). Adherence to dietary recommendations for IDDM was evaluated with a semistructured interview of adolescents. Adolescent and mother responses on the FRQ were combined to form a composite measure of family conflict. The ratings of dietary adherence used in this study were significantly related to family adaptability and the absence of illness-specific nonsupport, but not to reports of family conflict.

Miller-Johnson and colleagues (1994) assessed parent-child conflict amongst a sample of children and adolescents with IDDM and their mothers using the Parent-Child Scales conflict subscale (Hetherington & Clingempeel, 1992). In this study, regimen adherence was assessed by children, parents, and nurse coordinators. These measures of adherence were all associated with the measures of parent-child conflict completed by children (and adolescents) and parents. Further, this study found that these ratings of conflict were also associated with the children and adolescents' metabolic control.

Studies conducted by BJ Anderson and colleagues (1990), Hanson, De Guire, and colleagues (1992), and Wysocki (1993), also examined relationships between measures of family functioning and adolescents' metabolic control in IDDM

BJ Anderson and colleagues (1981) used the Moos Family Environment Scale (Moos & Moos, 1981) to assess adolescents' and mothers' perceptions of the social climate in their households. Adolescents with well-controlled diabetes (low HbA_{1c} levels) reported lower levels of household conflict and greater family cohesion than adolescents with poorly controlled diabetes (high HbA_{1c} levels).

Wysocki (1993) used the Parent-Adolescent Relationship Questionnaire (Robin, et al. 1990) to assess a range of aspects of family functioning, including parent-adolescent conflict, amongst a large sample of adolescents with IDDM and their mothers. Responses on the Overt-Conflict subscale of this measure, as completed by adolescents and their mothers, were significantly associated with the adolescents' metabolic control.

However, Hanson, De Guire, and colleagues (1992) reported that parent-adolescent conflict, rated using the Family Relationship Questionnaire, was not associated with metabolic control amongst a sample of adolescents with insulin dependent diabetes.

In the present study, adolescent, parent and combined measures of parent-adolescent conflict were associated with adolescents' adherence, as reported by the adolescents and their parents. Observations of BGM adherence were not related to these reports of conflict. Additional analysis revealed significant relationships between reports of parent-adolescent conflict and adolescents' metabolic control. Hierarchical multiple regression analyses determined that adolescent and combined adolescent and parent reports of conflict added to the variance in metabolic control accounted for by reports of adherence.

These results extend on previous research in several respects.

First, these findings replicate the findings of Hauser and colleagues (1990) and Miller-Johnson and colleagues (1994). These studies reported that adherence is related to parent-adolescent conflict. Further, the assessment of parent-adolescent conflict in this study was performed using a validated measure designed to assess this aspect of parent-adolescent relations. The use of a measure specifically addressing this aspect of family relations extends on the previous studies, which employed more general assessments of family relations. In addition, the assessment of adherence in this study involved independent reports from adolescents and parents, both of general tendencies to adhere to treatments and of adherence to specific aspects of IDDM management. Hauser and colleagues (1990) employed health provider ratings of adherence, while Miller-Johnson and colleagues (1994) used unvalidated child, parent, and nurse ratings of adherence. The more methodologically sophisticated assessments of adherence in this study add considerable weight to the findings of these previous investigations. The finding that these relations were detected using different measures than those employed in these previous studies indicates that these associations are not a product of the particular measures employed.

Second, the findings in this study relating parent-adolescent conflict to adolescents' metabolic control support the findings reported by BJ Anderson and colleagues (1981), Wysocki (1993), and Miller-Johnson and colleagues (1994). These authors reported significant associations between various measures of family functioning and adolescents' metabolic control. The findings of the present study offer a more specific

perspective, linking parent-adolescent conflict in particular with the adolescents' level of metabolic control. Again, the detection of these relations using different measures than those employed in these previous studies indicates that these associations are not a product of the particular measures employed.

Third, the finding that reports of parent-adolescent conflict contributed to the prediction of adolescents' metabolic control, when added to reports of adherence, extends upon the findings of Miller-Johnson and colleagues (1994), and Hanson, De Guire, and colleagues (1992). Miller-Johnson and colleagues (1994) detected significant associations between metabolic control and conflict, but found that the addition of conflict reports to adherence assessments did not improve the predictability of adolescents' metabolic control. Hanson, De Guire, and colleagues (1992) did not detect significant relations between adolescents' metabolic control and a measure of family relationships. The findings of the present study suggest that the more specific assessment of parent-adolescent conflict, rather than general parent-adolescent relations, or family conflict, is a more direct assessment of an aspect of family functioning influencing adolescents' metabolic control. The less significant relationships found using the conceptually broader measures in these previous studies may be due to a noise effect, that is, the inclusion in these assessments of aspects of family relations not linked to adolescents' metabolic control.

Finally, this study examined the variation in the association between parent-adolescent conflict and adolescents' adherence in relation to demographic characteristics of the study participants. This is an issue seldom addressed in the literature. Surprisingly, the association between these measures showed little variation in relation to

demographic characteristics. Although some of these characteristics showed variation in conflict-adherence associations, these could generally be attributed to imbalances in sample sizes according to these characteristics. Future studies could explore this issue using larger samples.

In sum, the results presented in this chapter supported the hypothesis that adherence would be lower amongst adolescents who experienced high levels of conflict with their parents than amongst adolescents who experienced less conflict with their parents.

8.5.2 Limitations of the Present Study and Future Directions for Investigations of the Relationship Between Patient Adherence and Parent-Adolescent Conflict

The discussion of the results in this study examining the relationship between measures of adherence and measures of parent-adolescent conflict has identified a number of limitations of the study, and identified avenues for further investigation.

First, information about pubertal status was not collected in this study. This information could provide valuable information about the changes in parent-child relations, and the influence of these relations on adherence, as children progress through this developmental stage.

Second, this study employed measures that rated the level of conflict experienced between adolescents and parents. The nature of this conflict, and the nature of its

resolution, were not assessed. Further, the topic of the conflict was not assessed. Measures assessing the nature of conflict and subject of the conflict would further the understanding of the relationship between parent-adolescent conflict and adolescents' adherence to medical regimens. For example, the nature of the relationship between conflict and adherence would be clarified by the use of a diabetes-specific conflict measure, as well as a general measure of conflict between adolescents and parents.

Third, an assessment of the parents' level of involvement with their adolescents would potentially provide additional information about the role of conflict in adolescents' regimen adherence. For example, conflict with parents who were closely involved in the day to day activities of the adolescents may relate to adherence differently than conflict with parents who were less involved in their adolescents' lives. The parents' level of involvement in the adolescents' IDDM management would be of particular interest in this assessment.

Fourth, future investigations should examine the differential influence of parent-adolescent conflict in single and dual parent households. Whether conflict with single parents influences adolescents' adherence differently than conflict with parents in intact marriages would be of interest to researchers and potentially useful information for adherence intervention strategies.

Finally, the comparison of adherence-conflict relations in this study were hampered by small sample sizes in certain demographic groups. In particular, the involvement of such a limited number of fathers in the study limited the ability of this investigation to examine the different roles played by mothers and fathers in their adolescents'

healthcare. Future studies should emphasise the recruitment of fathers into research of this kind. Further, the comparison of adolescents' behavioural patterns at different age levels or developmental stages, requires larger numbers of participants in each study group. For research investigating illnesses such as insulin dependent diabetes, recruitment of larger study samples may best be achieved through multi-site investigations. Investigations conducted on multiple sites also increase the generalisability of their results. This is an interesting avenue for future research.

CHAPTER NINE.

RESULTS: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND ADOLESCENT AUTONOMY.

This chapter examines the relationship between measures of adolescents' adherence to their diabetes treatment recommendations and reports of adolescents' autonomy. These analyses were designed to test the second hypothesis of this thesis. This chapter consists of three sections. First, adolescents' and parents' reports of adolescent autonomy are presented in relation to sample characteristics. Second, analyses are presented that examine the association between reports of adolescent autonomy and reports of adherence. Third, the association between reports of adolescent autonomy and adolescents' metabolic control (HbA_{1c}) is examined.

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9 RESULTS: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND ADOLESCENT AUTONOMY.

9.1 The Reporting of Adolescent Autonomy in Relation to Sample Characteristics.

This section examines obtained data from the measure of adolescent autonomy. The AFC was completed by participating adolescents and parents. The scoring of the AFC generates a total scale score as well as four sub-scales; Self- and Family-Care, Management Activity, Recreational Activity, and Social and Vocational Activity. **Table 9.1** displays distributions of scores on the AFC by adolescents and parents. The scoring range of the adolescent completed and parent completed AFCs are 0 to 252, where higher scores indicate a higher level of autonomy in the adolescents.

Table 9.2 reports distributions of scores on the AFC subscales completed by adolescents and parents. The scoring ranges on the Self- and Family-Care, Management Activity, Recreational Activity, and Social / Vocational Activity subscales are 0 to 88, 0 to 80, 0 to 64, and 0 to 20, respectively.

As may be seen from these tables, although the scores obtained by adolescents and parents did vary, this variance was not wide - almost all of the scores produced by both groups of informants fell between the 25 % and 75 % marks of the possible scoring range (i.e., scores between 63 and 189 on a total scale of 0 to 252). This lack of variation in obtained scores may limit the level of association between scores on this scale and other study variables.

The scoring distributions of these measures are examined in relation to: (1) adolescents' age, (2) adolescents' gender, (3) parents' age, (4) parents' gender, (5) parents' work status, and (6) household structure (i.e., single or dual parent households).

9.1.1 The Reporting of Adolescent Autonomy in Relation to Adolescents' Age.

The distributions of scores on the AFC according to adolescents' age are reported in **Table 9.3**. Distributions of scores on the subscales of the AFC according to adolescents' age are reported in **Tables 9.4** and **9.5**. Lower levels of autonomy were reported by younger adolescents and their parents than by older adolescents and their parents. One-way ANOVA of this variation revealed that these differences were statistically significant for the total AFC, (Adolescent: F (5,121) = 5.14, p = 0.0003. Parent: F (5,128) = 7.99, p < 0.0001), as well as for the Self- and Family-Care (Adolescent: F (5,126) = 2.42, p = 0.04. Parent: F (5,128) = 5.94, p = 0.0001), Management Activity, (Adolescent: F (5,125) = 12.68, p < 0.0001. Parent: F (5,129) = 9.06, p < 0.0001) and Social / Vocational Activity subscales (Adolescent: F (5,127) = 3.62, p = 0.004. Parent: F (5,129) = 4.14, p < 0.002). However, the variations in reports of Recreational Activity according to adolescents' age were not significant.

To determine whether these variations were linear (i.e., increasing autonomy with increasing age) or not (e.g., higher autonomy in 13 year olds than in other adolescents), correlations were calculated between adolescents' age and scores on the

AFC and its subscales by adolescents and parents. These associations are reported in **Table 9.6**. The effect sizes of the relationships between adolescents' age and scores on each of these measures varied, from small effects for the Recreational Activity subscale, to large effects for the Management Activity subscales. The total AFC showed moderately large effects according to adolescent age.

To further explore the association between reports of adolescents' autonomy and their age, the level of agreement between adolescents' and parents' reports of autonomy was examined in relation to these variables. These analyses are detailed in **Appendices F.1** and **F.2**. Overall, adolescents' and parents' responses on the AFC and its subscales were highly correlated. This correlation did not significantly vary according to adolescents' age.

9.1.2 The Reporting of Adolescent Autonomy in Relation to Adolescents' Gender.

The distributions of scores on the AFC by adolescents and parents according to adolescents' gender are reported in **Table 9.7**. Distributions of scores on the subscales of the AFC according to adolescents' gender are reported in **Table 9.8**. Female adolescents reported a higher mean level of autonomy on the total AFC than male adolescents. This pattern was not the result of a large difference in reporting on any one subscale, but because of slight differences in mean responses on each of the subscales between female and male adolescents. This pattern was not shown between the responses obtained from the parents of female adolescents and the parents of male adolescents.

Students' t test analyses revealed that mean scores on the adolescent completed AFC were significantly higher amongst the female adolescents than amongst the male adolescents (t (125) = 2.38, p = 0.02). Responses of the parents of male and female adolescents were not significantly different. Further t tests revealed significant differences in mean scores on the subscales of the AFC between female and male adolescents only for the adolescent reports of Management Activity (t (129) = 2.84, p = 0.005), for which the female adolescents produced a higher mean score than the male adolescents. On the remaining subscales, adolescent gender differences were not detected.

To further explore the association between reports of adolescents' autonomy and their gender, the level of agreement between adolescents' and parents' reports of autonomy was examined in relation to these variables. These analyses are detailed in **Appendix F.3**. Overall, adolescents' and parents' responses on the AFC and its subscales were highly correlated. This correlation did not significantly vary according to adolescents' gender.

9.1.3 The Reporting of Adolescent Autonomy in Relation to Parents' Age.

The distributions of scores on the AFC by adolescents and parents according to parents' age are reported in **Table 9.9**. Distributions of scores on the subscales of the AFC according to parents' age are reported in **Table 9.10**. As in previous chapters,

parents' age was grouped into (a) those under 40 years old, (b) those aged 40 to 45 years old, and (c) those aged over 45 years.

One-way ANOVAs examined the variation in adolescents' and parents' scores on the AFC and its subscales according to parents' age groups. The results of these analyses were not significant, with two exceptions. Adolescent and parent responses to the Management Activity subscale of the AFC were both significantly varied according to parents' age (Adolescent: F (2,128) = 5.14, p = 0.007. Parent: F (2,132) = 3.60, p = 0.03). Reports of adolescents' autonomy in Management Activity were higher amongst adolescents with older parents than amongst adolescents with younger parents.

9.1.4 The Reporting of Adolescent Autonomy in Relation to Parents' Gender.

The distributions of AFC scores according to whether the parent-form was completed by the adolescents' mother or father is reported in **Table 9.11**. Distributions of scores on the subscales of the AFC according to parents' gender are reported in **Table 9.12**. Adolescents reported very similar levels of autonomy, regardless of whether their mother or father completed the parent questionnaire. The mean level of autonomy reported by fathers was lower than the mean level reported by mothers. This difference was not significant. Similarly, responses by adolescents and parents to the four subscales of the AFC were not differentiated according to the gender of the participating parent.

9.1.5 The Reporting of Adolescent Autonomy in Relation to Parents' Work Status.

The distributions of AFC scores according to parents' work status are reported in **Table 9.13**. Distributions of scores on the subscales of the AFC according to parents' work status are reported in **Table 9.14**. Similar levels of autonomy were reported by and about adolescents whose participating parent worked outside the home and adolescents whose parents were primarily at home. Students' *t* tests revealed that mean scores by adolescents and parents on the AFC and its subscales were not significantly differentiated on the basis of participating parents' work status.

9.1.6 The Reporting of Adolescent Autonomy in Relation to Household Structure.

The distributions of scores on the AFC by adolescents and parents according to participants' household structure are reported in **Table 9.15**. Distributions of scores on the AFC subscales according to household structures are reported in **Table 9.16**.

Adolescents reported similar levels of autonomy in single and dual parent households. The mean level of adolescent autonomy reported by parents residing in single parent households was slightly greater than that reported by parents in dual parent households. This difference was not significant. However, parents' reports on the Management Activity subscale indicated greater autonomy in this aspect of functioning for adolescents residing in dual parent households than adolescents living in single parent households (t (133) = 2.73, p = 0.007). Further, adolescents' reports

of autonomy in Self- and Family-Care were significantly higher amongst adolescents in single parent households than in dual parent households (t (130) = 2.08, p = 0.04).

9.2 The Level of Association Between Measures of Adolescent Autonomy and Adherence.

The analyses presented in this section were designed to examine the association between the measures of adolescent autonomy and the measures of adherence to medical recommendations. Pearson correlations were employed to examine the level of association between these measures.

Separate analyses examined the associations between (1) adolescent reports of adherence and autonomy, (2) parent reports of adherence and autonomy, (3) cross-informant associations between reports of autonomy and adherence (e.g., between adolescent reports of autonomy and parent reports of adherence), and (5) associations between observed blood glucose monitoring adherence and reports of autonomy by adolescents and parents.

9.2.1 Adolescent Reports of Autonomy and of Adherence.

The level of correlation between the adolescent completed measure of autonomy and the adolescent completed GAS is shown in **Table 9.17**. The levels of correlation between the adolescent completed subscales of the AFC and the adolescent completed GAS are shown in **Table 9.18**. The effect size of the correlation between adolescents'

GAS scores and their total AFC scores was small, and not statistically significant. Effect sizes between the adolescent completed GAS and adolescent scores on each of the subscales of the AFC were also small. Adolescent GAS responses were only significantly associated with responses to the Recreational Activity subscale of the AFC, although the effect size of this association was moderately small.

The level of correlation between the adolescent completed measure of autonomy and the adolescent completed DSAS is shown in **Table 9.17**. The levels of correlation between the adolescent completed subscales of the AFC and the adolescent completed DSAS are shown in **Table 9.18**. The effect size of the correlation between adolescents' DSAS scores and their total AFC scores was small, and not statistically significant. Effect sizes between the adolescent completed DSAS and adolescent scores on each of the subscales of the AFC were also small. Like their GAS scores, adolescent DSAS responses were only significantly associated with responses to the Recreational Activity subscale of the AFC, although the effect size of this association was moderately small.

9.2.2 Parent Reports of Adolescent Autonomy and of Adherence.

The level of correlation between the parent completed measure of autonomy and the parent completed GAS is shown in **Table 9.17**. The levels of correlation between the parent completed subscales of the AFC and the parent completed GAS are shown in **Table 9.18**. The effect size of the correlation between parents' GAS scores and their total AFC scores was small, and not statistically significant. Effect sizes between the

parent completed GAS and parent scores on each of the subscales of the AFC were also small. Parent GAS responses were only significantly associated with responses to the Management Activity subscale of the AFC, although the effect size of this association was moderately small.

The level of correlation between the parent completed measure of autonomy and the parent completed DSAS is shown in **Table 9.17**. The levels of correlation between the parent completed subscales of the AFC and the parent completed DSAS are shown in **Table 9.18**. The effect size of the correlation between parents' DSAS scores and their total AFC scores was small, and not statistically significant. Effect sizes between the parent completed DSAS and parent scores on each of the subscales of the AFC were also small. Parents' DSAS responses were not significantly associated with their responses to any of the subscales of the AFC.

9.2.3 Cross-Informant Associations Between Reports of Adolescent Autonomy and Adherence.

The next analyses examined the association between (1) adolescents' reports of autonomy, and parents' reports of the adolescents' adherence, and (2) adolescents' reports of adherence, and their parents' reports of the adolescents' autonomy. These analyses were performed to examine from another angle the association between reported adolescent autonomy and adherence. The examination of cross-informant associations also reduces the vulnerability of the analyses to respondent biases (see **Section 8.2.4** for a discussion of this point).

Adolescent Reports of Autonomy and Parent Reports of Adherence.

The levels of association between adolescent reports on the AFC and parent scores on the GAS and DSAS are reported in **Table 9.17**. Associations between adolescent reports on the subscales of the AFC and parent scores on the GAS and DSAS are reported in **Table 9.18**. The effect sizes of these associations are consistent with the associations between adolescent responses on each of these measures, as well as between parent responses between these measures. None of these associations were statistically significant.

Parent Reports of Adolescent Autonomy and Adolescent Reports of Adherence.

The levels of association between parent reports on the AFC and adolescent scores on the GAS and DSAS are reported in **Table 9.17**. Associations between parent reports on the subscales of the AFC and adolescent scores on the GAS and DSAS are reported in **Table 9.18**. The effect sizes of these associations are consistent with the associations between parent responses on each of these measures, as well as between adolescent responses between these measures. Again, none of these associations were statistically significant.

9.2.4 Reports of Adolescent Autonomy and Observed Blood Glucose Monitoring Adherence.

The next analyses examined the relationship between reports of adolescent autonomy and observed blood glucose monitoring adherence. These analyses took three forms. First, the relationship between scores on the AFC and the observed BGM adherence was examined using the complete BGM adherence dataset. Second, relationships between AFC scores and observed BGM adherence over the final 20, 12, 8, and 4 days before assessment were examined separately. Third, the relationship between AFC scores and observed BGM adherence over the previous 28 days was examined separately for adolescents coded with Consistently High, Consistently Low, Rising, or Other patterns of BGM adherence over the assessment period. Each of these analyses were also performed separately for each of the four subscales of the AFC.

The Relationship Between Reports of Adolescent Autonomy and Observed Blood Glucose Monitoring Adherence.

The correlations between the objective recording of Blood Glucose Monitoring and the measures of adolescent autonomy are reported in **Table 9.19**.

The correlations between adolescent reports of autonomy and the BGM data were all weak - none of these associations reached the $p = 0.05$ significance level. The levels of association between BGM data and the parent reports of adolescent autonomy were slightly stronger. Nonetheless, only the parent responses to the first subscale of the

AFC, 'Self- & Family-Care' were significantly negatively correlated with BGM adherence at the 0.05 level.

The negative correlations reported here indicate that higher levels of reported autonomy were associated with lower levels of BGM adherence. These results are not in the direction predicted by the second hypothesis of this study - that greater levels of autonomy would be associated with greater levels of adherence. However, there were only two significant correlations out of ten comparisons made - a result only slightly greater than would be expected by chance alone.

The Relationship Between Reports of Adolescent Autonomy and Observed Blood Glucose Monitoring Adherence Over Different Time Frames.

The correlations between the BGM adherence data spanning different time frames and total scores on the AFC are reported in **Table 9.20**. These correlations are reported for the observed BGM adherence over the final 28, 20, 12, 8 and 4 days prior to assessment. The correlations between the BGM adherence data spanning different time frames and scores on each of the subscales of the AFC are reported in **Table 9.21**. These analyses were intended to examine the relationship between reports of adolescents' autonomy and adherence to BGM over different time frames. As reported in **Chapter 5**, observed BGM adherence varied significantly over the four weeks prior to assessment, increasing as attendance to the clinic approached.

The magnitude of the correlations between each of the measures of autonomy and the observed BGM adherence did not vary greatly when the time frame examined by this data was adjusted.

The Relationship Between Reports of Adolescent Autonomy and Observed Blood Glucose Monitoring Adherence, According to Observed Patterns of Adherence Over Time.

Table 9.22 reports the distribution of scores on the adolescent and parent scales of the AFC for each blood glucose monitoring adherence group (Consistently High, Consistently Low, Rising, Other). **Table 9.23** reports the distribution of scores on the adolescent and parent completed subscales of the AFC for each blood glucose monitoring adherence group (Consistently High, Consistently Low, Rising, Other).

The mean scores obtained on the adolescent completed AFC were similar amongst the groups of adolescents who were categorised with Consistently High, Consistently Low, and Other BGM adherence; the mean adolescent AFC score obtained by the adolescent categorised with Rising BGM adherence was lower. This pattern was reflected in the adolescent responses to the Self- and Family-Care subscale of the AFC, but not in their responses to the other subscales. The mean scores obtained on the parent completed AFC were highest amongst the parents of adolescents who were categorised with Other BGM adherence. The distributions of scores on the parent completed subscales of the AFC did not appear to vary systematically in relation to BGM adherence groups.

Oneway ANOVAs were performed for the adolescent and parent completed AFC scales (as dependent variables) against the four BGM adherence groups (the independent variable). These analyses were use to determine whether the level of autonomy reported between adolescents and parents varied between these groups. These analyses were also performed on the adolescent and parent completed subscales of the AFC in relation to BGM adherence groups. Reported levels of adolescent autonomy by adolescents and parents on the AFC were not significantly varied according to the BGM adherence groups. Similarly, responses on the subscales of the AFC by adolescents and parents were not significantly varied according to the BGM adherence groups.

A second approach employed to analyse the possible variation in reported adolescent autonomy according to the BGM adherence profiles was pursued. This approach involved the combination of the Rising and Other BGM adherence groups into a single group. The levels of autonomy reported by these adolescents and their parents were compared with those reported amongst the Consistently High and Consistently Low BGM adherence groups using oneway ANOVAs. Reported levels of adolescent autonomy on each of the scales were again not significantly varied according to these BGM adherence groups on any of the AFC reports.

Analyses of differences in the level of association between reports of adolescent autonomy and reports of adherence according to sample characteristics were not performed, because of the lack of association found between the measures of adherence and autonomy.

9.3 The Level of Association Between Measures of Adolescent Autonomy and Adolescents' Metabolic Control.

The analyses presented in this section were designed to examine the association between the measures of adolescent autonomy and adolescents' HbA_{1c} levels - the measure of their metabolic control. These analyses were performed to further examine the hypothesised relationship between adolescent autonomy and adolescents' adherence.

Correlations of the adolescent and parent completed AFC scales with adolescents' HbA_{1c} are displayed in **Table 9.24**. The correlations between both the adolescent and parent completed scales of the AFC and adolescents' HbA_{1c} levels were not significant. Correlations of the subscales of the AFC, as completed by adolescents and parents, with adolescents' HbA_{1c} are also displayed in **Table 9.24**. The correlations between these subscales and adolescents' HbA_{1c} levels were not significant, with the exception of parents' reports of Management Activity.

Because of the lack of association between the measures of autonomy and the measures of adherence and metabolic control, hierarchical regressions of the contributions of autonomy measures to the prediction of metabolic control by adherence assessments were not pursued.

CHAPTER TEN.

DISCUSSION: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND ADOLESCENT AUTONOMY.

This chapter discusses the results presented in ***Chapter 9****, describing the relationship between measures of patient adherence and adolescent autonomy in the present study. In parallel with* ***Chapter 9****, the sections of this chapter address: (1) the reporting of adolescent autonomy in relation to sample characteristics; (2) the level of association between measures of adolescent autonomy and adherence; and (3) the level of association between measures of adolescent autonomy and adolescents' metabolic control.*

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10 RESULTS: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND ADOLESCENT AUTONOMY.

10.1 The Reporting of Adolescent Autonomy in Relation to Sample Characteristics.

This section discusses the results presented in **Section 9.1**, examining the reporting of adolescent autonomy by adolescents and parents in this study. These reports are examined in relation to respondents' demographic characteristics.

The scoring distributions of these measures are discussed in relation to: (1) adolescents' age, (2) adolescents' gender, (3) parents' age, (4) parents' gender, (5) parents' work status, and (6) household structure.

10.1.1 The Reporting of Adolescent Autonomy in Relation to Adolescents' Age.

Previous studies have reported that adolescents' autonomy increases with their age (Howe, et al. 1993; Sigafoos, et al. 1988; Small, et al. 1988). In the present study, reports of autonomy obtained from adolescents and their participating parents were associated with the adolescents' age. Older adolescents reported higher levels of reported autonomy than younger adolescents. Correlations of adolescents' and parents' scores on the total scale of the Autonomous Functioning Checklist with the adolescents' age were significant. Correlations of adolescents' and parents' scores on

the Self- and Family-Care, Management Activity, and Social / Vocational Activity subscales with the adolescents' age were also significant.

This finding is consistent with the results of previous studies using other measures of adolescent autonomy, and other studies using the AFC to assess autonomy in adolescents (Hauser, et al. 1993; Howe, et al. 1993; Sigafoos, et al. 1988; Small, et al. 1988).

10.1.2 The Reporting of Adolescent Autonomy in Relation to Adolescents' Gender.

Previous studies examining adolescents' autonomy in relation to their gender have provided mixed results. Enright, Lapsley, Drivas & Fehr (1980) reported two studies examining the parental influences on adolescent identity and autonomy development. In these studies, the most crucial variable mediating autonomy development during adolescence was gender. In these studies males had higher autonomy scores than females. Enright and colleagues attributed this finding to differential sex-role socialisation, suggesting that males are encouraged to be assertive and autonomous, while females are rewarded for passivity and dependence. These findings were consistent with Blos' (1979) psychoanalytic theory, which, as Hill & Holmbeck (1986) noted, differentiates male and female adolescents' development of autonomy.

However, Sigafoos and colleagues (1988), using the AFC, reported that scores on the Self- and Family-Care, Recreational Activity and Social / Vocational Activity subscales, as well as on the total AFC scale, were higher for the female adolescents

than for the male adolescents in their sample. Howe and colleagues (1993), using the same measure to examine the autonomy of chronically ill adolescents, found that reports of autonomy were higher amongst male adolescents than amongst females.

In the present study, the autonomy reports obtained from adolescents revealed a similar gender difference as was reported in the study by Sigafoos and colleagues (1988). Female adolescents reported a higher mean level of autonomy on the total AFC than male adolescents. In contrast, the reports of adolescent autonomy obtained from parents did not indicate significant gender differences in adolescent autonomy.

The most probable explanation for the inconsistency in gender differences in reported adolescent autonomy lies in the varying methods used to assess autonomy in these studies. Enright and colleagues (1980) employed Kurtines' (1978) measure of autonomy, completed by seventh and eleventh grade adolescents. It is possible that the higher reported autonomy amongst males than females in this study was influenced by the measure employed. The studies by Sigafoos and colleagues (1988) and Howe and colleagues (1993) both involved the Autonomous Functioning Checklist. However, the study by Sigafoos and colleagues examined a normative sample of adolescents, whereas the Howe, et al. study examined the autonomy of adolescents with chronic medical conditions. It is possible that this difference in sampling foci was responsible for the observed variation in gender differences in autonomy.

The gender differences in autonomy reported in this study and the previous studies, although statistically significant, have not been large. It is also possible that these

differences were the result of chance alone. No studies have been reported in the literature which focus directly on gender differences in adolescent autonomy. The systematic investigation of this issue would clarify the relationship between the development of adolescent autonomy and adolescent gender.

10.1.3 The Reporting of Adolescent Autonomy in Relation to Parents' Age.

Previous studies have not reported variation in adolescents' autonomy in relation to parents' age. In the present study, adolescents of older parents reported higher levels of autonomy than adolescents of younger parents. Similarly, older parents reported higher levels of autonomy in their adolescents than younger parents. These variations were significant.

Although previous research has not investigated this issue, there is at least one possible account for this finding. It is intuitively appealing to suggest that older parents were more autonomy granting than younger parents. It is likely that amongst the sample of older parents, the adolescents involved in the study were positioned later in the household birth order than the adolescents of younger parents. This information was not collected as a part of this study; parents were only asked about the number of children under the age of twenty in the household. It is possible that parents are more autonomy granting of later children than of first born children. A previous study by Small and colleagues (1988) reported that parents of first-born children were more stressed and had less autonomous adolescents than parents of

later-born children. This issue, although outside the focus of the present study, may be worthy of further investigation.

10.1.4 The Reporting of Adolescent Autonomy in Relation to Parents' Gender.

As discussed in **Section 8.1.4**, the recruitment of fathers into research investigating children's health care is problematic. In this study, the small number of fathers involved reported a slightly, but not significantly, lower level of autonomy in their adolescents than did the participating mothers.

The generally similar reports of autonomy are consistent with the findings of Sigafoos and colleagues (1988), using the Autonomous Functioning Checklist. In the previous study, interrater reliability between mothers and fathers was high.

10.1.5 The Reporting of Adolescent Autonomy in Relation to Parents' Work Status.

The consistent level of reported adolescent autonomy between parents working outside the home and those primarily at home suggests that parental work status did not influence their ability to report on their adolescents' level of autonomy. This issue has not received previous empirical investigation.

10.1.6 The Reporting of Adolescent Autonomy in Relation to Household Structure.

Adolescents' level of autonomy did not vary in relation to their household structure. Adolescents' of single parents reported similar levels of autonomy to adolescents with two parents in the home. Parents' reports of autonomy were also not varied according to household structure.

These findings are consistent with those of previous studies using the AFC (Howe, et al. 1993; Sigafoos, et al. 1988). Other investigations of adolescent autonomy have also reported finding no variation according to household structure (e.g., SS Feldman & Quatman, 1988; Frank, Pirsch, & Wright, 1990; Pardeck & Pardeck, 1990; Silverberg & Steinberg, 1987; Small, et al. 1988). However, this absence of reported findings is partially due to sampling strategies in some studies, which have only included families with two resident parents (i.e., "intact families," e.g., Frank, et al. 1990; Silverberg & Steinberg, 1987).

10.2 The Level of Association Between Measures of Adolescent Autonomy and Adherence.

This section discusses the results presented in **Section 9.2**, examining the association between the measures of adolescent autonomy and the measures of adherence to medical recommendations. Adolescent, parent and cross-informant comparisons are examined.

The associations between (1) adolescent reports of adherence and autonomy; (2) parent reports of adherence and autonomy; (3) cross-informant associations between reports of autonomy and adherence (e.g., between adolescent reports of autonomy and parent reports of adherence); and (4) associations between observed blood glucose monitoring adherence and reports of autonomy are discussed.

10.2.1 Adolescent Reports of Autonomy and of Adherence.

The lack of significant relationships between the adolescents' reports of their autonomy and their scores on the GAS and DSAS may be interpreted in a number of ways.

First, these results do not provide support for the hypothesised relationship between adolescents' autonomy and their adherence to medical treatment, that is, adolescents' reports of autonomy and adherence were not directly associated. The consistency of this lack of association between each of the adolescent completed measures supports this interpretation. Adolescents' scores on the total AFC displayed very similar correlations with their scores on the GAS and on the DSAS.

Second, it is possible that the lack of association between adolescents' reports of autonomy and adherence were caused by limitations in the measures. As reported in **Section 9.1**, the scores obtained on the AFC did not vary widely, and this lack of variation may impede associations of this measure with other measures used in this study. The relative insensitivity of the AFC in this study may have obscured a

genuine relationship between adolescents' autonomy and their adherence. Further investigation, employing a variety of measures of adolescent autonomy, would seem to be warranted.

A third interpretation of this observed lack of association is based on the pattern of associations between adolescents' responses to the subscales of the AFC and their responses to the GAS and DSAS. Adolescents' reports of autonomy in Recreational Activity were significantly associated with their ratings of adherence, whereas their responses to each of the other AFC subscales were not associated with their adherence reports. Previous studies, such as that by Hauser and colleagues (1993) have reported significant relationships between measures of adolescent autonomy and adolescent regimen adherence. The focus of the autonomy measure in this previous study was primarily toward recreational autonomy. Hence it may be suggested that the difference in findings between the present study and that of Hauser and colleagues does not represent an inconsistency, but reflects the differing foci of the autonomy measures employed. Further, the finding in the present study that adolescents' ratings on the Recreational Activity autonomy subscale (i.e., their ratings of recreational autonomy) were associated with their ratings of adherence is consistent with the findings in the previous investigation.

A fourth interpretation, also based upon the pattern of associations between these measures, may also be forwarded. That is, adolescents' adherence may be associated with their experience of recreational autonomy but not their experience of other aspects of their autonomous functioning because their recreational autonomy is adversely influenced by their diabetes. It is conceivable that the adolescents' diabetes

does not influence their experience of vocational autonomy, or of the aspects defined by the management activity subscale, while their recreational activities are restricted by their illness. This issue has not been addressed in previous empirical research. In light of these later interpretations, it may be suggested that the association between different aspects of adolescents' autonomous functioning and their adherence is worthy of further investigation.

10.2.2 Parent Reports of Adolescent Autonomy and of Adherence.

The lack of significant relationships between the parent reports of their adolescents' autonomy and their scores on the GAS and DSAS may also be interpreted in several ways. These interpretations correspond with those described in relation to the adolescent reports of autonomy and adherence.

First, like the relationships between the adolescent reports of adherence and autonomy, these associations do not provide support for the second hypothesis of this thesis. That is, parents' reports of their adolescents' autonomy and adherence were not directly associated. Again, the consistency of the lack of association between each of the parent completed measures further supports this interpretation. Further, the associations between the parent completed measures of adolescent autonomy and adherence were of very similar magnitude to those obtained between the adolescent completed reports.

Second, it is also possible that this lack of association is due to limitations of the measures employed. The AFC may have failed to detect a genuine association between adolescents' adherence and their experience of autonomy.

An examination of the level of association between parent-responses to the subscales of the AFC and to the adherence measures elicits different findings from those obtained using the adolescent reports. None of the subscales of the AFC completed by parents were associated with their reports of adherence. These findings are not consistent with the findings examining the associations between adolescents' responses on these measures. One interpretation of this inconsistency is that adolescents who experience restrictions in their autonomy may be more aware of these restrictions than are their parents, although this issue has yet to be examined in the published literature. The inconsistency in associations between responses to the AFC subscales and the adherence measures by adolescents and parents suggests that future investigations of the relationship between different aspects of adolescents' autonomous functioning and their medical adherence should incorporate reports from both adolescents and their parents.

10.2.3 Cross-Informant Associations Between Reports of Adolescent Autonomy and Adherence.

Cross informant analyses further examined associations between reports of adherence and reports of adolescents' autonomy.

The associations between adolescents' reports of autonomy and parents' reports of adherence are consistent with the associations obtained within informants. The associations between parents' reports of their adolescents' autonomy and the adolescents' reports of adherence are again consistent with these findings.

The interpretation of these findings reflects the interpretation of the previously discussed associations between adolescents' responses on these measures, as well as the interpretation of the parents' responses on the same measures. That is, these findings may be interpreted as a lack of support for the hypothesised relationship between adolescents' autonomy and their adherence, or may be attributed to weaknesses in the measures used to assess autonomy and adherence in this study.

10.2.4 Reports of Adolescent Autonomy and Observed Blood Glucose Monitoring Adherence.

Observed blood glucose monitoring adherence was also poorly associated with adolescents' and parents' scores on the AFC. Again, these associations were not significant. Further, adolescents' responses on each of the subscales of the AFC were not related to observations of their BGM adherence. Parents' responses to the Management Activity, Recreational Activity, and Social / Vocational Activity subscales were not significantly associated with their adolescents' observed BGM adherence. Parents' responses to the Self- and Family-Care subscale of the AFC were significantly negatively correlated with their adolescents' observed BGM adherence. This association is in the opposite direction to that predicted by the second hypothesis

of this thesis. The finding of one significant association out of the ten comparisons made is only slightly greater than would be expected on the basis of chance alone.

Further analysis indicated that the level of association between reports of adolescents' autonomy and their observed BGM adherence did not vary greatly when the time frame examined by the BGM data was adjusted. Reports of adolescents' autonomy were not varied in relation to observed patterns of BGM adherence.

The lack of predicted association between observed BGM adherence and reports of adolescents' autonomy may be interpreted in the same ways as the previous findings that adolescents' and parents' reports of adherence were not related to their reports of autonomy. These findings may be seen to provide little support for the second hypothesis of this thesis, or they may be interpreted as an indication that the measures employed in this study were too insensitive to detect a real association between adolescents' adherence and their experience of autonomy.

An additional consideration which should be identified in relation to the analyses examining BGM adherence is that this information was only available from a group of adolescents with poor metabolic control. It is possible that the associations found using the BGM data may have been influenced by a sample bias. However, two other findings reported in **Chapter 9** refute this possibility. First, the associations between observed BGM adherence and reports of autonomy were of a similar magnitude to the associations between the other measures of adherence and the measures of autonomy. Second, amongst the whole sample (i.e., those from whom BGM data were obtained

and those from whom this data was not obtained), the adolescents' level of metabolic control was not associated with their level of reported autonomy (**Section 9.3**).

10.3 The Level of Association Between Measures of Adolescent Autonomy and Adolescents' Metabolic Control.

This section discusses the results presented in **Section 9.3**, examining the relationship between reports of adolescent autonomy and adolescents' level of metabolic control.

In light of the conceptual link between regimen adherence and health outcomes, the association between metabolic control and adolescent-autonomy was examined as an extension of the second hypothesis of this thesis. The importance of studying patient adherence lies in its association with the health outcomes of patients. The importance of the association between adolescent autonomy and adherence is reduced if the adolescents' autonomy is unrelated to their health outcomes. The hypothesised relationship between adolescent autonomy and health outcomes includes patient adherence as a mediating factor, nonetheless the direct association of autonomy with health outcome is pertinent to the understanding of the relationship between autonomy and adherence. Adolescents' HbA_{1c} assay levels were treated as the measure of health outcome for these analyses. To examine the level of association between adolescent autonomy and HbA_{1c} levels, Pearson correlations were used.

The initial analyses performed to examine the relationship between adolescents' autonomy and their metabolic control revealed only one significant association.

Parents' responses to the Management Activity subscale of the AFC were significantly negatively correlated with their adolescents' recorded HbA_{1c} assay levels. The direction of this association indicates that parents' reported greater Management autonomy in adolescents with better metabolic control (lower HbA_{1c} levels).

In a previous investigation, Ingersoll and colleagues (1992) observed that adolescents' level of cognitive maturity, which they equated with autonomy, was significantly associated with their level of metabolic control in insulin dependent diabetes. The results of the present study failed to replicate these findings using a different form of autonomy assessment. This inconsistency is likely to be the result of the different measures used in the present study and that of Ingersoll and colleagues (1992). Further investigation is needed to elucidate the relationship between adolescents' autonomy and their metabolic control.

Because of the general lack of association between reports of adolescents' autonomy and their level of metabolic control, further analysis of the relationships between adolescents' autonomy, adherence and metabolic control were not pursued.

10.4 Summary and Future Directions: The Relationship Between Patient Adherence and Adolescent Autonomy.

This section provides a synthesis of the findings discussed in this chapter, in light of the published literature. The implications of these findings to the wider literature and to future research are addressed.

10.4.1 The Relationship Between Patient Adherence and Adolescent Autonomy.

The findings discussed in this chapter examined the second hypothesis of this thesis. This hypothesis states that higher levels of reported adolescent autonomy will be associated with higher levels of reported adherence, that is, a direct association exists between adolescents' autonomy and adolescents' medical adherence.

In previous studies by Hauser and colleagues (1993) and Ingersoll and colleagues (1986), measures of adolescents' autonomy have been associated with measures of adolescents' adherence to IDDM regimens.

Ingersoll and colleagues (1986) used a paragraph completion measure to assess adolescents' cognitive maturity, which they equated with autonomy. Adherence to IDDM recommendations was assessed with "a set of psychologic, behavioural and achievement instruments" (p 621). Autonomy was positively associated with the adolescents' IDDM adherence.

Hauser and colleagues (1993) reported on the basis of three case studies that adolescents' adherence to IDDM recommendations was associated with their self-reliance, a concept closely linked to autonomy.

Although empirical investigation of this issue has been limited, a number of authors have suggested that adolescents' adherence and autonomy are likely to be linked. For example, La Greca (1990a) reviewed the adherence literature and suggested that

adolescents' adherence may be positively associated with their taking responsibility for their own medical care. Similarly, Hazzard and colleagues (1990) suggested that children of restrictive parents may be less adherent to their medical regimen because of resentment over interference in their autonomous development. Other authors have also endorsed the proposed association (e.g., Allen, et al. 1983; Coupey & Cohen, 1984; SB Johnson, et al. 1992).

Investigation involving adolescents experiencing illnesses other than IDDM have supported this association. For example, IM Friedman and colleagues (1986) examined the adherence of adolescents with epilepsy, using saliva phenobarbital assays as well as interviews. Autonomy was measures using a "Personal Freedom" scale of the California Test of Personality (see **Section 1.3.2.3**). This study demonstrated significant associations between medication compliance and perceived autonomy in a group of adolescents with epilepsy. However, this study did not employ a specific measure of autonomy, using instead a generic personality test. Further, Litt and colleagues (1982) examined the regimen adherence of adolescents with rheumatoid arthritis, using serum salicylate levels. Autonomy was assessed using a modified Eysenk Autonomy Scale. Adherence was positively related to autonomy in this study.

In the present study, adolescent and parent reports of the adolescents' autonomy were not associated with the adolescents' adherence, as reported by adolescents and their parents. Observations of BGM adherence were not related to these reports of adolescent autonomy. Additional analyses revealed no significant relationships between reports of adolescent autonomy and adolescents' metabolic control.

These results extend on previous research in several respects.

First, these findings varied from those reported by Hauser and colleagues (1993) and Ingersoll and colleagues (1986). There are a number of possible explanations for this variation in finding. Hauser and colleagues (1993) based their report on three single case studies. The explanatory power of case studies is limited. It is possible that the different findings in the present study result from the greater sample size employed. Further, the measures of autonomy used in these studies differed. Hauser and colleagues (1993) used more global assessments of family members' functioning, whereas the present study used a more specific assessment of adolescent autonomy. It is possible that general functioning is associated with adolescents' adherence, but the particular aspect of functioning assessed in the present study - adolescent autonomy - is not related to adherence. Ingersoll and colleagues (1986) used an assessment of cognitive maturity to assess adolescents' autonomy. Again, the assessment of autonomy in the present study specifically addressed autonomy, rather than a related construct.

In sum, the findings discussed in this chapter do not provide support for the second hypothesis of this thesis. However, it would be premature to conclude that adolescents' medical adherence is unrelated to their experience of autonomy. The following section discusses the limitations of the present study, and identifies avenues for further investigation.

10.4.2 Limitations of the Present Study and Future Directions for Investigations of the Relationship Between Patient Adherence and Adolescent Autonomy.

The discussion of the results in this study examining the relationship between measures of adherence and measures of adolescent autonomy has identified a number of limitations of the study, and identified several avenues for future research.

First, the measure of autonomous functioning employed in this study did not detect wide variations in autonomy levels amongst the participating adolescents. Given the size of the sample involved in this study (n = 135), and the age range involved (12 to 17 years of age), the lack of variability in obtained scores on the AFC may indicate a lack of sensitivity in this measure. The use of a more sensitive measure of adolescents' autonomous functioning would facilitate a more sensitive assessment of the relationship between adolescents' autonomy and their adherence to medical regimens.

Second, as discussed in **Chapter 8**, the small sample size in certain demographic groups in this study limited the examination of the different roles played by, for example, mothers and fathers. The recruitment of larger samples of fathers into research investigating their children's health care requires at least one of two approaches: (1) the collection of data from multiple sites, or (2) the development of specific approaches that are likely to increase the participation rate of fathers. Clearly, studies which include fathers' participation as well as that of mothers, rather than instead of mothers, will be better able to examine the differing roles of these family members in children and adolescents' health behaviour.

Third, the findings of this study suggest that adolescents of older parents may be granted more autonomy than adolescents of younger parents. This pattern may be concomitant with the birth order of adolescents; previous research has suggested that first born adolescents are granted less autonomy (i.e., experience more parental restriction) than later born adolescents. These issues are worthy of further investigation.

Fourth, associations between responses to the subscales of the AFC suggest that different aspects of adolescents' autonomous functioning relate differently to their regimen adherence. For example, adolescents' reported autonomy in Recreational Activity was most closely associated with their reported adherence. This suggestion provides some explanation for the inconsistency in adherence-autonomy relations observed between this study and some previous investigations (e.g., Hauser, et al. 1993; Ingersoll, et al. 1986). The relationship between different aspects of adolescents' psychosocial functioning and their medical adherence is worthy of further investigation.

Clarification of the relationships between different aspects of adolescents' autonomy may also lead to more fruitful examinations of the association between adolescents' autonomy and their level of metabolic control. The assessment of this association in the present study was limited by the measure of autonomy employed. Further investigation, using other measures of autonomy, is needed to elucidate the relationship between adolescents' autonomy and their metabolic control.

CHAPTER ELEVEN.

RESULTS: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND THE PROPOSED ANTECEDENTS OF ADHERENCE.

This chapter examines the relationship between measures of adolescents' adherence to their diabetes treatment recommendations and the measures of proposed antecedents of patient adherence. These analyses were conducted as part of the secondary aims of this thesis; to examine the applicability of the Six-Factor Model of Adherence to adolescents' adherence. This chapter consists of three sections. First, adolescents' and parents' reports of antecedents of adherence are presented in relation to sample characteristics. Second, analyses are presented that examine the association between reports of these proposed antecedents and reports of adherence. Finally, the associations between reports of proposed antecedents of adherence and adolescents' metabolic control (HbA_{1c}) are examined.

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Fotheringham MJ, Couper JJ, Sawyer MG. (1997). Associations between adolescents' metabolic control, IDDM adherence and objective data of blood glucose monitoring. *Proceedings of the Australian Diabetes Society, 1997* A 93.

11 RESULTS: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND THE PROPOSED ANTECEDENTS OF ADHERENCE.

11.0 Introduction.

The proposed antecedents of adherence examined in this study were based upon the framework of the Six-Factor Model of Adherence. These antecedents include: (1) effective communication of information; (2) rapport with health professionals; (3) client's beliefs and attitudes; (4) client's social climate and norms; (5) behavioural intentions; and (6) supports for and barriers to adherence. According to the heuristic framework of the model, the first two factors are prerequisites for the last four factors, which are sequentially ordered (Gritz, et al. 1989). These factors are assessed using the Adherence Determinants Questionnaire (ADQ) and the Health Value Scale (HVS) (DiMatteo, Hays, et al. 1993; Lau, et al. 1986). In addition, knowledge of IDDM treatment was assessed using the Diabetes Knowledge Questionnaire (based on Dunn, et al. 1984).

The analyses presented in this chapter examined the bivariate associations between each of the measures of these proposed antecedents and the measures of adherence. **Chapter 13** presents results examining the multivariate association between the measures of these antecedents and the measures of adherence. These analyses were conducted as part of the secondary aim of this thesis; to examine the applicability of the Six-Factor Model of Adherence to adolescents' adherence.

11.1 The Reporting of The Proposed Antecedents of Adherence in Relation to Sample Characteristics.

This section examines obtained data from the measures of antecedents of adherence. The ADQ, HVS, and DKQ were completed by participating adolescents and parents. The ADQ consists of seven scales: (*a*) Interpersonal Aspects of Care, (*b*) Perceived Utility, (*c*) Perceived Severity, (*d*) Perceived Susceptibility, (*e*) Subjective Norms, (*f*) Intentions to Adhere, and (*g*) Supports / Barriers. **Table 11.1** displays distributions of scores on the ADQ by adolescents and parents.

As may be seen from **Table 11.1**, mean reports of Interpersonal Aspects of Care by adolescents and parents indicated generally good rapport between these respondents and health professionals involved in the adolescents' IDDM care. Adolescents and parents reported high mean levels of perceived utility of IDDM treatment. Reports of perceived severity of IDDM indicated that, on average, respondents did not rate IDDM as a very severe illness. Adolescents perceived themselves to be relatively highly susceptible to hypoglycaemia or hyperglycaemia, as did their parents. Reports on the Subjective Norms scale indicated that expectations held by members of the adolescents' social networks were not influential on their adherence. The distribution of scores on this scale was narrow. Mean reports from adolescents and parents indicated strong Intentions to Adhere to IDDM treatment in the future. Finally, mean responses to the Supports / Barriers scale indicated the presence of supports to adherence, and the absence of barriers to adherence (i.e., responses to this scale indicated general support for adherence).

Table 11.2 reports distributions of scores on the HVS and DKQ scales completed by adolescents and parents. As may be seen from this table, mean responses to the Health Value Scale by adolescents and parents indicated a high level of importance attributed to having good health. Responses to the Diabetes Knowledge Questionnaire indicated good knowledge of IDDM treatment.

The scoring distributions of these measures are examined in relation to: (1) adolescents' age, (2) adolescents' gender, (3) parents' age, (4) parents' gender, (5) parents' work status, and (6) household structure.

11.1.1 The Reporting of The Proposed Antecedents of Adherence in Relation to Adolescents' Age.

The distributions of scores on the scales of the ADQ and on the Health Value Scale and the Diabetes Knowledge Questionnaire according to adolescents' age are reported in **Tables 11.3** to **11.7**. Responses on these scales by adolescents and parents did not vary greatly according to adolescents' age. Associations between responses to these measures by adolescents and parents and adolescents' age are reported in **Table 11.8**. Parents' responses to the Subjective Norms scale were significantly associated with adolescents' age. This association was negative, indicating that parents' perception of the influence of adolescents social networks on their adherence was increasingly unfavourable to adherence with the adolescents' increasing age. Adolescents' responses to the DKQ were significantly associated with their age, indicating that

older adolescents possessed greater knowledge of diabetes management than younger adolescents.

To further explore the association between adolescents' age and responses to the scales of the ADQ and the HVS, the levels of agreement between adolescents' and parents' responses were examined in relation to this characteristic. These analyses are detailed in **Appendices G.1** and **G.2**. Overall, adolescents' and parents' responses on the ADQ and HVS were highly correlated. These correlations did not significantly vary according to adolescents' age.

11.1.2 The Reporting of The Proposed Antecedents of Adherence in Relation to Adolescents' Gender.

The distributions of scores on the scales of the ADQ and on the Health Value Scale and the Diabetes Knowledge Questionnaire according to adolescents' gender are reported in **Tables 11.9**, **11.10** and **11.11**. Responses on these scales by adolescents and parents did not vary greatly according to adolescents' gender.

Students' *t* tests were employed to examine differences in responses to these measures according to adolescents' gender. Overall, 18 tests of this nature were undertaken. If all 18 tests were independent of each other there is a probability of 0.60 that one or more of the tests would be statistically significant at $p = 0.05$ when in fact there are no true differences with respect to all 18 variables under scrutiny. The assumption that the tests are all independent of one another is a poor one, however, because many of

these variables 'overlap' in terms of what they measure and are correlated with one another. If one were to 'tighten' the significance level for the individual tests to 0.003, the overall probability of finding a significant result where one does not exist is 0.05. Due to the inadequacy of the assumption this overly strict criteria has not been applied here, but the reader should be aware of this potential problem.

Students' *t* test analyses revealed that mean scores on the parent completed Perceived Severity scale were significantly higher amongst the parents of the male adolescents than amongst the parents of the female adolescents (t (130) = 2.56, p = 0.01). Responses of the male and female adolescents were not significantly different. Further *t* tests revealed differences in mean scores on the DKQ between parents of female and male adolescents (t (132) = 2.91, p = 0.004), for which the parents of male adolescents produced a higher mean score than the parents of female adolescents. Again, male and female adolescents' responses to this scale were not significantly different. On the remaining scales, adolescent gender differences were not detected.

To further explore the association between adolescents' gender and responses to the scales of the ADQ and the HVS, the levels of agreement between adolescents' and parents' responses were examined in relation to this characteristic. These analyses are detailed in **Appendix G.3**. Overall, adolescents' and parents' responses on the ADQ and HVS were highly correlated. These correlations did not significantly vary according to adolescents' gender.

11.1.3 The Reporting of The Proposed Antecedents of Adherence in Relation to Parents' Age.

The distributions of scores on the ADQ, HVS, and DKQ by adolescents and parents according to parents' age group are reported in **Tables 11.12**, **11.13** and **11.14**. As in previous chapters, parents' age was grouped into (a) those under 40 years, (b) those between 40 and 45 years old, and (c) those over 45 years old.

One-way ANOVAs examined the variation in adolescents' and parents' scores on the ADQ scales and the HVS and DKQ according to parents' age groups. The results of these analyses were not significant.

11.1.4 The Reporting of The Proposed Antecedents of Adherence in Relation to Parents' Gender.

The distributions of scores on the ADQ, HVS and DKQ according to the gender of the participating parent are reported in **Tables 11.15**, **11.16** and **11.17**. Responses by adolescents and parents to these measures were similar, regardless of whether the parent participating in the study was the adolescents' mother or father.

Because of the small number of fathers participating in this study, formal analyses of differences in scores obtained on these measures according to parent gender were not performed.

11.1.5 The Reporting of The Proposed Antecedents of Adherence in Relation to Parents' Work Status.

The distributions of scores on the ADQ, HVS and DKQ according to the participating parents' work status are reported in **Tables 11.18**, **11.19** and **11.20**. Similar responses by adolescents and parents were obtained on these measures, regardless of whether the parent participating in the study worked outside the home or was primarily in the home.

Students' *t* test analyses revealed that mean scores on the parent completed Subjective Norms scale were significantly lower amongst the parents working outside the home than amongst the parents who were primarily at home (t (131) = 2.26, p = 0.03). Further *t* tests revealed differences in mean scores on the DKQ between parents working outside the home and those primarily at home (t (131) = -2.07, p = 0.04), for which the parents working outside the home produced a higher mean score. On the remaining scales, differences were not detected according to parental work status.

11.1.6 The Reporting of The Proposed Antecedents of Adherence in Relation to Household Structure.

The distributions of scores on the ADQ, HVS and DKQ according to participants' household structure are reported in **Tables 11.21**, **11.22** and **11.23**. Again, very similar mean responses were obtained from each of these measures by adolescents and

parents regardless of whether these respondents resided in single parent or dual parent households.

Students' *t* test analyses did not reveal differences in mean scores on adolescent or parent completed ADQ, HVS and DKQ scales according to household structure; with one exception. Parents' responses to the Supports / Barriers scale were higher amongst those residing in dual parent households than those residing in single parent households (t (130) = 2.04, p = 0.04).

11.2 The Level of Association Between Measures of Proposed Antecedents of Adherence, and Adherence.

The analyses presented in this section were designed to examine the association between the measures of proposed antecedents of adherence and the measures of adherence to medical recommendations employed in this study. Pearson correlations were employed to examine the level of association between these measures.

Separate analyses examined the associations between (1) adolescent reports of adherence and the proposed antecedents, (2) parent reports of adherence and the proposed antecedents, (3) cross-informant associations between reports of proposed antecedents and adherence (e.g., between adolescent reports of adherence and parent reports of antecedent factors), and (4) associations between observed blood glucose monitoring adherence and reports of proposed adherence antecedents by adolescents and parents.

11.2.1 Adolescents Reports of Antecedents and of Adherence.

The levels of correlation between the adolescent completed measures of proposed antecedents of adherence and the adolescent completed GAS are reported in **Table 11.24**. The effect sizes of the correlations between adolescents' responses to the scales of the ADQ and the GAS were moderate to large, with the exceptions of Perceived Susceptibility and Subjective Norms, which showed no association with adolescents' reports of general adherence. The associations of the remaining scales of the adolescent completed ADQ with the adolescent completed GAS were all statistically significant. Further, adolescents' responses to the HVS were significantly associated with their responses to the GAS. However, adolescents' scores on the DKQ were not significantly related to their reports of general adherence.

The level of correlation between the adolescent completed measures of proposed antecedents of adherence and the adolescent completed DSAS are reported in **Table 11.24**. The effect sizes of the correlations between adolescents' responses to the scales of the ADQ and the DSAS were moderate to small. The associations of DSAS scores with scores on the Perceived Utility, Perceived Severity, Intentions to Adhere, and Supports / Barriers scales were statistically significant. The associations of DSAS scores with the Interpersonal Aspects of Care, Perceived Susceptibility, and Subjective Norms scales were not significant. Adolescents responses to the HVS were significantly associated with their responses to the DSAS. However,

adolescents' scores on the DKQ were not significantly related to their reports of diabetes-specific adherence.

11.2.2 Parents Reports of Antecedents and of Adherence.

The level of correlation between the parent completed measures of proposed antecedents of adherence and the parent completed GAS are reported in **Table 11.25**. The effect sizes of the correlations between parents' responses to the scales of the ADQ and the GAS ranged from small (e.g., Perceived Susceptibility) to large (e.g., Intentions to Adhere). Only the Perceived Susceptibility and Subjective Norms scales completed by parents were not significantly associated with their responses to the GAS. Parent reports of health value (HVS) produced a moderately small, but statistically significant, association with parent reports of general adherence (GAS). Parents' diabetes knowledge scores (DKQ) were not associated with their reports of general adherence (GAS).

The level of correlation between the parent completed measures of proposed antecedents of adherence and the parent completed DSAS are reported in **Table 11.25**. The effect sizes of the correlations between parents' responses to the scales of the ADQ and the DSAS were generally small. Parent responses to the Perceived Utility, Intentions to Adhere, and Supports / Barriers scales were significantly associated with their responses to the DSAS. Parents responses to the remaining scales of the ADQ were not associated with their reports of diabetes-specific adherence (DSAS). Parent reports of health value (HVS) produced a small, but

statistically significant, association with parent reports of diabetes-specific adherence (DSAS). Parents' diabetes knowledge scores (DKQ) were not associated with their reports of diabetes-specific adherence (DSAS).

11.2.3 Cross-Informant Associations Between Reports of Antecedents and Adherence.

The next analyses examined the association between (1) adolescents' reports of proposed antecedents of adherence, and parents' reports of the adolescents' adherence, and (2) adolescents' reports of adherence, and their parents' reports of the proposed antecedents of adherence. These analyses were performed to examine from another angle the association between reported adherence and its proposed antecedents. The examination of cross-informant associations also reduces the vulnerability of the analyses to respondent biases (see **Section 8.2.4** for a discussion of this point).

Adolescent Reports of Antecedents and Parent Reports of Adherence.

The levels of correlation between the adolescent completed measures of proposed antecedents of adherence and the parent completed GAS are reported in **Table 11.24**. The effect sizes of the correlations between adolescents' responses to the scales of the ADQ and their parents' responses to the GAS were moderate, and significant, with the exceptions of the Perceived Susceptibility and Subjective Norms scales, which were not significantly associated with parent reports of general adherence. Adolescents' reports of health value (HVS) produced a small but significant association with their

parents' reports of general adherence (GAS). Adolescents' diabetes knowledge scores (DKQ) were not associated with their parents' reports of general adherence (GAS).

The level of correlation between the adolescent completed measures of proposed antecedents of adherence and the parent completed DSAS are reported in **Table 11.24**. The effect sizes of the correlations between adolescents' responses to the scales of the ADQ and the DSAS were smaller than those associated the measures of antecedent with the GAS. Only the Perceived Utility and Intentions to Adhere scales of the ADQ completed by adolescents were significantly associated with their parents' reports of diabetes-specific adherence (DSAS). Adolescents' reports of health value (HVS) produced a small but significant association with their parents' reports of diabetes-specific adherence (DSAS). Adolescents' diabetes knowledge scores (DKQ) were not associated with their parents' reports of diabetes regimen adherence (DSAS).

Parent Reports of Antecedents and Adolescent Reports of Adherence.

The levels of correlation between the parent completed measures of proposed antecedents of adherence and the adolescent completed GAS are reported in **Table 11.25**. The effect sizes of the correlations between parents' responses to the scales of the ADQ and their adolescents' responses to the GAS were small to moderate. Only the Perceived Utility, Intentions to Adhere, and Supports / Barriers scales completed by adolescents were significantly associated with parents' reports of general adherence (GAS). Parents' reports of health value (HVS) produced a small but significant association with their adolescents' reports of general adherence (GAS). Parents'

diabetes knowledge scores (DKQ) produced a small, but statistically significant association with their adolescents' reports of general adherence (GAS).

The level of correlation between the parent completed measures of proposed antecedents of adherence and the adolescent completed DSAS are reported in **Table 11.25**. The effect sizes of the correlations between adolescents' responses to the scales of the ADQ and the DSAS were also small. Only the Intentions to Adhere scale of the ADQ completed by parents was significantly associated with the adolescents' reports of diabetes-specific adherence (DSAS). Parents' reports of health value (HVS) produced a small but significant association with their adolescents' reports of diabetes-specific adherence (DSAS). Parents' diabetes knowledge scores (DKQ) were not associated with their adolescents' reports of diabetes regimen adherence (DSAS).

11.2.4 Reports of Antecedents and Observed Blood Glucose Monitoring.

The next analyses examined the relationship between reports of proposed antecedents of adherence and observed blood glucose monitoring adherence. These analyses took three forms. First, the relationships between scores on the ADQ, HVS and DKQ and the observed BGM adherence were examined using the complete BGM adherence dataset. Second, relationships between scores on these scales and observed BGM adherence over the final 20, 12, 8, and 4 days before assessment were examined separately. Third, the relationship between these scale scores and observed BGM adherence over the previous 28 days was examined separately for adolescents coded

with Consistently High, Consistently Low, Rising, or Other patterns of BGM adherence over the assessment period.

The Relationship Between Reports of Antecedents and Observed Blood Glucose Monitoring Adherence.

The correlations between the objective recording of Blood Glucose Monitoring and the measures of proposed antecedents of adherence are reported in **Table 11.26.**

The correlations between reports of antecedents of adherence and the BGM data were generally small. Only adolescent responses to the Intentions to Adhere scale, and parent responses to the Subjective Norms and Intentions to Adhere scales of the ADQ were significantly related to observed levels of BGM adherence. Responses by adolescents and parents to the HVS and DKQ were not significantly associated with observed BGM adherence levels.

The Relationship Between Reports of Antecedents and Observed Blood Glucose Monitoring Adherence Over Different Time Periods.

The correlations between the BGM adherence data spanning different time frames and adolescent scores on the scales of the ADQ, as well as the HVS and DKQ, are reported in **Table 11.27**. The correlations between the BGM adherence data spanning different time frames and parent scores on the scales of the ADQ, as well as the HVS and DKQ, are reported in **Table 11.28**. As in previous chapters, these correlations are reported for the observed BGM adherence over the final 28, 20, 12, 8 and 4 days prior

to assessment. These analyses were intended to examine the relationship between reports of the proposed antecedents of adherence and observed adherence to BGM over different time frames. As reported in **Chapter 5**, observed BGM adherence varied significantly over the four weeks prior to assessment, increasing as attendance to the clinic approached.

The magnitude of the correlations between each of the measures of adherence antecedents and the observed BGM adherence did not vary greatly when the time frame examined by this data was adjusted. Adolescents' reports of Intentions to Adhere were significant over each of the time frames assessed. Adolescents' responses to the Perceived Utility and Perceived Severity scales were associated with observed BGM adherence over the final 12, 8 and 4 days before clinic attendance, but not with observed BGM adherence over the longer time frames. Parents' responses to the Subjective Norms and Intentions to Adhere scales of the ADQ were significantly associated with observed BGM adherence over each of the time frames assessed. None of the other parent responses to these measures were associated with observed BGM adherence over any of the assessed time frames.

The Relationship Between Reports of Antecedents and Observed Blood Glucose Monitoring Adherence, According to Observed Patterns of Adherence Over Time.

Table 11.29 reports the distributions of scores on the adolescent completed ADQ, HVS and DKQ for each of the blood glucose monitoring adherence groups (Consistently High, Consistently Low, Rising, and Other). **Table 11.30** reports the

distributions of scores on the parent completed ADQ, HVS and DKQ for each blood glucose monitoring adherence group.

The mean scores on the adolescent completed measures of antecedents were similar amongst the groups of adolescents who were categorised with Consistently High, Consistently Low, Rising and Other BGM adherence. Mean scores obtained on the parent completed measures were not greatly varied according to BGM adherence group.

Oneway ANOVAs were performed for the adolescent and parent completed measures (as dependent variables) against the four BGM adherence groups (the independent variable). These analyses were used to determine whether the reports of antecedents of adherence by adolescents and parents varied between these groups.

Responses by adolescents and parents on most scales of the ADQ were not significantly varied according to the BGM adherence groups. However, responses by parents to the Intentions to Adhere scale were significantly varied by BGM adherence group (F (3,74) = 3.66, p = 0.02). Post hoc analyses using Tukey's Honestly Significant Difference revealed significant differences between the responses obtained from parents of adolescents exhibiting Consistently High and Consistently Low BGM adherence. Responses to the HVS and DKQ by adolescents and parents were not significantly varied according to the BGM adherence groups.

As in previous chapters, a second approach was employed to analyse the possible variation in reported adolescent autonomy according to the BGM adherence profiles.

This approach involved the combination of the Rising and Other BGM adherence groups into a single group. The responses on the antecedent scale by these adolescents and their parents were compared with those reported amongst the Consistently High and Consistently Low BGM adherence groups using oneway ANOVAs.

Again, only parent responses to the Intentions to Adhere scale were significantly varied by BGM adherence group (F (2,74) = 5.56, p = 0.01). Post hoc analyses using Tukey's Honestly Significant Difference revealed significant differences between the responses obtained from parents of adolescents exhibiting Consistently High and Consistently Low BGM adherence, and between the adolescents exhibiting Rising and Consistently Low BGM adherence patterns.

11.3 The Level of Association Between Measures of Proposed Antecedents of Adherence and Adolescents' Metabolic Control.

The analyses presented in this section were designed to examine the association between the measures of proposed antecedents of adherence and adolescents' HbA_{1c} levels - the measure of their metabolic control. These analyses were performed to further examine the relationship between the proposed antecedents of adherence and the adolescents' adherence. The correlations between both the adolescent and parent completed measures of antecedents and adolescents' HbA_{1c} levels were generally small (**Table 11.31**).

Adolescent scores on the Interpersonal Aspects of Care, Perceived Utility, and Supports / Barriers scales were significantly correlated with the adolescents' HbA_{1c} levels. Parent scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity, Intentions to Adhere and Supports / Barriers scales were all significantly correlated with adolescents' HbA_{1c} levels. Adolescent and parent scores on the Health Value Scale and Diabetes Knowledge Questionnaire were not significantly related to the adolescents' level of metabolic control.

The final analyses that were conducted examined whether the ratings of proposed adherence antecedents accounted for unique variance in HbA_{1c} assay levels once the adherence reports were entered into regression equations first. Four hierarchical multiple regression analyses (HMRAs) were conducted, using adolescents' HbA_{1c} assay results as the dependent variable. The first of these analyses involved the adolescent responses to the antecedent measures, entered after the adolescent completed GAS (**Table 11.32**). The second of these analyses involved the adolescent responses to the antecedent measures, entered after the adolescent completed DSAS (**Table 11.33**). The third of these analyses involved the parent responses to the antecedent measures, entered after the parent completed GAS (**Table 11.34**). The final of these analyses involved the parent responses to the antecedent measures, entered after the parent completed DSAS (**Table 11.35**).

Adolescent Reports of Adherence and Proposed Antecedents.

As reported in **Table 11.32**, adolescent responses to the proposed antecedents of adherence measures added a significant amount of the variance in *Step 2* after the

adolescent reports of general adherence had been entered. Specifically, responses to the Supports / Barriers scale accounted for additional variance in HbA_{1c} results after the adolescents' adherence reports had been included in the regressions. As indicated in **Table 11.33**, adolescent responses to the DSAS did not have great enough predictive power for the HMRA to be conducted; this analysis was halted at *Step 1*.

Parent Reports of Adherence and Proposed Antecedents.

As reported in **Table 11.34**, parent responses to the proposed antecedents of adherence measures did not significantly improve prediction of adolescents' metabolic control, above the prediction afforded by parents' responses to the General Adherence Scale. Similarly, as reported in **Table 11.35**, parent responses to the proposed antecedents of adherence measures did not significantly improve the prediction of adolescents' metabolic control, above the prediction afforded by parents' responses to the Diabetes Specific Adherence Scale.

CHAPTER TWELVE.

DISCUSSION: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND THE PROPOSED ANTECEDENTS OF ADHERENCE.

This chapter discusses the results presented in ***Chapter 11****, describing the relationship between the measures of patient adherence and a series of proposed antecedents of adherence in the present study. In parallel with* ***Chapter 11****, the sections of this chapter address: (1) the reporting of the proposed antecedents of adherence in relation to sample characteristics; (2) the level of association between measures of proposed antecedents and adherence; and (3) the level of association between measures of proposed antecedents of adherence and adolescents' metabolic control.*

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Fotheringham MJ, Couper JJ, Sawyer MG. (1997). Associations between adolescents' metabolic control, IDDM adherence and objective data of blood glucose monitoring. *Proceedings of the Australian Diabetes Society, 1997* A 93.

12 DISCUSSION: THE RELATIONSHIP BETWEEN PATIENT ADHERENCE AND THE PROPOSED ANTECEDENTS OF ADHERENCE.

12.1 The Reporting of The Proposed Antecedents of Adherence in Relation to Sample Characteristics.

This section discusses the results presented in **Section 11.1**, examining the reporting of proposed antecedents of adherence by adolescents and parents in this study. These reports are examined in relation to respondents' demographic characteristics.

The scoring distributions of these measures are examined in relation to: (1) adolescents' age; (2) adolescents' gender; (3) parents' age; (4) parents' gender; (5) parents' work status; and (6) household structure.

12.1.1 The Reporting of The Proposed Antecedents of Adherence in Relation to Adolescents' Age.

The findings of the present study suggest that adolescents' and parents' perceptions of their diabetes treatment (i.e., the utility of the treatment and interpersonal aspects of medical care) did not vary with the adolescents' age. Further, adolescents' and parents' health beliefs (i.e., perceived susceptibility and severity of diabetes) did not appear to vary with the adolescents' age. Adolescents' and parents' intentions to adhere in the future and their perceptions of supports and barriers to adherence were

not varied according to the adolescents' age. Parents' perceptions, but not adolescents' perceptions, of the adolescents' social influences were slightly negatively associated with the adolescents' age, indicating that parents' of older adolescents perceived the social influences of their adolescents to be less supportive of regimen adherence than did the parents of the younger adolescents. The reported health value of adolescents and parents was not varied according to the adolescents' age. Diabetes knowledge amongst adolescents and parents was not associated with the adolescents' age.

Few previous studies have reported on the variation of these factors in relation to adolescents' age. Previous investigations using the ADQ have involved adult samples of patients. These studies have not reported age influences on responses to these measures. Schlenk and Hart (1984) reported that patients with diabetes held a uniformly high value on health. SB Johnson, and colleagues (1982) reported that adolescents' diabetes knowledge was not varied according to their age; the diabetes knowledge of parents was not assessed.

The findings of the present study suggest that adolescents' age was not a strong influence on their health beliefs and perceptions of medical treatment. This finding extends upon previously published research, which has not directly addressed this issue.

12.1.2 The Reporting of The Proposed Antecedents of Adherence in Relation to Adolescents' Gender.

With the exceptions of parents' perceptions of the severity of diabetes and knowledge of diabetes (both higher amongst the parents of male adolescents), reports of adolescents' and parents' health beliefs and perceptions of treatment were not varied according to the adolescents' age.

While previous research has not reported on this issue, the lack of variation is not surprising. There is little basis for expectations of gender differences in health beliefs or perceptions of diabetes treatment.

12.1.3 The Reporting of The Proposed Antecedents of Adherence in Relation to Parents' Age.

Similarly, the lack of variation in adolescents' and parents' reports of health beliefs and perceptions of treatment according to parents' age is not unexpected. No previous studies examining adolescents with insulin dependent diabetes have examined the variation in these perceptions, but there is no theorised link between health beliefs and parental age.

12.1.4 The Reporting of The Proposed Antecedents of Adherence in Relation to Parents' Gender.

Again, adolescents' and parents' reports of health beliefs and perceptions of treatment were not varied according to parents' gender. As has been noted in previous chapters, the number of male parents involved in this study was small, so the ability of the present study to detect differences in reports according to parents' gender was limited. Previous investigations have not identified parental gender as a source of variation in health beliefs.

12.1.5 The Reporting of The Proposed Antecedents of Adherence in Relation to Parents' Work Status.

Parents employed outside of the home produced lower scores on the Subjective Norms scale than parents who were primarily at home. The reports of the adolescents of these groups of parents did not vary in this manner. Parents employed outside the home produced higher Diabetes Knowledge scores than those primarily at home, although their adolescents' diabetes knowledge was not varied. Responses on the remaining scales by adolescents and parents did not vary according to the parents' work status.

Variations in these reports were not expected. No previous studies have identified variations in health beliefs or perceptions of IDDM treatment according to parental work status. The reason for the more negative perceptions of adolescents' social

influences on adherence by parents employed outside the home than by parents at home is unclear. It is possible that this result was due to chance, or to some factor not considered in the present study. This issue could be resolved by further investigation. If replicated, this finding would suggest that this was not due to chance, and further examination of this issue could clarify the causes of this variation.

The finding that parents employed outside the home had a higher level of knowledge about diabetes treatment than parents who were at home is surprising. It may have been expected that parents who were primarily in the home were the adolescents' primary care-givers, and that they would therefore have a greater knowledge of diabetes treatment than parents employed outside the home. The finding that the reverse pattern has occurred is difficult to interpret. It should be noted that the mean levels of knowledge displayed in these groups, although statistically significantly different, were similar. However, the distribution of scores obtained by parents who were primarily at home was wider than the distribution obtained by those who worked outside the home. One possible explanation for this finding is that the parents who participated in the study who were working outside the home were more strongly motivated toward the management of their adolescents' diabetes. These parents left work to attend the clinic, whereas those parents who were primarily at home required less motivation to attend the clinics. It is possible that more motivated parents have a better understanding of diabetes treatment than less motivated parents. This issue is beyond the focus of the present study, however future investigation could clarify this point. Further, the replication of the present finding in future studies would suggest that this relationship was not due to chance alone.

12.1.6 The Reporting of The Proposed Antecedents of Adherence in Relation to Household Structure.

The final demographic characteristic by which reports of health beliefs and perceptions of treatment were examined was household structure. The only variation in reports by adolescents or parents according to this characteristic was that parents residing in dual parent households reported higher levels of support for their adolescents' adherence than single parents. This finding has not been reported in previous investigations. It is possible that this difference occurred because of the additional support for the adolescent's adherence supplied by the second parent in the household. However, this interpretation is refuted by the lack of differentiation in reports by adolescents on this measure according to household structure. An alternative interpretation is that the participating parents who resided in two-parent households reported more support for adherence as a consequence of the marital support they received, which the single parents would be unlikely to receive. This interpretation extends beyond the focus of the present study, but could be tested by future investigations.

12.2 The Level of Association Between Measures of Proposed Antecedents of Adherence, and Adherence.

This section discusses the results presented in **Section 11.2**, examining the association between the measures of proposed antecedents of adherence and the measures of adherence to medical recommendations. The associations between (1) adolescent

reports of adherence and proposed antecedents of adherence, (2) parent reports of adherence and proposed antecedents of adherence, (3) cross-informant associations between reports of proposed antecedent of adherence and reports of adherence, and (4) associations between observed blood glucose monitoring adherence and reports of proposed antecedents of adherence are discussed.

12.2.1 Adolescent Reports of Proposed Antecedents of Adherence, and Adherence.

Significant associations were detected between adolescents' reports of general and diabetes-specific adherence and (1) their perceptions of the utility of IDDM treatment, (2) their intentions to adhere to treatment, (3) their reports of supports and barriers to adherence, and (4) their health value. A significant association was detected between adolescents' reports of interpersonal aspects of their care and their general adherence, but not their diabetes-specific adherence. Significant negative associations were found between adolescents' reports of illness severity and general and diabetes-specific adherence. Adolescents' reports of Perceived Susceptibility, Subjective Norms, and Diabetes Knowledge were not associated with their reports of adherence. These findings may be interpreted in several ways.

First, the significant associations between adolescents' reports of adherence and responses on several of the measures of proposed antecedents of adherence may be interpreted in similar ways to the significant association found between the measures of adherence and parent-adolescent conflict, which were discussed in **Chapter 8**. These findings may be interpreted as indicating a genuine relationship between these

proposed antecedent factors and adolescents' medical adherence. These findings may also be interpreted in terms of a shared method variance. For example, some adolescents may have responded in socially desirable manners to each of these measures. Alternatively, some adolescents may have responded according to a tendency to give positive responses, i.e., an acquiescence bias, or yea-saying (Streiner & Norman, 1995). The likelihood of this interpretation is reduced by the finding that some of the adolescent completed measures of proposed antecedents were not significantly associated with the adolescent completed measures of adherence.

Second, the lack of significant associations between adolescents' reports of adherence and some of the measures of proposed antecedents of adherence may be interpreted in ways similar to the lack of association between the measures of adherence and adolescent autonomy, which were discussed in **Chapter 10**. These results may indicate that there is no relationship between these proposed antecedents and the adolescents' medical adherence. However, these findings may also reflect a lack of sensitivity in the measures employed. This interpretation is particularly plausible in the case of the Subjective Norms scale, for which the distribution of scores obtained by adolescents was very narrow.

The most plausible interpretation of the mixed findings relating adolescent completed measures of proposed antecedents of adherence and adolescent completed measures of adherence is that some of the proposed antecedents of adherence were in fact related to the adolescents' adherence, but other proposed antecedents were not linked to the adolescents' adherence. That is, adolescents' adherence was associated with their rapport with health professionals, their perceptions of the utility of their IDDM

treatment, their intention to adhere to their treatment in the future, and their experience of adherence supports or the absence of barriers to adherence. Adolescents' health value also appeared to be linked to their adherence. In contrast, adolescents' perceptions of their susceptibility to their diabetes, their perceptions of subjective norms for adherence, and their knowledge of their IDDM regimen, were not linked to their adherence.

12.2.2 Parent Reports of Proposed Antecedents of Adherence, and Adherence.

Parents' responses to the measures of the proposed antecedents of adherence were associated with their reports of adherence in a manner extremely consistent with adolescents' responses. Significant associations were detected between parents' reports of general and diabetes-specific adherence and (1) their perceptions of the utility of IDDM treatment, (2) their intentions to adhere to treatment, (3) their reports of supports and barriers to adherence, and (4) their health value. A significant association was detected between parents' reports of interpersonal aspects of their adolescents' care and general adherence, but not diabetes-specific adherence. A significant negative association was found between parents' reports of illness severity and general adherence but not diabetes-specific adherence. Parents' reports of Perceived Susceptibility, Subjective Norms, and Diabetes Knowledge were not associated with their reports of adherence. These findings may be interpreted in several ways.

First, the significant associations between parents' reports of adherence and responses on several of the measures of proposed antecedents of adherence may be interpreted in similar ways to the significant association found between the measures of adherence and parent-adolescent conflict, which were discussed in **Chapter 8**. These findings may be interpreted as indicating a genuine relationship between these proposed antecedent factors and adolescents' medical adherence. These findings may also be interpreted in terms of a shared method variance. These correlations may be the result of the participating parents completing these measures with a form of response bias. The likelihood of this interpretation is reduced by the finding that some of the parent completed measures of proposed antecedents were not significantly associated with the parent completed measures of adherence.

Second, the lack of significant associations between parents' reports of adherence and some of the measures of proposed antecedents of adherence may be interpreted in ways similar to the lack of association between the measures of adherence and adolescent autonomy, which were discussed in **Chapter 10**. These results may indicate that there is no relationship between these proposed antecedents and the adolescents' medical adherence. However, these findings may also reflect a lack of sensitivity in the measures employed. This interpretation is particularly plausible in the case of the Subjective Norms scale, for which the distribution of scores obtained by parents was very narrow.

The most plausible interpretation of the mixed findings relating parent completed measures of proposed antecedents of adherence and parent completed measures of adherence is that some of the proposed antecedents of adherence were in fact related

to the adolescents' adherence, but other proposed antecedents were not linked to the adolescents' adherence. The plausibility of this interpretation is further enhanced by the great consistency in associations between parent responses on these measures and adolescent responses on the same measures. That is, the same antecedent factors which were related to adherence according to adolescent responses were also related to adherence according to parent responses, and the same antecedent factors were unrelated to adherence according to both adolescent and parent reports.

According to the participating parents' reports, adolescents' adherence was associated with their rapport with health professionals, their parents' perceptions of the utility of their IDDM treatment, their parents' intention that they adhere to their treatment in the future, and their experience of adherence supports or the absence of barriers to adherence (as perceived by parents). Parents' health value also appeared to be linked to the adolescents' adherence.

In contrast, parents' perceptions of their adolescents' susceptibility to diabetes, parents' perceptions of their adolescents' subjective norms for adherence, and parents' knowledge of the IDDM regimen, were not linked to their adolescents' adherence.

12.2.3 Cross-Informant Associations Between Reports of Proposed Antecedents of Adherence, and Adherence.

Cross-informant analyses further examined the associations between reports of adherence and of proposed antecedents of adherence. As discussed in previous

chapters, these analyses provide a more stringent examination of the relationships between measures by eliminating the potential influence of respondent biases.

The first cross-informant analyses examined the associations between adolescents' responses to the measures of proposed antecedents of adherence and parents' responses to the adherence measures. These associations were extremely consistent with the within-informant associations discussed in the previous two sections.

All of the adolescent completed antecedent measures which were significantly associated with adolescent reports of adherence were also significantly associated with parent reports of adherence, although the adolescent completed Perceived Severity and Supports / Barriers measures were only significantly linked with parent reported general adherence, and the Health Value scale was only significantly related to parent reported diabetes-specific adherence. The adolescent completed antecedent measures which were not associated with adolescent completed measures of adherence were also not associated with parent completed measures of adherence.

The next cross-informant analyses examined the associations between parents' responses to the measures of proposed antecedents of adherence and adolescents' responses to the adherence measures. Again, these associations were extremely consistent with the within-informant associations discussed in the previous two sections.

The parent completed antecedent measures which were significantly associated with parent reports of adherence, were also significantly associated with adolescent reports

of adherence. The parent completed antecedent measures which were not significantly associated with parent reports of adherence, were not significantly associated with adolescent reports of adherence.

These findings strongly support the interpretation that the observed associations between some of the antecedent measures of adherence and adherence were not the result of shared method variances, but were indications of links between the assessed variables. That is, these findings support the contention that adolescents' regimen adherence was associated with (1) rapport with health professionals, (2) perceptions of the utility of their IDDM treatment, (3) intentions to adhere to treatment in the future, (4) the experience of adherence supports or the absence of barriers to adherence, and (5) the value attributed to good health by adolescents and parents. These findings further support the contention that adolescents' regimen adherence was not related to (1) perceptions of their susceptibility to diabetes, (2) perceptions of subjective norms for adherence, and (3) knowledge of their IDDM regimen.

12.2.4 Reports of Proposed Antecedents of Adherence and Observed Blood Glucose Monitoring Adherence.

Observed blood glucose monitoring adherence was less closely related to reports of the proposed antecedents of adherence. In fact, significant associations between these reports and observed BGM adherence were only detected for the Intentions to Adhere scale as completed by adolescents and parents, and the Subjective Norms scale completed by parents.

Further analysis indicated that the level of association between reports of the proposed antecedents and observed BGM adherence did not vary greatly when the time frame examined was adjusted. However, adolescents' reports of Perceived Utility and Perceived Severity were significantly associated with observed BGM adherence over the final days before Outpatient Clinic attendance. This finding could indicate that adolescents' responses to these scales were influenced by their adherence over the final days before assessment.

Other analyses revealed that most reports of proposed antecedents of adherence were not varied according to observed BGM adherence groups (Consistently High, Consistently Low, Rising, and Other BGM adherence groups). The exception to this pattern was parent reports of Intentions to Adhere, which indicated significantly greater intentions to adhere to treatment in the future amongst parents of adolescents exhibiting consistently high BGM adherence than amongst parents of adolescents exhibiting consistently low BGM adherence.

These findings are considerably different from those relating reports of proposed adherence antecedents with adolescent and parent reports of adherence. There are at least four possible explanations for these contrasting findings.

First, these findings may indicate that the results obtained relating reports of adherence with reports of proposed antecedents were in part the result of shared method variances. However, the cross-informant relationships between these reports reduce the plausibility of this interpretation. This consistency refutes the

interpretation of the non-significant associations as an indication of shared method variances.

Second, the lower levels of association between reports of proposed antecedents and observed BGM adherence than between these antecedent reports and the questionnaire measures of adherence may reflect the specific nature of the BGM adherence measure. It may be seen that for all of the analyses examining adolescent and parent reports of adherence, the level of association with the antecedent measures was greater for the GAS than for the DSAS. It is possible that the proposed antecedents of adherence are closely related to general tendencies to adhere to treatment, but less closely related to adherence to a range of specific IDDM management activities, including blood glucose monitoring.

Third, as has already been noted, the observed blood glucose monitoring adherence information only assesses adherence to one aspect of a multi-component regimen. While the proposed antecedents of adherence may be poorly related to adherence to this aspect of the IDDM management regimen, these factors may be more closely linked with adherence to other aspects of the regimen. For example, adolescents' rapport with health professionals may be more closely linked with adherence to insulin administration recommendations or dietary recommendations, than to blood glucose monitoring adherence.

A fourth interpretation of the inconsistency in associations of the proposed antecedents of adherence with the reports of adherence and the observed BGM adherence relates to the sample from which BGM data was obtained. These data were

collected from a group of adolescents with poor metabolic control. It is possible that the weaker associations found using the BGM data may be the result of a sample bias. Results of the analyses examining the association between reports of proposed antecedents of adherence and the adolescents' metabolic control provide little support for this interpretation (**Section 11.3**). Although some reports of antecedents of adherence were significantly related to adolescents' metabolic control, the patterns of association did not reflect either the associations between these antecedent measures and adolescent and parent reports of adherence or the observed BGM adherence.

12.3 The Level of Association Between Proposed Antecedents of Adherence and Adolescents' Metabolic Control.

This section discusses the results presented in **Section 11.3**, examining the relationship between reports of proposed antecedents of adherence and adolescents' level of metabolic control.

As has been discussed in regard to the assessments of adolescents' metabolic control in relation to reports of parent-adolescent conflict and adolescent autonomy, the value of these analyses is based in the conceptual link between regimen adherence and health outcomes. The relevance of this link to the analyses in this study is discussed in **Chapters 8** and **10**, and the examination of this influence is discussed in **Section 1.1.2.5** *The Relationship Between Patient Adherence and Health Status* in the Literature Review. Metabolic control is the most commonly used index of health outcomes for insulin dependent diabetes.

The initial analyses performed to examine the relationship between proposed antecedents of adherence and adolescents' metabolic control revealed associations which were generally consistent with, but weaker than, the associations between these reports of adherence antecedents and reports of adherence. The associations between adolescent and parent responses to the Interpersonal Aspects of Care, Perceived Utility, and Supports / Barriers scales, and parent responses to the Perceived Severity and Intentions to Adhere scales were significantly correlated with adolescents' metabolic control.

On the basis of these findings, further analyses were conducted which examined whether reports of proposed antecedents of adherence accounted for unique variance in metabolic control, after reports of adherence had already been entered into regression equations.

Adolescents' reports of each of the proposed antecedents were entered into hierarchical regression analyses of metabolic control, after their reports of adherence had been entered first. The addition of these reports of proposed antecedents accounted for significant additional variance in metabolic control, after the reports of general adherence were considered. In this analysis, only one proposed antecedent scale was a significant predictor in the final equation, the Supports / Barriers scale. The analysis of the addition of adolescents' reports of proposed antecedents of adherence after the reports of diabetes-specific adherence were entered into the regression of adolescents' metabolic control could not be performed, because of the lack of significant prediction of metabolic control by this measure of adherence (Cliff,

1987). Parents' reports of proposed antecedents did not significantly add to the understanding of metabolic control provided by their reports of general and diabetes-specific adherence.

Before interpreting these findings, it should be recognised that parents' reports of adherence (both general and specific) accounted for greater proportions of the variation in adolescents' metabolic control than the adolescents' reports of adherence. As such, the requirements for parents' reports of the proposed antecedents of adherence to significantly add to the predictability of metabolic control over their adherence reports was more stringent than for the adolescents' reports. With this point in mind, it appears reasonable to suggest that adolescents' reports of the proposed antecedents of adherence added to the predictability of adolescents' metabolic control established from the reports of adherence obtained from the adolescents.

This finding provides some additional support for the proposed influence of these factors on the adherence of these adolescents. However, only adolescents' reports of the presence of supports for, and the absence of barriers to, adherence added to the accountability of their metabolic control. Each of the other proposed antecedents, as reported by adolescents, and all of the proposed antecedents as reported by parents, did not add to the prediction of adolescents' metabolic control. Therefore the support for the influence of these antecedents is not strong.

12.4 Summary and Future Directions: The Relationship Between Patient Adherence and Proposed Antecedents of Adherence.

This section provides a synthesis of the findings discussed in this chapter, in light of the published literature. The implications of these findings to the wider literature and to future research are addressed.

12.4.1 The Relationship Between Patient Adherence and Proposed Antecedents of Adherence.

The findings discussed in this chapter examined the relationship between a series of proposed antecedents of adherence, derived from studies of adult patients, and adolescents' adherence. As identified by Litt and Cuskey (1980), the factors which influence medical adherence in adults may also influence the medical adherence of adolescents. The examination of the relationship of these variables with adolescents' adherence was performed to determine whether factors associated with adults' medical adherence also influenced the adherence of these adolescents. **Chapter 13** presents analyses which examine the applicability of a model of adult medical adherence to this group of adolescents, with the inclusion of factors hypothesised to influence adherence amongst adolescents in particular.

The literature examining relationships between health beliefs and regimen adherence is considerable. Some previous studies have used the Adherence Determinants Questionnaire to assess factors most frequently associated with adherence. DiMatteo, Hays, and colleagues (1993) reported on the development and validation of the

Adherence Determinants Questionnaire, in studies of the adherence of adult patients with cancer. This study also employed the General Adherence Scale and an illness specific measure of adherence to cancer-treatment recommendations. In their study, significant correlations were detected between reports of general adherence and responses to the Supports / Barriers, Intentions to Adhere, Perceived Utility, and Interpersonal Aspects of Care scales. Further, the Supports / Barriers and Intentions to Adhere scales were significantly associated with objective assessments of adherence (DiMatteo, Hays, et al. 1993).

DiMatteo, Sherbourne, and colleagues (1993) examined the adherence of groups of adult patients with diabetes, hypertension or heart disease in relation to their health beliefs and their rapport with health professionals. Illness severity was positively associated with regimen adherence, as was rapport between patients and health professionals.

Ried and Christensen (1988) found that adherence by adult female patients to drug-taking recommendations was significantly associated with their reports of the presence of supports and the absence of barriers to adherence. Further, in this study, patients' reports of intentions to adhere to treatment and perceptions of the utility of treatment were significantly related to their self-reported adherence. Patients' reports of subjective norms for adherence were not associated with their reports of adherence.

SH Kaplan and colleagues (1989) reported that rapport between patients and health professionals was associated with the patients' health outcomes. This association was

interpreted as being mediated by patient satisfaction and adherence, although these issues were not directly examined.

Studies examining the relationship between health value and regimen adherence have provided mixed results. Schlenk and Hart (1984) reported that the adherence of adults with IDDM was not strongly related to their value of health. This study used a modified version of Rokeach's (1973) value ranking list; the range of responses obtained on this measure by participants in the study was very narrow. It is likely that the findings of the Schlenk and Hart study were limited by the measure employed.

Abella and Heslin (1984) reported that adults' adherence to preventive health behaviour recommendations was strongly related to their health value, such that those who attributed a higher value to health were more adherent. This study used the same measure of health value as the study by Schlenk and Hart (1984), however, the range of responses obtained in the more recent study was wider. This greater range of responses may have caused the inconsistency in findings between the two studies.

Lau and colleagues (1986) developed and validated a measure of health value, which was used in the present study, as well as in a study by Kennedy and colleagues (1991). The study by Kennedy and colleagues reported that adherence to preventive health behaviours was mildly associated with health value. Similarly, Lonnquist and colleagues (1992) reported that health value was related to participation in preventive health behaviours.

Several studies have noted that diabetes knowledge is not directly predictive of IDDM regimen adherence or metabolic control (e.g., Auslander, Bubb, Rogge, & Santiago, 1993; Beeney & Dunn, 1990; Dunn, Beeney, Hoskins, & Turtle, 1990; McCaul, Glasgow, & Schafer, 1987). Nonetheless, knowledge of the regimen is considered a necessary prerequisite to adherence (Fotheringham & Sawyer, 1995; SB Johnson, et al. 1982).

In the present study, adolescent and parent measures of both general and diabetes-specific adherence were associated with reports of perceived treatment utility, health value, intentions to adhere in the future, and the presence of supports for or the absence of barriers to adherence. Reports of the perceived severity of illness by adolescents and parents were negatively associated with their reports of general and diabetes-specific adherence (i.e., higher adherence levels were associated with lower perceived severity). Adolescents' and parents' perceptions of the interpersonal aspects of the adolescents' medical care were associated with their reports of general adherence, but not with reports of diabetes-specific adherence. Reports by adolescents and parents of diabetes knowledge, social influences (subjective norms) on adherence, and perceptions of susceptibility to hypoglycaemia or hyperglycaemia, were not related to reports of adherence. Objective assessments of BGM adherence were associated with adolescent and parent responses to the Intentions to Adhere and Subjective Norms scales, but not to the other scales in the ADQ. Adolescents' level of metabolic control (HbA_{1c}) was associated with reports from adolescents and parents of interpersonal aspects of diabetes care, the perceived utility of diabetes treatment, and the presence of supports for adherence or absence of barriers to adherence.

The results of the present study extend on previous research in several respects.

First, these findings replicate the findings of DiMatteo, Hays, and colleagues (1993), using an adolescent sample of patients. The associations between each of the scales of the ADQ and the measures of adherence were very similar in the study by DiMatteo, Hays and colleagues (1993) and the present study: significant associations were found in both studies between the Perceived Utility, Intentions to Adhere, and Supports / Barriers scales. The previous study detected a significant association between responses to the Interpersonal Aspects of Care scale and reports of general adherence, using the General Adherence Scale; the present study also detected significant associations between responses to this scale and reports by adolescents and parents to the General Adherence Scale. Further, the present study and the study by DiMatteo, Hays, and colleagues (1993) both found that responses to the Subjective Norms and Perceived Susceptibility scales were not directly associated with reports of adherence. However, the findings of the present study differed from those of DiMatteo, Hays, and colleagues (1993) in some respects. In the present study, reports of health value were significantly associated with reports of adherence; this association was not found in the previous study. Further, the objective assessments of adherence in the two studies were associated with different ADQ scales: DiMatteo, Hays, and colleagues (1993) found associations between objective assessments of adherence and the Supports / Barriers and Intentions to Adhere scales, whereas the present study found associations with the Intentions to Adhere and Subjective Norms scales.

The very strong consistency in findings between the present study and the study by DiMatteo, Hays, and colleagues (1993) may be interpreted in two ways. The great consistency in findings may be the result of a shared bias - both studies used the same measures of general adherence (GAS) and of antecedents of adherence (ADQ). It is possible that the consistency in findings is the result of biases in these measures. This interpretation is supported by the different findings in this and the previous study regarding health value. The previous study did not find health value to be related to adherence, using a modified version of the Health Value Scale. The present study did find health value to be related to adherence, using the original Health Value Scale (see **Chapter 3**). However, the study samples in the two studies were very different: DiMatteo, Hays, and colleagues (1993) investigated adult samples of patients with various forms of cancer, using self-report measures only; whereas the present study investigated adolescents with IDDM, using adolescent self-reports as well as parent reports.

It is also possible that the consistent findings in the two studies were caused by genuine associations between factors assessed by the ADQ and regimen adherence. This possibility is supported by consistent findings in other investigations that have used other measures of adherence and its proposed antecedents (e.g., DiMatteo, Sherbourne, et al. 1993; Ried & Christensen, 1988; SH Kaplan, et al. 1989).

Second, the present study extends on previous research by assessing the relationship between factors which have been found to be associated with medical adherence in adult samples, in a sample of chronically ill adolescents. This is an important development, as previous research involving the medical adherence of adolescents has

not addressed these associations. An understanding of what factors influence adolescents' medical adherence is important to the development of strategies to improve this adherence.

Third, the findings in the present study that diabetes knowledge was not a strong influence on adherence, and that the general level of knowledge in this sample was high, is consistent with the findings of previous investigations (e.g., Auslander, et al. 1993; Beeney & Dunn, 1990; Dunn, et al. 1990; McCaul, et al. 1987). These findings suggest that patient education should not be the major focus of interventions intended to improve regimen adherence. Further, the finding that perceptions of the severity of the illness were negatively associated with adherence suggests that interventions which focus on the serious consequences of nonadherence to IDDM regimens may have a deleterious effect on adolescents' adherence. Instead, these results suggest that education and intervention should focus on positive aspects of the manageability of insulin dependent diabetes. This suggestion is consistent with findings of some other recent investigations (e.g., Aversa & Kimberlin, 1996; Dracup, et al. 1994; Gudas, Koocher, & Wypij, 1991).

In sum, the findings discussed in this chapter support the applicability of factors associated with medical adherence in adults to the investigation of adherence in adolescent patients.

12.4.2 Limitations of the Present Study and Future Directions for Investigations of the Relationship Between Patient Adherence and Proposed Antecedents of Adherence.

The discussion of the results of this study examining the relationship between the measures of the proposed antecedents of adherence and the measures of adherence has identified a number of limitations of the study, and identified several avenues for future investigation.

First, only a small number of fathers participated in this study. The need for recruitment of larger samples of fathers into research investigating their children's health care was discussed in **Chapter 8**.

Second, the finding in this study that parents who were employed outside the home reported more negative perceptions of their adolescents' social influences than parents who were primarily at home is intriguing. The replication of this finding, and the exploration of the causes of this effect, could prove valuable.

Third, the finding that parents employed outside the home had a higher level of knowledge about diabetes treatment than parents who were at home is surprising. The examination of this finding in future studies could determine (1) whether this trend is replicable, and (2) what other factors influence this trend. It is possible that parents who leave paid employment to attend Outpatient Clinics are more motivated toward their child's health-care than parents who leave home to attend these clinics. This issue could be a fruitful avenue for future investigation.

Fourth, the finding that parents in two-parent households perceived greater support for their adolescent children's adherence than parents in single-parent households deserves further investigation. Whether this variation was influenced by parents' experience of marital support or some other influence could not be determined in the present study.

Finally, the findings presented in this chapter have examined a series of factors related to adherence amongst adults, using an adolescent sample. This examination should be replicated in further investigations of adolescents with conditions other than IDDM, to determine whether the consistency in results found between the present study and previous research is influenced by the diagnostic group under scrutiny. For example, it is possible that the adherence of adolescents with asthma or cystic fibrosis may not be influenced by these factors. This issue deserves further examination.

CHAPTER THIRTEEN.

RESULTS: THE MULTIVARIATE PREDICTION OF PATIENT ADHERENCE.

This chapter examines the relationship between measures of adolescents' adherence and measures of all of the variables hypothesised in this thesis to relate to adherence. These variables include: parent-adolescent conflict, adolescent autonomy, and each of the proposed antecedents of adherence. The multivariate analyses presented in this chapter build on the bivariate analyses reported in previous chapters. This chapter consists of three sections. First, adolescents' and parents' reports of adherence are examined in relation to the variables of the Six-Factor Model of Adherence. Second, analyses are presented which assess the improvement of this model for adolescent adherence by the addition of measures of parent-adolescent conflict and adolescent autonomy. Third, adolescents' metabolic control and the reports of their adherence are examined in relation to the predictor variables assessed in this study, without the constraints of a heuristic model, to determine the closest prediction of adherence and metabolic control by these measures.

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13 RESULTS: THE MULTIVARIATE PREDICTION OF PATIENT ADHERENCE.

13.1 Evaluation of the Six-Factor Model of Adherence.

The analyses presented in this section were designed to examine the association between the measures of adherence to medical recommendations and the combined measures of the proposed antecedents of adherence (i.e., the Six-Factor Model of Adherence). The heuristic framework of the SFMA is provided by Gritz and colleagues (1989); this framework is illustrated in **Figure 1.5**. Separate analyses examining the associations between these variables were conducted for adolescent and parent reports.

13.1.1 Adolescent Reports of Adherence and Factors of the Six-Factor Model of Adherence.

Hierarchical multiple regression analyses (HMRAs) were performed with adolescents' reports of adherence as the dependent measures, and adolescents' responses to the scales of the Adherence Determinants Questionnaire, the Health Value Scale and the Diabetes Knowledge Questionnaire as the independent variables. These analyses were performed separately for adolescents' general (GAS) and diabetes-specific (DSAS) adherence reports.

The first step of the regression equations involved the entry of reports of Supports / Barriers, as these were defined by Gritz and colleagues (1989) as having the most direct influence on adherence (*Step 1,* **Figure 13.1**; see Tabachnick & Fidell (1989) for a discussion of this methodology). Hierarchical blocks were then entered into the regression equation in order of proximity of theorised effect on adherence. The improvement of the prediction of adherence by the addition of reports of Intentions to Adhere (*Step 2*), followed by health beliefs (*Step 3*; including Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms, and Health Value), and then Interpersonal Aspects of Care and Diabetes Knowledge (*Step 4*) was assessed.

Tables 13.1 and **13.2** display the Beta coefficients of each variable at its point of entry, the R^2 for each Step of the regression, as well as the change in R^2 caused by the entry of each block (i.e., each Step), and the results of the test of significance of this change. **Tables 13.1** and **13.2** report this information for the prediction of adolescent responses to the GAS and DSAS, respectively.

Prediction of Adolescents' Reports of General Adherence (GAS).

At *Step 1*, with Supports / Barriers in the equation, R^2 was significantly predicted; so further tests were made (**Table 13.1**). In *Step 2*, the addition of Intentions to Adhere into the regression equation, resulted in a significant increment in R^2. At *Step 3*, the entry of a block of health belief variables (Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms, and Health Value), resulted in a further

significant increment in R^2. The addition of the fourth block of variables, Interpersonal Aspects of Care and Diabetes Knowledge, did not improve R^2.

Prediction of Adolescents' Reports of Diabetes-Specific Adherence (DSAS).

At *Step 1*, with Supports / Barriers in the equation, R^2 was significantly predicted; so further tests were made (**Table 13.2**). In *Step 2*, the addition of Intentions to Adhere into the regression equation, resulted in a significant increment in R^2. At *Step 3*, the entry of a block of health belief variables (Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms, and Health Value), resulted in a further significant increment in R^2. The addition of the fourth block of variables, Interpersonal Aspects of Care and Diabetes Knowledge, did not improve R^2. At each step of this regression, the level of prediction afforded by the independent variables was smaller than that obtained in the analysis examining adolescents' reports of general adherence.

13.1.2 Parent Reports of Adherence and Factors of the Six-Factor Model of Adherence.

Hierarchical multiple regressions were next performed with parents' reports of adherence as the dependent measures, and parents' responses to the scales of the Adherence Determinants Questionnaire, the Health Value Scale and the Diabetes Knowledge Questionnaire as the independent variables. These analyses were

performed separately for parents' general (GAS) and diabetes-specific (DSAS) adherence reports.

These analyses followed the same framework as the analyses examining adolescents' responses to these measures, illustrated in **Figure 13.1**. **Tables 13.3** and **13.4** report the results of these analyses, examining parent reports of general adherence and diabetes-specific adherence, respectively.

Prediction of Parents' Reports of General Adherence (GAS).

At *Step 1*, with Supports / Barriers in the equation, R^2 was significantly predicted; so further tests were made (**Table 13.3**). In *Step 2*, the addition of Intentions to Adhere into the regression equation, resulted in a significant increment in R^2. The addition of a third block of variables, measuring health beliefs (Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms, and Health Value), did not result in a significant increment in R^2. In light of the lack of predictive power in the third block, the fourth block was not entered into the equation (Cliff, 1987).

Prediction of Parents' Reports of Diabetes-Specific Adherence (DSAS).

At *Step 1*, with Supports / Barriers in the equation, R^2 was significantly predicted; so further tests were made (**Table 13.4**). In *Step 2*, the addition of Intentions to Adhere into the regression equation, resulted in a significant increment in R^2. At *Step 3*, the entry of a block of health belief variables (Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms, and Health Value), did not result in a

further significant increment in R^2, so no further variables were entered into the regression equation (Cliff, 1987).

In parallel with the adolescent HMRAs, at each step of the regression of parents' DSAS responses the level of prediction afforded by the independent variables was smaller than that obtained in the analysis examining parents' reports of general adherence.

13.2 Evaluation of the Six-Factor Model of Adherence With the Addition of Adolescent Variables.

The analyses presented in this section were designed to examine the possible improvement in the prediction of adherence by the addition of two aspects of adolescent functioning to the factors of the Six-Factor Model of Adherence; parent-adolescent conflict and adolescent autonomy. Separate analyses examining the associations between these variables were conducted for the adolescent and parent reports.

13.2.1 Adolescent Reports of Adherence, Parent-Adolescent Conflict, Adolescent Autonomy and Factors of the Six-Factor Model of Adherence.

Hierarchical multiple regressions were performed using adolescents' reports of adherence as the dependent measures, and adolescents' responses to the scales of the Adherence Determinants Questionnaire, the Health Value Scale, the Diabetes

Knowledge Questionnaire, the Conflict Behavior Questionnaire and the subscales of the Autonomous Functioning Checklist as the independent variables. These analyses were performed separately for adolescents' general (GAS) and diabetes-specific (DSAS) adherence reports.

The framework defined by Gritz and colleagues (1989), employed in the analyses detailed in **Section 13.1**, was modified to include the reports of parent-adolescent conflict and adolescent autonomy. In the current analyses, as in the previous analyses, adolescents' reports of adherence were first regressed with their reports of Supports / Barriers to adherence (*Step 1*). The second block of variables entered into the regression differed in these analyses: reports of Intentions to Adhere were entered along with reports of parent-adolescent conflict and responses to each of the subscales of the AFC (Self- and Family-Care, Management Activity, Recreational Activity, and Social / Vocational Activity). The decision was made to enter the conflict and autonomy variables at this point in the regression because these variables were expected to have a more direct influence on adherence than the health belief variables. These variables were expected to have a similar influence on adolescents' adherence as intentions to adhere. Therefore these variables were included in the second step of the regression. The third and fourth blocks of these hierarchical regression analyses were the same as those detailed in **Section 13.1**: In the third step, measures of health beliefs (Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms, and Health Value) were entered, followed by Interpersonal Aspects of Care and Diabetes Knowledge (*Step 4*). This process is illustrated in **Figure 13.2**.

Tables 13.5 and **13.6** report the results of these analyses, examining adolescent reports of general adherence and diabetes-specific adherence, respectively.

Prediction of Adolescents' Reports of General Adherence (GAS).

At *Step 1*, with Supports / Barriers entered into the regression equation, R^2 was significantly predicted; so further tests were made (**Table 13.5**). In *Step 2*, the addition of Intentions to Adhere, the Conflict Behavior Questionnaire, and the subscales of the Autonomous Functioning Checklist (Self- and Family-Care, Management Activity, Recreational Activity, and Social / Vocational Activity) into the regression equation, resulted in a significant increment in R^2. At *Step 3*, the entry of the block of health belief variables (Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms, and Health Value), resulted in a further significant increment in R^2. The addition of the fourth block of variables, Interpersonal Aspects of Care and Diabetes Knowledge, did not improve R^2.

Prediction of Adolescents' Reports of Diabetes-Specific Adherence (DSAS).

At *Step 1*, with Supports / Barriers in the equation, R^2 was significantly predicted; so further tests were made (**Table 13.6**). In *Step 2*, the addition of Intentions to Adhere, the Conflict Behavior Questionnaire, and the subscales of the Autonomous Functioning Checklist (Self- and Family-Care, Management Activity, Recreational Activity, and Social / Vocational Activity) into the regression equation, resulted in a significant increment in R^2. At *Step 3*, the entry of the block of health belief variables (Perceived Utility, Perceived Severity, Perceived Susceptibility, Subjective Norms,

and Health Value), resulted in a further small but significant increase in R^2. The addition of the fourth block of variables, Interpersonal Aspects of Care and Diabetes Knowledge, did not improve R^2 significantly. Like the analyses reported in **Section 13.1.1**, at each step of this regression, the level of prediction afforded by the independent variables was smaller than that obtained in the analysis examining adolescents' reports of general adherence.

13.2.2 Parent Reports of Adherence, Parent-Adolescent Conflict, Adolescent Autonomy and Factors of the Six-Factor Model of Adherence.

Hierarchical multiple regressions were next performed with parents' reports of adherence as the dependent measures, and parents' responses to the scales of the Adherence Determinants Questionnaire, the Health Value Scale, the Diabetes Knowledge Questionnaire, the Conflict Behavior Questionnaire and the subscales of the Autonomous Functioning Checklist as the independent variables. These analyses were performed separately for parents' general (GAS) and diabetes-specific (DSAS) adherence reports.

These analyses followed the same framework as the analyses examining adolescents' responses to these measures. **Tables 13.7** and **13.8** report the results of these analyses, examining parent reports of general adherence and diabetes-specific adherence, respectively.

Prediction of Parents' Reports of General Adherence (GAS).

At *Step 1*, with Supports / Barriers in the equation, R^2 was significantly predicted; so further tests were made (**Table 13.7**). At *Step 2*, the addition of Intentions to Adhere, the Conflict Behavior Questionnaire, and the subscales of the AFC into the regression equation, resulted in a significant increment in R^2. The addition of the third block of variables, measuring health beliefs, did not result in a significant increment in R^2. In light of the lack of predictive power in the third block, the fourth block was not entered into the equation (Cliff, 1987).

Prediction of Parents' Reports of Diabetes-Specific Adherence (DSAS).

At *Step 1*, with Supports / Barriers in the equation, R^2 was significantly predicted; so further tests were made (**Table 13.8**). In *Step 2*, the addition of Intentions to Adhere, the Conflict Behaviour Questionnaire, and the subscales of the Autonomous Functioning Checklist into the regression equation resulted in a significant increment in R^2. At *Step 3*, the entry of the block of health belief variables did not result in a further significant increment in R^2, so no further variables were entered into the regression equation (Cliff, 1987).

13.3 The Maximal Prediction of Adherence and Metabolic Control.

The analyses presented in this section were designed to determine the best possible prediction of adolescents' adherence and metabolic control on the basis of the reports collected from the adolescents and their parents in this study.

13.3.1 The Maximal Prediction of Reported Adherence.

The analyses presented in this section, unlike the previous analyses reported in this chapter, were not constrained by a heuristic model. As such, the analyses presented in this section involved Stepwise Multiple Regressions, not Hierarchical Multiple Regressions, because the former type of regression analysis is appropriate for exploratory analysis where the goal is the maximal prediction of the dependent variable (Cliff, 1987; WL Hays, 1988; Nunnally & Bernstein, 1994; Tabachnick & Fidell, 1989). In Stepwise Multiple Regression Analysis, the equation "starts out empty and independent variables are added one at a time if they meet statistical criteria, but they may also be deleted at any step where they no longer contribute significantly to regression[1] ... stepwise regression is considered the surest path to the best prediction equation" (Tabachnick & Fidell, 1989, p 147).

[1] In the SMRAs presented in this chapter, the significance criterion for entry into the equation was $p < 0.05$, and for removal from the equation was $p > 0.1$.

The Maximal Prediction of Adolescents' Reports of General Adherence.

The first Stepwise Multiple Regression Analysis (SMRA) examined the prediction of adolescents' reports of general adherence. The predictor variables included in this analysis were those measures that had revealed significant bivariate associations with reported adherence in the analyses reported in previous chapters. Specifically, adolescent reports of parent-adolescent conflict, recreational autonomy, Interpersonal Aspects of Care, Perceived Utility of treatment, Perceived Severity, Intentions to Adhere, Supports / Barriers, and Health Value were regressed against reports of general adherence. This analysis accounted for a significant proportion (57.0 %) of the variance in adherence reports (F (2,122) = 19.04, $p < 0.0001$). The significant predictors of adolescents' reports of general adherence were Perceived Utility, Supports / Barriers, and Health Value (**Table 13.9**).

The Maximal Prediction of Adolescents' Reports of Diabetes-Specific Adherence.

The second SMRA examined the prediction of adolescents' reports of diabetes-specific adherence. The predictor variables included in this analysis were the same as those in the previous analysis. This analysis also accounted for a significant proportion (40.0 %) of the variance in adherence reports (F (2,122) = 11.44, $p <$ 0.0001). The significant predictors of adolescents' reports of diabetes-specific adherence were recreational autonomy and intention to adhere in the future (**Table 13.10**).

The Maximal Prediction of Parents' Reports of General Adherence.

The third SMRA examined the prediction of parents' reports of general adherence. The predictor variables included in this analysis were the same as those in the previous analyses, with the exception of recreational autonomy, which was excluded from this analysis because parent reports on this measure were not associated with the parents' adherence reports. This analysis accounted for a significant proportion (58.8 %) of the variance in adherence reports (F (2,122) = 64.47, $p < 0.0001$). The significant predictor of parents' reports of general adherence was intention to adhere in the future (**Table 13.11**).

The Maximal Prediction of Parents' Reports of Diabetes-Specific Adherence.

The fourth SMRA examined the prediction of parents' reports of diabetes-specific adherence. The predictor variables included in this analysis were the same as those in the previous analysis. This analysis accounted for a significant proportion (41.1 %) of the variance in adherence reports (F (2,122) = 24.76, $p < 0.0001$). The significant predictor of parents' reports of diabetes-specific adherence was intention to adhere in the future (**Table 13.12**).

13.3.2 The Maximal Prediction of Metabolic Control.

The final analysis presented in this thesis examined the prediction of adolescents' metabolic control on the basis of the reports obtained from adolescents and parents.

The reports employed as predictor variables in this regression were the reports of adherence and all other reports that had revealed significant bivariate associations with the adolescents' metabolic control in the analyses reported in previous chapters. Specifically, adolescent reports of Interpersonal Aspects of Care, Perceived Utility, and Supports / Barriers, parent reports of Management Activity, Interpersonal Aspects of Care, Perceived Utility, Perceived Severity, Intentions to Adhere, and Supports / Barriers, and combined reports of parent-adolescent conflict were regressed against the adolescents' metabolic control. This analysis accounted for a significant proportion (48.4 %) of the variance in metabolic control (F (3,119) = 12.11, $p < 0.0001$). The significant predictors of adolescents' metabolic control in this regression were parents' reports of management autonomy, parents' reports of perceived severity of diabetes, and adolescents' reports of supports and barriers to adherence (**Table 13.13**).

CHAPTER FOURTEEN.

DISCUSSION: THE MULTIVARIATE PREDICTION OF PATIENT ADHERENCE.

This chapter discusses the results presented in ***Chapter 13****, describing the relationship between measures of adolescents' adherence and measures of each of the variables hypothesised in this thesis to relate to adherence. In parallel with* ***Chapter 13****, the sections of this chapter address: (1) adolescents' and parents' reports of adherence in relation to the variables of the Six-Factor Model of Adherence; (2) the improvement of this model for adolescent adherence by the addition of measures of parent-adolescent conflict and adolescent autonomy; and (3) the maximal prediction of adherence and metabolic control from the predictor variables assessed in this study.*

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14 DISCUSSION: THE MULTIVARIATE PREDICTION OF PATIENT ADHERENCE.

14.1 Evaluation of the Six-Factor Model of Adherence.

This section discusses the results presented in **Section 13.1**, examining the association between the measures of adherence to medical recommendations and the combined measures of the proposed antecedents of adherence. The heuristic framework of the SFMA is provided by Gritz and colleagues (1989).

The SFMA was first described by DiMatteo and DiNicola (1982). The framework for this model is illustrated in **Figure 1.5**, based on the structure described by Gritz and colleagues (1989). The construction of the hierarchical regression analyses used in this study to test this model is illustrated in **Figure 13.1**. As may be seen from this figure, there is at least one limitation to this analysis. Previous adherence, which is included as part of the model, is not assessed in this study, and so this test is not complete. It may be argued that the adolescents' level of metabolic control is an index of their previous adherence. However, as discussed in **Section 1.1.2.1** of the *Literature Review*, biological assays make poor indicators of adherence. Although adherence is often a strong predictor of metabolic control in insulin dependent diabetes, other factors may influence these assays; metabolic control is a measure of biological functioning, not of behaviour (Dunbar, 1980). Previous adherence could be assessed using a longitudinal design; this form of assessment is outside the scope of this thesis. However, the author is examining adherence over a period of 19 months, as part of another study of adolescents' adherence to IDDM self-care

recommendations. This longitudinal study will allow the examination of previous adherence in a sample of adolescents with IDDM (Taylor, et al. 1996, 1997).

Despite this limitation, the examination of the applicability of the heuristic structure of the SFMA to the adherence of the adolescents involved in this study was considered to be of value. These analyses examined adolescents' and parents' reports separately. Hierarchical Multiple Regression Analyses (HMRAs) were used to examine the prediction of adherence reports by the variables of the SFMA, entered according to the structure of the model. Hierarchical analyses were employed because these analyses are the most appropriate form of multiple regression to test the structure of theoretical models (Cliff, 1987; WL Hays, 1988; Nunnally & Bernstein, 1994; Tabachnick & Fidell, 1989). This form of regression examines the prediction of a dependent variable according to the predictive variables of a theory, *in accordance to the relational structure defined by the theory* (Tabachnick & Fidell, 1989)[1].

It should be noted that the analyses discussed in this chapter only examined adolescents' and parents' reports of adherence; the objective blood glucose monitoring adherence data were not included in these analyses. This decision was made for two reasons. First, as discussed in **Chapters 3** and **4**, these data were only collected from a subsample of 75 of the adolescents involved in the study. The regressions reported in **Chapter 13**, and discussed in this chapter examine as many as 14 predictor variables. Norman and Streiner (1994) recommend for multiple regression analyses that the number of cases examined "be a minimum of 5 or 10 times the number of

variables entered into the equation" (p 116). Tabachnick and Fidell (1989) suggest that the regression's "power may be unacceptably low no matter what the case-to independent variables ratio if you have fewer than 100 cases" (p 128-9). In light of these recommendations, the sample of adolescents from whom BGM adherence data was obtained was considered to be too small. Second, as discussed in **Chapter 4**, the adolescents from whom the BGM adherence data were obtained differed from those who did not provide this information in terms of their (poorer) metabolic control. In light of this consideration, the analysis of this data could be expected to provide different information than was the focus of this chapter and of the previous chapter.

14.1.1 Adolescent Reports of Adherence and Factors of the Six-Factor Model of Adherence.

The findings of the analysis of the variation in adolescent reported general adherence according to the variables of the SFMA provide partial support for the structure of the model. The first three steps of the regression provided statistically significant increases in the prediction of variance in reported adherence. These steps included the entry of the supports and barriers to adherence, intentions to adhere, health beliefs (i.e., Perceived Utility, Perceived Severity, Perceived Susceptibility), social norms and health value aspects of the model. However, the final step of the regression (interpersonal aspects of care) did not add to the prediction of adolescents' general adherence reports. According to Gritz and colleagues' (1989) description of the

[1] It is recognised that other statistical procedures, such as Structural Equation Modeling, could also be considered appropriate for this analysis (e.g., Bollen, 1989; Goldberger & Duncan, 1973). However, in this thesis hierarchical regression analyses were chosen to examine these relations.

model, interpersonal aspects of care, including communication of information (i.e., patients' regimen knowledge), is a "critical prerequisite" to adherence (p 712).

Further, the overall level of variance in adolescents' reports of adherence accounted for by this regression was not large[2]. In this analysis, the variables of the SFMA predicted less than 40 % of the variance in adolescents' reports of general adherence. Although this result is not very high, it does compare favourably with the findings reported by DiMatteo, Hays, and colleagues (1993), who used the same measures. These authors reported that these measures of the variables of the SFMA, with the addition of a measure of previous adherence, accounted for around 25 % of the variance in adherence to a range of different cancer treatment regimens in adults.

In the present analysis of the prediction of variance of adolescents' general adherence ratings, the Supports / Barriers and Health Value scales were significant predictors of general adherence in the final equation. These findings are similar to those reported by DiMatteo, Hays, and colleagues (1993), who also found that the Supports / Barriers scale was the greatest predictor of reported adherence in their multivariate analyses. The findings of DiMatteo, Hays and colleagues (1993) differed from those of the present study in that the previous study did not find Health Value to be a close predictor of reported adherence. However, in the previous study Health Value was measured using a modified version of the Health Value Scale, with two additional items (see **Section 4.2.3.2**). This modified version appeared to be a less accurate

[2] Cohen (1988) recommends the following conventions for the description of multiple regression effect sizes: small, $R^2 = 0.02$; medium, $R^2 = 0.13$; large, $R^2 = 0.51$.

predictor of adherence than the original scale devised by Lau and colleagues (1986). The present study used the original form of the Health Value Scale.

The findings of the analysis of the variation in adolescent reported diabetes-specific adherence according to the variables of the SFMA also provide partial support for the structure of the model. Again, the first three steps of the regression provided statistically significant increases in the prediction of variance in reported adherence, and the final step of the regression did not significantly increase this prediction. Overall, the amount of variance accounted for by the variables of the SFMA was smaller in the present analyses than in the analysis of adolescents' reports of general adherence. In this regression, the model variables accounted for approximately one quarter of the variance in adolescents' reports of diabetes-specific adherence.

The level of prediction afforded by each step of the regression was more consistent in the analysis of DSAS responses than in the analysis of responses to the GAS. In the analysis accounting for responses to the DSAS, each of the first three steps accounted for around 7 or 8 % of the variance in adherence reports. In the analysis accounting for responses to the GAS, the first step (Supports / Barriers) accounted for almost 25 % of the variance, and was improved by around 6 % in the subsequent two steps.

The moderately large effect size of the regression of adolescents' DSAS responses is consistent with the findings reported by DiMatteo, Hays, and colleagues (1993) examining the reports of adherence to specific aspects of a series of cancer control regimens, which involved the regression of the same SFMA variables.

Interestingly, adolescents' responses to the Perceived Susceptibility scale were a significant predictor of their responses to the DSAS in this multivariate analysis. This result differs from the findings examining responses to the GAS, in which Supports / Barriers and Health Value were the significant predictors.

14.1.2 Parent Reports of Adherence and Factors of the Six-Factor Model of Adherence.

The findings of the analysis of the variation in parents' reports of adherence according to the variables of the Six-Factor Model of Adherence provide less support for this model. The regressions of parents' responses to the General Adherence Scale and Diabetes Specific Adherence Scale were halted at the third step, due to the absence of significant changes in the proportion of variance in GAS and DSAS responses accounted for by the independent variables with the entry of the variables of this step. That is, the addition of the health beliefs, social norms, and health value variables did not improve the prediction of parents' reports of adherence over the prediction afforded by the supports / barriers and intentions to adhere variables (*Steps 1 & 2*). In light of this finding, the interpersonal aspects of care variables (*Step 4*) were not entered into the regression. This requirement is one of the basic assumptions of hierarchical regression analysis (Cliff, 1987).

This does not imply that the variables of the SFMA were unrelated, or poorly related, to parents' reports of adherence. The Supports / Barriers scale accounted for 20 % of the variance in GAS reports, and 9 % of the variance in DSAS reports. The Intentions

to Adhere scale accounted for a further 17 % of the variance in GAS responses and another 10 % of the variance in parents' response to the DSAS. However, the entry of the third step of the regression did not greatly improve on this level of predictive power.

The lack of improvement in the prediction of parents' adherence reports by the addition of their reports of health beliefs does not stem from poor associations between these variables and the adherence reports. As reported in **Chapter 11**, the bivariate associations between these measures and the adherence measures were, in general, moderately strong. Instead, the lack of significant improvement in prediction of adherence reports by the entry of the third block of variables in these HMRAs stems from the tendency toward multicollinearity in the predictor variables, that is, some of these variables were highly correlated. **Appendices H.1** and **H.2** contain the correlations between responses to each of these scales by adolescents and parents. The correlations between these variables means that variables entered into the regression at a later point did not account for unique variance in adherence. Although this result does not refute the influence of the variables of the SFMA on adherence, it does not support the structure of the model.

14.2 Evaluation of the Six-Factor Model of Adherence With the Addition of Adolescent Variables.

Because of the mixed support for the structure of the Six-Factor Model of Adherence provided by the analyses in **Section 13.1**, the decision was made to proceed with

further analyses. These analyses examined the accountability of variation in reports of adherence according to the variables of the SFMA with the addition of parent-adolescent conflict and adolescent autonomy variables. This section discusses the findings of these analyses, which were presented in **Section 13.2**.

Again, these analyses examined adolescents' and parents' reports separately. Hierarchical Multiple Regression Analyses were again used to examine the prediction of adherence reports. The new variables in the regression, parent-adolescent conflict and adolescent autonomy, were entered into the regression at the second step, that is, at the same point as the Intentions to Adhere variable of the SFMA (**Figure 13.2**).

14.2.1 Adolescent Reports of Adherence, Parent-Adolescent Conflict, Adolescent Autonomy and Factors of the Six-Factor Model of Adherence.

The findings of the analysis of the variation in adolescent reported general adherence according to the variables of the SFMA with the addition of parent-adolescent conflict and adolescent autonomy support the inclusion of these later variables. Overall, the level of prediction of adolescents' general adherence reports was similar to, but slightly greater than, that discussed in **Section 14.1**. Again, the first three steps of the regression significantly improved the prediction of adolescents' general adherence reports over that afforded by the previous step. However, in the analysis involving parent-adolescent conflict and adolescent autonomy in the second step, the improvement in the proportion of variance in GAS scores explained by the regression rose by almost 12 %, compared with an improvement of only 5 % in the equivalent

analysis which did not include conflict or autonomy variables. The third and fourth steps of the equation provided similar increments in improvement of prediction of adolescents' general adherence reports in the equations including and excluding the conflict and autonomy reports.

Overall, the level of prediction of adolescents' general adherence ratings afforded by the modified model accounted for over 42 % of the variance in these reports. By comparison, the variables of the SFMA alone (i.e., without the conflict or autonomy variables) accounted for 37 % of this variance. This result compares favourably with previous studies examining the multivariate prediction of IDDM adherence in groups of adolescent patients. For example, two studies by Hanson and colleagues (Hanson, et al. 1987a; Hanson, De Guire, et al. 1992) using a variety of family relations and psychosocial functioning variables, were able to account for only 17 % and 19 % of the variances in adherence self-reports.

As discussed in **Section 14.1.1**, the significant predictors of adolescents' reports of general adherence in the final regression of SFMA variables were supports and barriers to adherence and health value. In the regression of adolescents' reports of adherence with the SFMA variables and parent-adolescent conflict and adolescent autonomy, the significant predictors were again supports and barriers to adherence and health value, as well as recreational autonomy. As reported in **Chapter 9**, adolescents' reports of recreational autonomy (i.e., the Recreational Activity subscale of the AFC) were the only adolescent reports of autonomy that were significantly correlated with the adolescents' reports of adherence. However, this correlation was

smaller than the correlation, reported in **Chapter 7**, between adolescents' reports of conflict with their parents and their reports of adherence.

The explanation for the lack of a significant prediction of adolescents' general adherence reports by their reports of parent-adolescent conflict in the multivariate analyses lies in the correlation of these conflict reports with the adolescents' responses to the scales measuring variables in the SFMA. That is, as reported in **Appendix H.3**, adolescents' conflict reports were significantly correlated with their responses to most of the subscales of the ADQ. In particular, adolescents' responses to the CBQ and the Supports / Barriers and Intentions to Adhere scales were significant. Given the influence of these variables on the regression equation, the association of CBQ scores with these scales meant that CBQ scores did not account for unique variance in reports of adherence (Tabachnick & Fidell, 1989). Another way to look at this relationship is to say that the bivariate association between adolescents' reports of general adherence and parent-adolescent conflict was significant, but that when the variables of the SFMA were controlled for, the effect of this relationship was stifled (PA Baghurst, personal communication, 22 December, 1997).

The finding that recreational autonomy was a significant predictor of general adherence in the multivariate analysis provides some support for the second hypothesis of this thesis. This finding adds further weight to the suggestion made in **Chapter 10**, that although the measures of autonomy used in this study did not have strong bivariate relationships with the measures of adherence, the issue of autonomy is worthy of further investigation in relation to adolescents' adherence.

The findings of the analysis of the variation in adolescent reported diabetes-specific adherence according to the variables of the SFMA with the addition of parent-adolescent conflict and adolescent autonomy further support the inclusion of the additional variables. The overall level of prediction of adolescents' diabetes-specific adherence reports was slightly greater than that discussed in **Section 14.1.1**. Again, the first three steps of the regression significantly improved the prediction of adolescents' general adherence reports over that afforded by the previous step. However, in the analysis involving parent-adolescent conflict and adolescent autonomy in the second step, the improvement in the proportion of variance in DSAS scores explained by the regression rose by 14 %, compared with an improvement of less than 8 % in the equivalent analysis which did not include conflict or autonomy variables. The third and fourth steps of the equation provided similar increments in improvement of prediction of adolescents' diabetes-specific adherence reports in the equations including and excluding the conflict and autonomy reports.

Overall, the level of prediction of adolescents' diabetes-specific adherence ratings afforded by the modified model accounted for 32 % of the variance in these reports. By comparison, the variables of the SFMA alone (i.e., without the conflict or autonomy variables) accounted for less than 24 % of this variance. This result also compares favourably with the level of prediction of adherence self reports achieved by Hanson and colleagues in two separate investigations (Hanson, et al. 1987a; Hanson, De Guire, et al. 1992).

As discussed in **Section 14.1.1**, the significant predictor of adolescents' reports of diabetes-specific adherence in the final regression of SFMA variables was perceived

susceptibility. In the regression of adolescents' reports of diabetes-specific adherence with SFMA variables and parent-adolescent conflict and adolescent autonomy, the significant predictors were perceived susceptibility and recreational autonomy. Again, adolescents' reports of parent-adolescent conflict, which demonstrated strong bivariate correlations with reported adherence in **Chapter 7**, were not significant predictors of adherence when the variables of the SFMA were controlled.

The finding that recreational autonomy was a significant predictor of diabetes-specific adherence in the multivariate analysis provides further support for the suggestion that adolescents' autonomy is an issue worthy of further investigation in relation to their adherence.

14.2.2 Parent Reports of Adherence, Parent-Adolescent Conflict, Adolescent Autonomy and Factors of the Six-Factor Model of Adherence.

The findings of the analysis of the variance in parent reported general adherence according to the variables of the SFMA with the addition of parent-adolescent conflict and adolescent autonomy provide little support for the inclusion of these later variables. Overall, the level of prediction of parents' general adherence reports was similar to that discussed in **Section 14.1.2**. Again, the first two steps of the regression significantly improved the prediction of parents' general adherence reports. In the analysis that involved only the variables of the SFMA, the second step of the hierarchical regression accounted for 17 % of the variance in adherence reports above that accounted for by the previous step. In the new analysis, involving the variables of

the SFMA as well as parent-adolescent conflict and adolescent autonomy, the second step (which included these additional variables) accounted for 18 % of the variance above that afforded by the first step. The inclusion of parent-adolescent conflict and adolescent autonomy in the regression therefore provided a very marginal improvement in the prediction of parents' reports of general adherence.

Overall, the level of prediction of parents' general adherence ratings afforded by the modified model when the regression was halted accounted for 39 % of the variance in these reports. By comparison, the variables of the SFMA alone (i.e., in the regression that did not include conflict or autonomy variables) accounted for 37 % of this variance. Again, this result compares favourably with previously published studies that have examined the multivariate prediction of adolescents' IDDM adherence (e.g., Hanson, et al. 1987a; Hanson, De Guire, et al. 1992; Ried & Christensen, 1988). Further, this level of prediction compares favourably with the level of prediction achieved in some larger studies of groups of adult patients (e.g., DiMatteo, Hays, et al. 1993; Sherbourne, et al. 1992).

Parents' reports of conflict and autonomy were not among the significant predictors of general adherence in the final regression involving these variables. The same variables were found to be significant predictors of parents' general adherence reports in the regression equations involving and not involving conflict and autonomy; these were supports / barriers to adherence and intentions to adhere.

Parents' reports of parent-adolescent conflict displayed strong, significant bivariate correlations with the parent reports of adherence, as was identified in **Chapter 7**. The

finding that these reports of conflict were not significant predictors of adherence in the multivariate analyses is worthy of examination.

Like the adolescent reports of parent-adolescent conflict, the parent reports of parent-adolescent conflict were correlated with these respondents' responses to many of the scales of the Adherence Determinants Questionnaire. Particularly strong associations were detected between parents' responses to the Conflict Behavior Questionnaire and the Intentions to Adhere and Supports / Barriers scales of the ADQ (**Appendix H.4**). These scales were the first predictor variables entered into the hierarchical regression involving the conflict scores. As such, although the parents' reports of conflict would have accounted for a proportion of the variance in adherence ratings (based on the bivariate association), this variance was not unique. The Supports / Barriers and Intentions to Adhere scales had already been entered into the regression, and their close correlation with the conflict score prevented this later variable from predicting unique variance in adherence reports (Tabachnick & Fidell, 1989).

Like the adolescents' reports discussed in **Section 14.2.1**, these reports could also be described so that the bivariate association between the parents' reports of general adherence and parent-adolescent conflict was significant, but that when the variables of the SFMA were controlled for, the effect of this relationship was stifled (PA Baghurst, personal communication, 22 December, 1997).

The findings of the analysis of the variation in parent reported diabetes-specific adherence according to the variables of the SFMA with the addition of parent-adolescent conflict and adolescent autonomy provide support for the inclusion of the

additional variables. The overall level of prediction of parents' diabetes-specific adherence reports was greater than that discussed in **Section 14.1.2**. Again, the first two steps of the regression significantly improved the prediction of parents' general adherence reports over that afforded by the previous step. However, in the analysis involving parent-adolescent conflict and adolescent autonomy in the second step, the improvement in the proportion of variance in DSAS scores explained by the regression rose by 18 %, compared with an improvement of less than 10 % in the equivalent analysis which did not include conflict or autonomy variables. The third step of the equation provided similar increments of improvement in prediction of parents' diabetes-specific adherence reports in the equations including and excluding the conflict and autonomy reports.

Overall, the level of prediction of parents' diabetes-specific adherence ratings afforded by the modified model accounted for 32 % of the variance in these reports. By comparison, the variables of the SFMA alone (i.e., without the conflict or autonomy variables) accounted for less than 20 % of this variance. Remarkably, the proportion of the variance in parents' reports of diabetes-specific adherence accounted for by the modified model of adherence is the same as the proportion of variance in adolescents' reports of diabetes-specific adherence accounted for by this modified model. This consistency supports the utility of the addition of parent-adolescent conflict and adolescent autonomy to the SFMA when examining adolescents' medical adherence. Further, this result compares favourably with previous studies examining the multivariate prediction of adherence in groups of patients with chronic illnesses (e.g., DiMatteo, Hays, et al. 1993; Hanson, et al. 1987a; Hanson, De Guire, et al. 1992; Ried & Christensen, 1988 Sherbourne, et al. 1992).

As discussed in **Section 14.1.2**, the significant predictor of parents' reports of diabetes-specific adherence in the regression of SFMA variables was Intentions to Adhere. In the regression of parents' reports of diabetes-specific adherence with the SFMA variables and the measures of parent-adolescent conflict and adolescent autonomy, the significant predictors were Supports / Barriers and Intentions to Adhere.

Again, parents' reports of parent-adolescent conflict and adolescent autonomy were not significant predictors in the regression with reports on the DSAS. The explanation for the lack of significant prediction by conflict reports of adherence reports, despite the significant bivariate relationship between these measures, has been addressed in previous sections. However, it is interesting to note that although these variables were not found to be significant predictors of parents' reports of diabetes-specific adherence in this analysis, their inclusion in the analysis substantially increased the proportion of variance in these adherence reports that was accounted for by the regression equation. This finding provides support for the inclusion of these variables in the examination of adolescents' adherence to medical regimens.

14.3 The Maximal Prediction of Adherence and Metabolic Control.

This section discusses the results presented in **Section 13.3**; the analyses discussed in this section were intended to determine the greatest possible prediction of adolescents' reported adherence and of their metabolic control.

14.3.1 The Maximal Prediction of Reported Adherence.

The analysis of the variation in adolescent reports of general adherence, according to the factors assessed in this thesis that demonstrated significant bivariate relationships with reported adherence, accounted for a large proportion of the variance in adherence reporting (57 %). The measures that were found to be significant multivariate predictors of adolescents' reports of general adherence were Perceived Utility, Supports / Barriers, and Health Value. These results are similar to those discussed in the first section of this chapter, examining the predictive value of the SFMA. In particular, it should be noted that two variables of the SFMA, Supports / Barriers and Health Value, were significant predictors of general adherence in both of these regressions.

The analysis of the variation in adolescent reports of diabetes-specific adherence accounted for a considerable proportion of the variance in adherence reporting (40 %). The measures that were found to be significant multivariate predictors of adolescents' reports of diabetes-specific adherence were Recreational Activity and Supports / Barriers. These results differ from those discussed in the first section of this chapter examining the prediction of diabetes-specific adherence on the basis of the SFMA. In the previous analysis, Perceived Susceptibility was a significant predictor of adolescents' reports of this adherence. However, this finding is consistent with the findings of the regressions of adolescents' reports of general adherence.

The analyses of the variation in parents' reports of general adherence and diabetes-specific adherence accounted for very similar proportions of variance in these reports as the analyses of the adolescents' reports.

The analysis of the variation in parent reports of general adherence accounted for a large proportion of the variance in adherence reporting (59 %). The sole variable that was found to be a significant multivariate predictor of parents' reports of general adherence was intention to adhere in the future. This finding is similar to that discussed in the first section of this chapter, examining the predictive value of the SFMA. In the examination of parents' reports of general adherence in relation to the SFMA, Intentions to Adhere and Supports / Barriers were significant predictors of general adherence in the regression.

The analysis of the variation in parent reports of diabetes-specific accounted for a considerable proportion of the variance in adherence reporting (41 %). The variable that was found to be significant multivariate predictors of parents' reports of diabetes-specific adherence was intention to adhere in the future. This finding is again similar to that discussed in the first section of this chapter. In the examination of parents' reports of general adherence in relation to the SFMA, Intentions to Adhere was the significant predictor of diabetes-specific adherence in the regression.

Like the findings presented in **Sections 14.1** and **14.2**, these findings compare well with those of previous investigations (e.g., Brownlee-Duffeck, et al. 1987; Hanson, et al. 1987a; Jacobson, et al. 1987; Jacobson, et al. 1990). **Section 14.4** discusses these findings in light of the published literature.

14.3.2 The Maximal Prediction of Metabolic Control.

The analysis of the variation in adolescents' metabolic control, according to the factors assessed in this thesis that demonstrated significant bivariate relationships with this metabolic control, accounted for a large proportion of the variance (48 %). This is a strong finding. Previous investigations of adolescents' IDDM adherence have typically accounted for less than 20 % of the variance in HbA_{1c} results (e.g., BJ Anderson, et al. 1990; Brownlee-Duffeck, et al. 1987; Hanson, De Guire, et al. 1992; Hanson, et al. 1987a).

These findings suggest that the understanding of adolescents' metabolic control in insulin dependent diabetes is improved by the measures employed in this thesis. However, the replication of these findings in another setting would reinforce the strength of this conclusion. These findings also suggest that certain aspects of adolescents' and parents' health beliefs should be the focus of interventions intended to improve adolescents' metabolic control. For example, adolescents' perceptions of supports to adherence were a significant predictor of adolescents' metabolic control. While a direct association between this perception and the metabolic control of adolescents is not postulated, these perceptions do appear to be linked to the adolescents' health status. These perceptions could be targeted in future intervention research designed to improve metabolic control.

14.4 Summary and Future Directions: The Multivariate Prediction of Adolescents' Adherence and Metabolic Control.

This section provides a synthesis of the findings discussed in this chapter, in light of the published literature. The implications of these findings to the wider literature and to future research are addressed.

14.4.1 The Multivariate Prediction of Adherence and Metabolic Control by Adolescents.

The first findings discussed in this chapter examined the multivariate prediction of adherence, based on a series of variables theorised to influence adherence (DiMatteo & DiNicola, 1982; Gritz, et al. 1989). The findings discussed in this chapter also examined the potential improvement in the prediction of adherence by the addition of assessments of parent-adolescent conflict and adolescent autonomy to the predictor variables defined by the model. These later findings were intended to gain a clearer insight into adherence amongst adolescents with chronic illnesses. Further findings examined the maximal prediction of adolescents' adherence and metabolic control, using the reports collected in this study.

In previous studies by Schlenk and Hart (1984), Hanson and colleagues (1987a, Hanson, De Guire, et al. 1992), Brownlee-Duffeck and colleagues (1987), and Jacobson and colleagues (1987, 1990), multivariate analyses have been reported to account for the variation in adherence of adolescents with IDDM. Further studies by

IM Friedman and colleagues (1986), Ried and Christensen (1988), and DiMatteo and colleagues (DiMatteo, Hays, et al. 1993; Sherbourne, et al. 1992) have performed similar analyses to predict adherence in other groups of patients.

Schlenk and Hart (1984) examined the prediction of IDDM adherence amongst a group of 30 adults, using measures of health locus of control, health value, and social support. These authors were able to account for 53 % of the variance in reported general adherence and between 8 % and 58 % of the adherence to specific aspects of IDDM management. However, the small sample size involved in this study made the use of multiple regression analyses inadvisable (WL Hays, 1988; Norman & Streiner, 1994; Tabachnick & Fidell, 1989).

Hanson and colleagues (1987a) examined the prediction of adolescents' IDDM regimen adherence and HbA_{1c} by the use of measures of stress, social competence, family relations, diabetes knowledge, and the adolescents' age. These analyses accounted for almost 19 % of the variance in self-reported adherence and nearly 15 % of the variance in metabolic control. A more recent study by this group of researchers examined the prediction of adolescents' IDDM adherence and HbA_{1c} using illness-specific and general family relations measures. In this study, the predictor variables were able to account for 17 % of the variance in self-reported adherence, although metabolic control could not be significantly predicted (Hanson, De Guire, et al. 1992).

Brownlee-Duffeck and colleagues (1987) examined the prediction of adolescents' and adults' IDDM regimen adherence, as well as their metabolic control, according to variables of the health belief model (i.e., health beliefs). These variables accounted

for 52 % of the variance in adherence amongst the participating adolescents and 40 % of the variance in adherence amongst the participating adults. Overall, these variables accounted for 41 % of the variance in self-reported adherence of the combined sample. The same variables accounted for 20 % of the variance in the adolescents' metabolic control, and 19 % of the variance in the adults' metabolic control (16 % for the combined sample).

Jacobson and colleagues (1987) examined the prediction of children and adolescents' adherence to IDDM self-care recommendations using measures of self-esteem, health locus of control, social functioning, and age. These variables accounted for 55 % of the variance in adherence. This study was limited by the small sample size involved (19 children and 38 adolescents with recent onset IDDM), and by the measurement of adherence employed: in this study, health provider estimates of adherence were used, the methodological weakness of this form of adherence assessment was discussed in **Section 1.1.2.1** of the *Literature Review*.

In another study by this group of researchers, adolescents' adherence to IDDM self-care recommendations was examined in relation to locus of control, adaptive strength, ego defence, adolescent age, and adjustment (Jacobson, et al. 1990). Using hierarchical multiple regression, these variables accounted for 47 % of the variance in the health provider estimated adherence of the 61 participating adolescents. This finding was weakened by two aspects of the design of the study. First, the sample size involved in the study was too small to test this number of variables in a multiple regression analysis (WL Hays, 1988; Norman & Streiner, 1994; Tabachnick & Fidell,

1989). Second, as in the previous study by this group of researchers, adherence was assessed using a health provider estimate.

Anderson and colleagues (1990) were able to account for 13 % of the variance in metabolic control of adolescents with IDDM, using a measure of family responsibility for diabetes management. Johnson and colleagues (1992) accounted for 28 % of the variance in metabolic control of children and adolescents with IDDM using structural equation modeling of age, diabetes duration, and adherence measures in a longitudinal study.

Investigations of adherence amongst other groups of patients have revealed similar levels of prediction of adherence. IM Friedman and colleagues (1986) accounted for 36 % of the variance in adherence to epilepsy medication of a group of 25 adolescents, using measures of autonomy and self-esteem. Unfortunately, this study involved only a very small number of participants, and used an unreliable measure of autonomy, as discussed in **Section 10.4.1**. Further, adherence was assessed in this study using biological assays; as discussed in **Section 1.1.2.1**, assays are measures of physiological functioning, not of behaviour.

Ried and Christensen (1988) examined the predictive power of Health Belief Model (HBM) and Theory of Reasoned Action (TRA) variables for the adherence of adolescents to medication prescriptions. The HBM variables accounted for only 10 % of the variance in self-reported adherence. The addition of the TRA variables in a hierarchical regression improved the prediction of adherence; the combined predictive

power of these models accounted for 29 % of the variance in these adolescents' adherence.

Sherbourne and colleagues (1992) examined the adherence of 1198 adults with non-insulin dependent diabetes, hypertension, or heart disease, in relation to variables in the SFMA. In this large scale study, 26 % of the variation in self-reports of general adherence were accounted for by the SFMA variables, as was 15 % of the variation in illness-specific adherence. In another study by this group of authors, DiMatteo, Hays, and colleagues (1993) examined the general and illness-specific adherence of four groups of adult patients with abnormal pap smears (n = 56), breast cancer (n = 131), head / neck cancer (n = 91), and obesity (n = 87). The Adherence Determinants Questionnaire and Health Value Scale were used to measure the variables of the SFMA, and predict adherence. Using standard multiple regressions, the SFMA variables accounted for 26 %, 29 %, 27 %, and 10 % of the variation in reported general adherence in the four groups of patients, respectively. Further, the SFMA variables accounted for 26 %, 0 %, 63 %, and 49 % of the variation in reported illness-specific adherence in these respective groups of patients. In this study, the Supports / Barriers variable was the significant predictor of general adherence in all groups, and of illness-specific adherence in all groups other than breast cancer. Intentions to Adhere was a significant predictor of illness-specific adherence amongst the head/neck group. Unfortunately, standard multiple regression analyses were used, so that although the predictive power of the SFMA variables could be determined, the structure of the model could not be tested.

The present study examined the prediction of IDDM adherence amongst a group of 135 adolescents, using measures of variables from the Six-Factor Model of Adherence (supports and barriers to adherence, intentions to adhere, health beliefs, social norms, health value, and interpersonal aspects of care), completed by adolescents and parents. These variables, entered into a hierarchical regression according to the structure of the SFMA, were able to account for 37 % and 24 % of the variances in adolescent reported general and diabetes-specific adherence, and 37 % and 20 % of the variances in parent reported general and diabetes-specific adherence, respectively. The present study further examined the prediction of IDDM adherence amongst this group of adolescents, using the measures of variables from the SFMA, with the addition of measures of parent-adolescent conflict and adolescent autonomy. This more comprehensive model of adherence prediction was able to account for 42 % and 32 % of the variances in adolescent reported general and specific adherence, and 39 % and 32 % of the variances in parent reported general and specific adherence, respectively. Using Stepwise regressions, the present study was able to account for 57 % and 59 % of the variances in adolescents' and parents' reports of general adherence, and 40 % and 41 % of these respondents' reports of diabetes-specific adherence. The findings of the present study were also able to account for 48 % of the variance in adolescents' metabolic control.

The findings discussed in this chapter extend on previous research in several respects.

First, the findings discussed in this chapter provide some empirical support for the predictive power and the structure of the Six-Factor Model of Adherence, when applied to a sample of chronically ill adolescents. Previous research has identified the

utility of this model in relation to large adult samples of patients (DiMatteo, Hays, et al. 1993; Sherbourne, et al. 1992). The present study extends on these studies by determining that this model can be successfully applied to adolescents' medical adherence.

Further, in the present study the supports / barriers variable was a significant predictor of adherence in all of the regression equations predicting general adherence, and in one regression of diabetes-specific adherence. Intentions to Adhere was also a significant predictor of parents' reports of adherence. These results closely replicate the pattern of findings reported by DiMatteo, Hays and colleagues (1993) examining these variables. It may be argued that the significant influence of Supports / Barriers was caused by its early introduction to the Hierarchical Regressions discussed in this chapter. However, the consistency of these findings with those of DiMatteo, Hays and colleagues (1993), who used only a standard multiple regression, tends to refute this argument. Further, the finding that Supports / Barriers was also a significant predictor of adolescent reported general adherence in the Stepwise Regression further refutes the argument that this variable's influence on adherence was caused by its early entry into the Hierarchical Regression. Rather, these findings suggest that perceptions of support for adherence and the absence of barriers to adherence is important to the adherence of these adolescents.

Second, the findings presented in this chapter suggest that the prediction of adolescents' adherence by the SFMA may be improved by the addition of measures of parent-adolescent conflict and adolescent autonomy. In this study, these measures were included in the model at the same point as the Intentions to Adhere variable.

The addition of these variables to the SFMA has not been examined in previously published research.

Third, the use of parents' reports in this study provided additional support for the influence of the variables of the Six-Factor Model of Adherence. Previous studies have employed only self-report measures to test the SFMA. (DiMatteo, Hays, et al. 1993; Sherbourne, et al. 1992). The finding in this study that the level of prediction of adherence by parents' reports was similar to the level of prediction obtained using adults' self-reports in previous studies provides further support for the relevance of this model.

However, although the findings involving parents' reports supported the influence of the variables of the SFMA, these findings were less supportive of the structure of the model. The hierarchical regressions used to examine the model's structure, although providing a reasonably strong level of prediction of adherence, did not support the structure of the model. Previous studies examining the SFMA have not tested the heuristic structure proposed for the model by Gritz and colleagues (1989). For example, as already mentioned, DiMatteo, Hays, and colleagues (1993) used standard multiple regressions rather than hierarchical regressions to examine the relationship between SFMA variables and adherence. Standard multiple regressions, while able to determine the relative predictive power of different predictive variables, are not able to test the structure of the model (WL Hays, 1988; Tabachnick & Fidell, 1989).

Further, parents' reports provided mixed support for the addition of parent-adolescent conflict and adolescent autonomy variables to the model. The analyses involving the

prediction of parents' reports of general adherence accounted for 37 % of the variance in these reports using the SFMA variables alone, and 39 % of this variance using the SFMA variables with the addition of the conflict and autonomy measures. The analyses involving the prediction of parents' reports of diabetes-specific adherence accounted for 20 % of the variance in these reports using the SFMA variables alone, and 32 % of this variance using the SFMA variables with the addition of the conflict and autonomy measures.

Fourth, the analyses discussed in this chapter accounted for around 30 - 40 % of the variance in reports of adherence reports using variables of the Six-Factor Model of Adherence as well as parent-adolescent conflict and adolescent autonomy variables. This result is consistent with previous studies of adolescents' adherence using other predictive measures. However, a number of previous studies examining the multivariate prediction of adolescents' adherence have employed small samples, limiting the interpretability of these analyses (e.g., IM Friedman, et al. 1986; Jacobson, et al. 1987; Jacobson, et al. 1990; Schlenk & Hart, 1984). The present study examined the multivariate prediction of adolescents' adherence using a sample size of sufficient magnitude to meaningfully conduct these analyses (WL Hays, 1988; Tabachnick & Fidell, 1989; Norman & Streiner, 1994).

Further, the findings of this study extend on previous studies that have examined the predictive utility of theoretical models of health behaviour for the understanding of adolescents' medical adherence. The proportion of variance in adherence accounted for in the present study was greater than that found by Ried and Christensen (1988), who accounted for 10 % of the variance in adolescents' medication adherence using

the Health Belief Model, and 19 % of this variance using the Theory of Reasoned Action. Brownlee-Duffeck and colleagues (1987) accounted for 52 % of the variance in adolescents' adherence to IDDM self-care recommendations, using health belief variables derived from the HBM. The findings of the present study suggest that the SFMA is at least as useful as the HBM in understanding adolescents' medical adherence.

Finally, the findings of this study indicated that the measures employed here were able to provide a high level of prediction of adolescents' adherence and metabolic control. The level of prediction of metabolic control, in particular, was greater than has been reported in a number of previously published investigations. These findings suggest that the factors examined in this study are important to the understanding of adolescents' IDDM adherence and metabolic control, and that these factors are worthy of examination in intervention studies designed to improve adherence and metabolic control.

14.4.2 Limitations of the Present Study and Future Directions for the Multivariate Prediction of Medical Adherence by Adolescents.

The discussion of the results in this study examining the multivariate prediction of adolescents' adherence has identified several limitations of the study, and identified some avenues for future research.

First, this study used a cross-sectional design. The testing of the Six-Factor Model of Adherence should include a measure of previous adherence. This measurement requires a longitudinal design. The examination of adolescents' adherence in relation to the variables of the SFMA in a longitudinal investigation would allow a more complete examination of the utility of this model in understanding adherence. This type of investigation could potentially improve the level of prediction of adherence afforded by the present study. As has already been identified, the author is presently involved in a longitudinal investigation of adolescents' IDDM adherence, including an intervention program designed to improve this adherence (Taylor, et al. 1996, 1997).

A second limitation of the analyses discussed in this chapter related to the use of multiple regression. Multiple regression analyses are only able to examine linear relationships between variables (Cliff, 1987; WL Hays, 1988; Tabachnick & Fidell, 1989). It is possible that curvilinear or nonlinear relationships exist between adherence and the predictor variables assessed, which provide a more accurate understanding of the relationship between these variables. These relationships were not assessed by the regression analyses conducted in this study. The analysis of nonlinear relationships between reported adherence and the variables of the SFMA is beyond the scope of this thesis. This issue could be investigated in future studies of adolescents' medical adherence.

Third, no previous studies have published examinations of the utility of the SFMA in understanding adolescents' medical adherence. The findings of the present study examining parents' reports of adherence did not provide the same level of support for the inclusion of the conflict and autonomy variables to the regressions as the findings

examining the adolescents' reports. Future studies should also examine reports from adolescents and parents, to determine whether the results obtained in this study are replicable, or whether the patterns discussed in this chapter differ with other samples of adolescents. Future studies could also explore the possible causes of the differences in findings observed between the adolescent and parent reports.

Finally, the replication of these findings, particularly the findings addressing the prediction of metabolic control, would reinforce the strength of the conclusions drawn in this chapter. The present findings suggest that the factors investigated in this study should be the focus of interventions intended to improve adolescents' metabolic control. This appears to be a valuable avenue for future investigation.

CHAPTER FIFTEEN.

CONCLUSIONS.

This chapter reviews the aims of this thesis, and provides a synthesis of the findings of the study in light of these aims. The implications of these findings for future research and for clinical practice are addressed. Limitations of the study are identified.

15 CONCLUSIONS.

15.0 A Review of the Aims of This Thesis.

The principal aim of this thesis was to examine adherence to medical recommendations of adolescents with IDDM. In particular, the influences of two specific issues were studied; these were parent-adolescent conflict and adolescent autonomy.

This thesis investigated several components of adolescents' adherence. Measures included (1) their adherence to a range of specific aspects of their medical recommendations, (2) their general tendency to adhere or not to adhere to medical recommendations, and (3) an objective assessment of their blood glucose monitoring adherence. Each of the measures of adherence, as well as the measures of adolescent autonomy and parent-adolescent conflict, were completed by participating adolescents and parents. Adolescents' metabolic control was assessed by HbA_{1c} assay.

The relationship between adolescents' adherence and a range of factors related to adults' adherence in the Six-Factor Model of Adherence were also examined, to determine the applicability of this model to adolescents' regimen adherence.

15.0.1 Thesis Hypotheses.

Two hypotheses were tested in the study:

1. Adolescents for whom reports of greater levels of conflict with their parents are obtained will be less adherent to their diabetes treatment recommendations than adolescents for whom reports of lower levels of conflict with their parents are obtained.

2. Adolescents for whom reports of greater levels of autonomy are obtained will be more adherent to their diabetes treatment recommendations than adolescents for whom reports of lower levels of autonomy are obtained.

15.1 A Synthesis of the Thesis Findings in Light of these Aims.

This section summarises the main findings of this thesis, in reference to the thesis aims.

15.1.1 The Assessment of Patient Adherence

The measures of adherence employed in this thesis were: adolescent completed reports of adherence on the General Adherence Scale (GAS) and Diabetes Specific Adherence Scale (DSAS); parent completed reports on the GAS and DSAS; and observations of

BGM adherence. In **Chapters 5** and **6**, large correlations were detected between each of these measures, suggesting that these measures were assessing the same general construct: patient adherence.

The level of adherence reported by adolescents and parents was not associated with the adolescents' age. The level of observed BGM adherence varied according to adolescents' age, with greater adherence observed in the younger adolescents than in the older adolescents. The level of adherence reported by adolescents and parents did not vary according to the gender of the adolescent. The observed level of BGM adherence was also not associated with adolescents' gender. Reports of adherence obtained from adolescents were only weakly associated with the adolescents' HbA_{1c} levels, while reports obtained from parents, and observations of BGM adherence were moderately associated with the adolescents' HbA_{1c} levels.

Blood glucose monitoring adherence levels varied over the four weeks prior to assessment, becoming increasingly high as clinic appointments approached. The variation in BGM adherence levels formed a linear trend. In light of this finding, subsequent analyses involving the BGM adherence information were performed using data spanning a variety of time frames. Finally, patterns of BGM adherence over the four weeks prior to Outpatient Clinic attendance were coded as Consistently High, Consistently Low, Rising, or Other. Responses to questionnaire measures of adherence were found to be differentiated by these groups. Therefore, subsequent analyses involving BGM adherence were also performed separately for adolescents classified with Consistently High BGM adherence, Consistently Low BGM adherence, Rising BGM adherence and Other BGM adherence patterns.

In sum, these findings suggest that the assessment of patient adherence in this study was comprehensive, and relevant to the health outcomes of the adolescents assessed.

15.1.2 The Relationship Between Patient Adherence and Parent-Adolescent Conflict.

In **Chapters 7** and **8**, adolescent, parent and combined measures of parent-adolescent conflict were associated with adolescents' adherence, as reported by the adolescents and their parents. Observations of BGM adherence were not related to these reports of conflict. Additional analyses revealed significant relationships between reports of parent-adolescent conflict and adolescents' metabolic control. Hierarchical multiple regression analyses determined that adolescent and combined adolescent and parent reports of conflict added to the variance in metabolic control accounted for by reports of adherence.

In sum, the results summarised in this section supported the first hypothesis of this thesis; that adherence would be lower amongst adolescents who experienced high levels of conflict with their parents than amongst adolescents who experienced less conflict with their parents.

These finding have implications for future investigations. The findings of this thesis suggest that adolescents' conflict with their parents is linked to their medical adherence. This is a valuable contribution. Little previous research has addressed this issue directly. It may be suggested on the basis of these findings that future

investigations of patient adherence that involve adolescent samples should consider this issue. Further, this issue should be examined in relation to the adherence of adolescents to other medical regimens, for example, the influence of conflict on adolescents' adherence to asthma treatment. It is unlikely that conflict is only associated with adherence to diabetes treatment. However, this finding should be replicated with other diagnostic groups.

These findings also have implications for clinical practice and interventions for adolescents with diabetes. These findings indicate that the medical adherence and metabolic control of adolescents with diabetes are associated with their level of conflict with their parents. The medical care of adolescents with IDDM should also appreciate the potential influence of parent-adolescent conflict. Interventions designed to improve adolescents' adherence, or their level of metabolic control, should include a consideration of conflict resolution strategies for adolescents and their parents.

15.1.3 The Relationship Between Patient Adherence and Adolescent Autonomy.

In **Chapters 9** and **10**, adolescent and parent reports of the adolescents' autonomy were not associated with the adolescents' adherence, as reported by adolescents and their parents. Observations of BGM adherence were not related to these reports of adolescent autonomy. Additional analyses revealed no significant relationships between reports of adolescent autonomy and adolescents' metabolic control.

In sum, the findings summarised in this section do not provide support for the second hypothesis of this thesis. However, as discussed in **Chapter 10**, it seems premature to conclude that adolescents' medical adherence is unrelated to their experience of autonomy.

These finding have implications for future investigations. The lack of a direct association between adolescents' autonomy and their regimen adherence in this study suggests that adolescents' adherence is not associated with their overall level of autonomy. However, the finding that adolescents' perceptions of their recreational autonomy were associated with their adherence suggests that this form of autonomy may be related to their medical adherence. The investigation of this issue is worthy of future research, particularly in light of the finding, reported in **Chapters 13** and **14**, that this adherence measure significantly added to the prediction of the adolescents' adherence when examined in conjunction with reports of adherence and its antecedents.

15.1.4 The Relationship Between Patient Adherence and Proposed Antecedents of Adherence.

In **Chapters 11** and **12**, adolescent and parent measures of both general and diabetes-specific adherence were associated with reports of perceived treatment utility, health value, intentions to adhere in the future, and the presence of supports for or the absence of barriers to adherence. Reports of the perceived severity of illness by adolescents and parents were negatively associated with their reports of general and

diabetes-specific adherence (i.e., higher adherence levels were associated with lower perceived severity). Adolescents' and parents' perceptions of the interpersonal aspects of the adolescents' medical care were associated with their reports of general adherence, but not with reports of diabetes-specific adherence. Reports by adolescents and parents of diabetes knowledge, social influences (subjective norms) on adherence, and perceptions of susceptibility to hypoglycaemia or hyperglycaemia, were not related to reports of adherence. Objective assessments of BGM adherence were associated with adolescent and parent responses to the Intentions to Adhere and Subjective Norms scales, but not to the other scales in the ADQ. Adolescents' level of metabolic control (HbA_{1c}) was associated with reports from adolescents and parents of interpersonal aspects of diabetes care, the perceived utility of diabetes treatment, and the presence of supports for or the absence of barriers to adherence.

In sum, the findings summarised in this section support the applicability of factors associated with medical adherence in adults to the investigation of adherence in adolescent patients.

These findings have implications for future investigations and for clinical practice and interventions for adolescents with diabetes. The influence of these issues should be examined in relation to the adherence of adolescents to other medical regimens. It is possible that these influences vary in their importance in relation to different types of medical recommendation. For example, interpersonal aspects of care may have a more positive influence on adherence to medical recommendations that are simple, and less influence on recommendations that are difficult to follow or are painful. This suggestion is supported by the finding in this study that interpersonal aspects of care

were more closely associated with general adherence tendencies than with adherence to specific aspects of diabetes self-care. This is an interesting avenue for future research.

The implications of these findings for clinical practice include the highlighting of the relevance of the doctor-patient relationship to the adherence of adolescents. The finding that diabetes knowledge was not associated with regimen adherence or metabolic control suggests that interventions intended to improve adherence or metabolic control should not focus exclusively on this knowledge, although it may be noted that the general level of diabetes knowledge in this sample was high. Similarly, the finding that perceptions of the severity of diabetes were inversely associated with adherence suggests that interventions with too great a focus on the serious consequences of diabetes (i.e., long-term complications) could have a counterproductive effect. For example, excessive attention to the severity of diabetes may promote a sense of hopelessness in these adolescents.

The findings of this study also suggest that interventions should focus on perceptions of the utility of diabetes treatment, which were associated with the adherence and metabolic control of the participating adolescents. This suggests that adherence-promoting interventions should highlight, for example, the positive findings from the Diabetes Control and Complications Trial, which suggests that careful glycaemic control can greatly reduce the risk of long-term complications (e.g., DCCT, 1993).

15.1.5 The Multivariate Prediction of Adolescents' Adherence and Metabolic Control.

Chapters 13 and **14** examined the prediction of adolescents' IDDM adherence, using measures of variables from the Six-Factor Model of Adherence (supports and barriers to adherence, intentions to adhere, health beliefs, social norms, health value, and interpersonal aspects of care), completed by adolescents and parents. These variables, entered into a hierarchical regression according to the structure of the SFMA, were able to account for 37 % and 24 % of the variances in adolescent reported general and diabetes-specific adherence, and 37 % and 20 % of the variances in parent reported general and diabetes-specific adherence, respectively. These chapters further examined the prediction of IDDM adherence amongst this group of adolescents, using the measures of variables from the SFMA, with the addition of measures of parent-adolescent conflict and adolescent autonomy. This more comprehensive model of adherence prediction was able to account for 42 % and 32 % of the variances in adolescent reported general and specific adherence, and 39 % and 32 % of the variances in parent reported general and specific adherence, respectively.

Using Stepwise regressions, the present study was able to account for 57 % and 59 % of the variances in adolescents' and parents' reports of general adherence, and 40 % and 41 % of these respondents' reports of diabetes-specific adherence. The findings of the present study were also able to account for 48 % of the variance in adolescents' metabolic control.

In sum, these findings provide support for the structure and relevance of the SFMA in the understanding of adolescents' medical adherence, although the findings obtained from parents' reports provided less support for the structure of the model than the findings obtained from the adolescents' reports. These findings also supported the inclusion of parent-adolescent conflict and adolescent autonomy with this model when assessing the medical adherence of adolescents. Further, these findings indicate a high level of prediction of adherence reports and metabolic control.

These findings have implications for adherence research. The high level of prediction of adherence reports found in this study suggests that the factors examined in the study, including parent-adolescent conflict and adolescent autonomy, were important to the understanding of these adolescents' adherence. The examination of the adherence of adolescents with other chronic conditions, and the adherence of adolescents to acute treatment regimens, in relation to these factors, could improve our understanding of this health behaviour. Further, the high level of prediction of the adolescents' metabolic control suggests that these factors are relevant to the understanding of psychosocial influences on adolescents' health status. The examination of specific issues identified in this thesis, including, for example, adolescents' recreational autonomy, could further inform this understanding.

These findings also have implications for clinical practice and intervention strategies. The findings from this study suggest that an appreciation of the importance of psychosocial issues such as parent-adolescent conflict and adolescent autonomy, and of health beliefs and the presence of a supportive environment for adherence are relevant to the clinical management of adolescents. The promotion of adherence

should take into account these influences. The improvement of adolescents' illness control should address the issues identified in this thesis, as these issues have accounted for a large proportion in the variation in the participating adolescents' level of metabolic control.

15.2 Limitations of the Thesis Findings.

The findings of this thesis were limited by a number of aspects of the study design. This section summarises these limitations.

A range of characteristics of participants and their functioning have been identified which could have further informed the analyses conducted in this thesis. These include: pubertal status, the nature of parent-adolescent conflict and its resolution, parents' level of involvement with their adolescents (**Chapter 8**), and adolescents' birth order (**Chapter 10**).

The small number of fathers involved in the study limited the ability of this investigation to examine the different roles played by mothers and fathers in their adolescents' health-care. Future studies should emphasise the recruitment of fathers into research of this kind.

The measure of autonomous functioning employed in this study did not detect wide variations in autonomy levels amongst the participating adolescents. Given the size of the sample involved in this study and the age range involved, the lack of variability in

obtained scores on the AFC may indicate a lack of sensitivity in this measure. The use of a more sensitive measure of adolescents' autonomous functioning would facilitate a more sensitive assessment of the relationship between adolescents' autonomy and their adherence to medical regimens. Further, associations between responses to the subscales of the AFC suggest that different aspects of adolescents' autonomous functioning relate differently to their regimen adherence. This issue may be worthy of further investigation.

Finally, this study used a cross-sectional design. The examination of adolescents' adherence in relation to the variables involved in this study in a longitudinal investigation would allow a more complete understanding of adolescents' adherence.

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Adolescents' Adherence to Chronic Medical Regimens: Parent-Adolescent Conflict and Adolescent Autonomy in Relation to Adherence to Insulin Dependent Diabetes Treatment Regimens.

Volume Two.

Michael Fotheringham.
B.A. (Honours - Psychology). University of Adelaide.

A thesis submitted in fulfilment of the requirements of the degree of
Doctor of Philosophy, Department of Psychiatry,
University of Adelaide.

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Appendix I.3: Taylor JD, Fotheringham MJ, Sawyer MG, Couper JJ. (1996). Ambulatory intervention in adolescents with insulin dependent diabetes: Impact of metabolic control and psychosocial functioning. *Proceedings of the Australian Diabetes Society, 1996* A 62. 331

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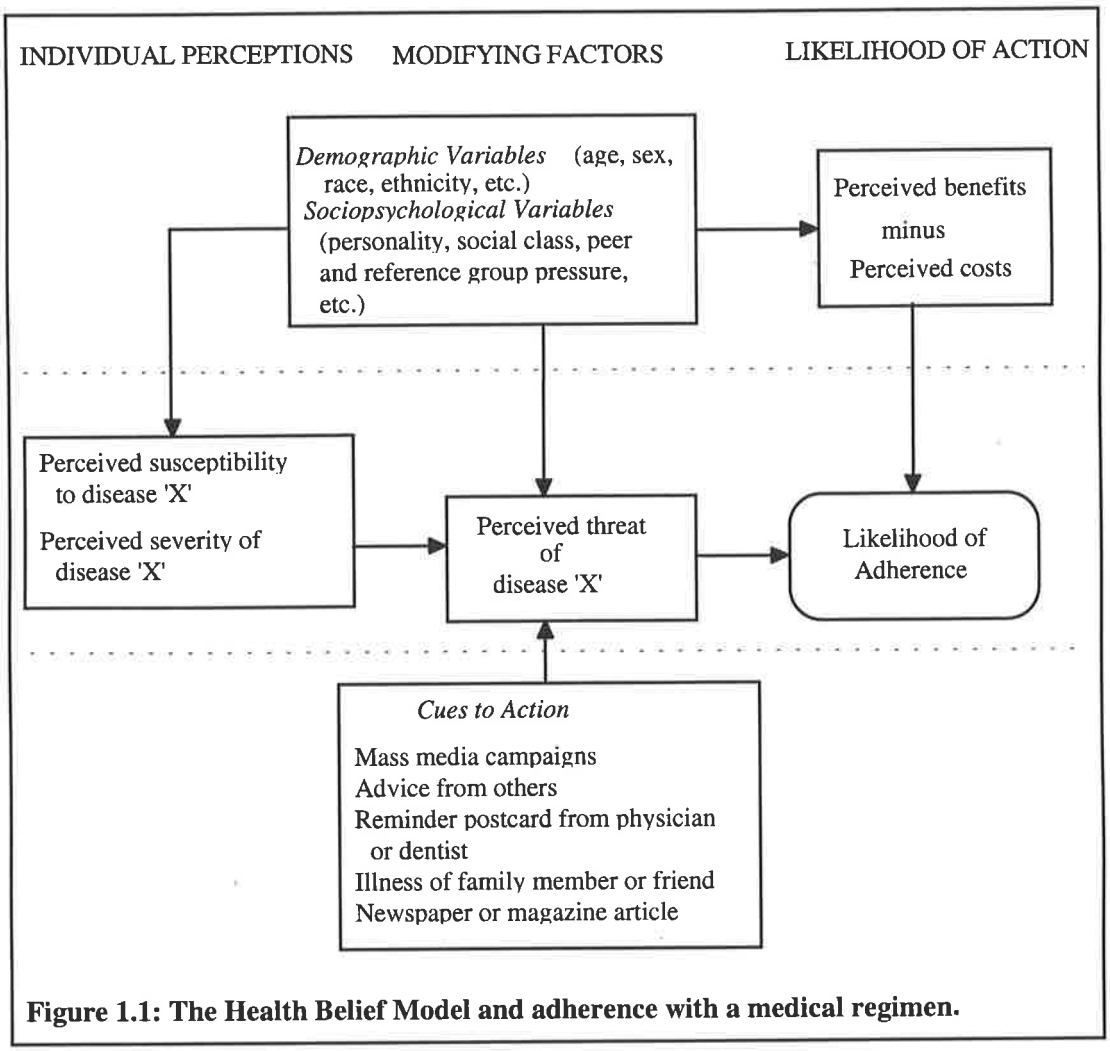


Figure 1.1: The Health Belief Model and adherence with a medical regimen.

Source: Adapted from Dunbar and Stunkard (1979).

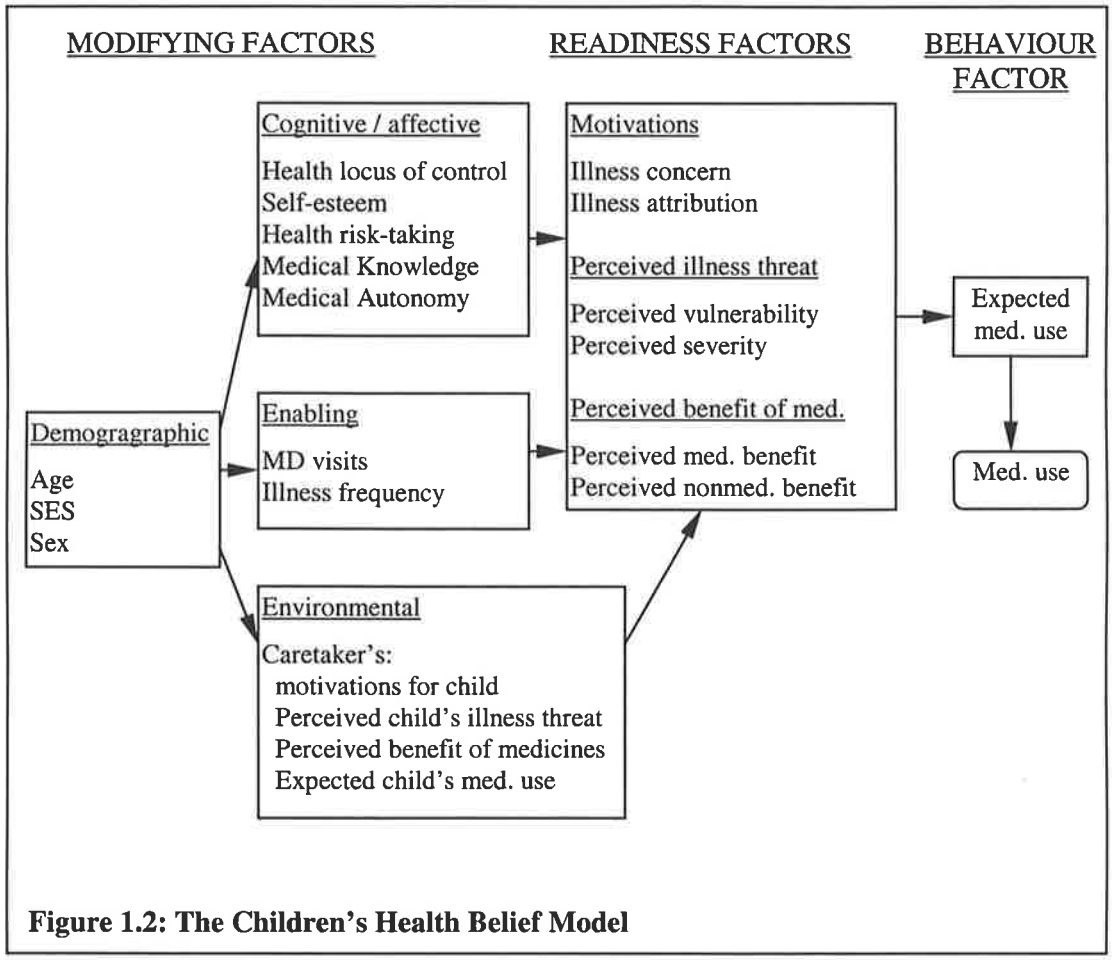


Figure 1.2: The Children's Health Belief Model

Source: Bush and Iannotii (1988).

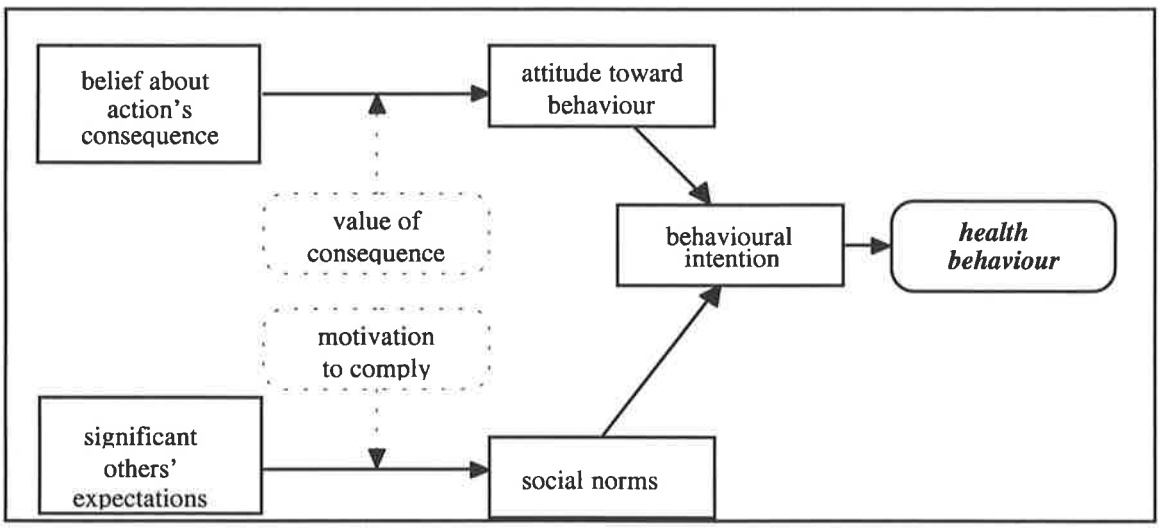


Figure 1.3: The Theory of Reasoned Action.

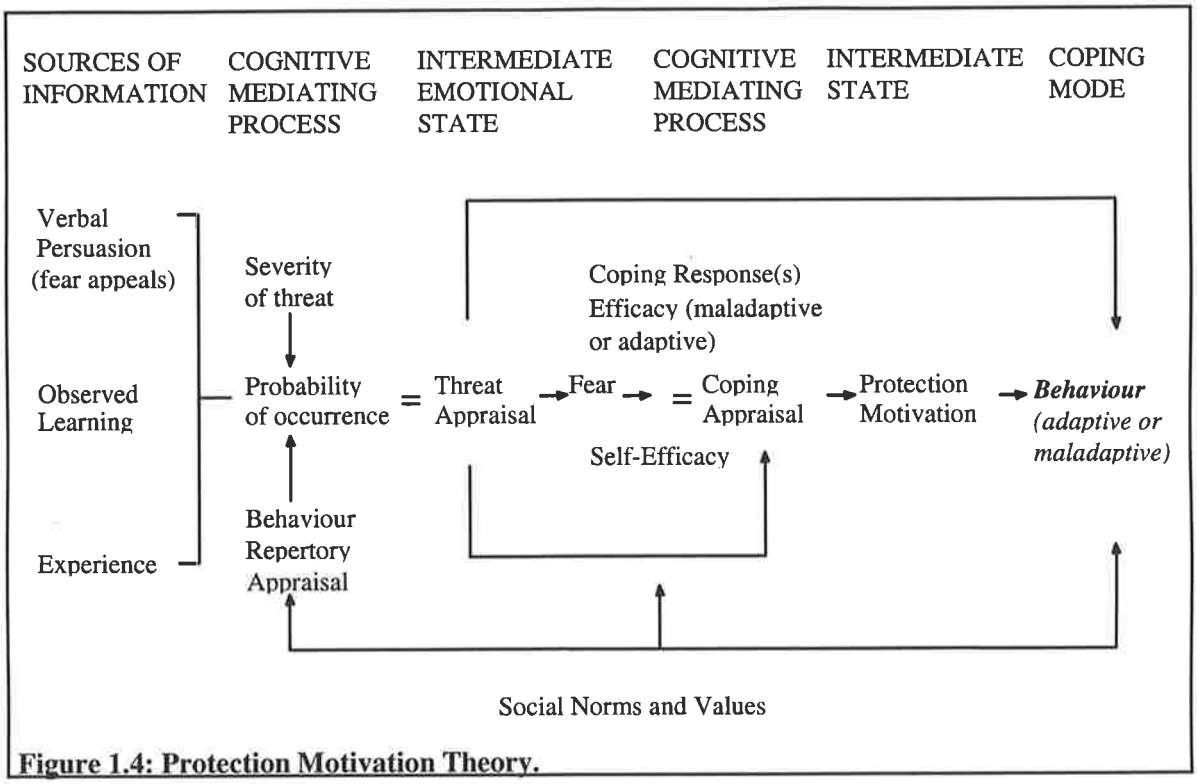


Figure 1.4: Protection Motivation Theory.

Source: Adapted from Tanner, Hunt, Eppright (1991).

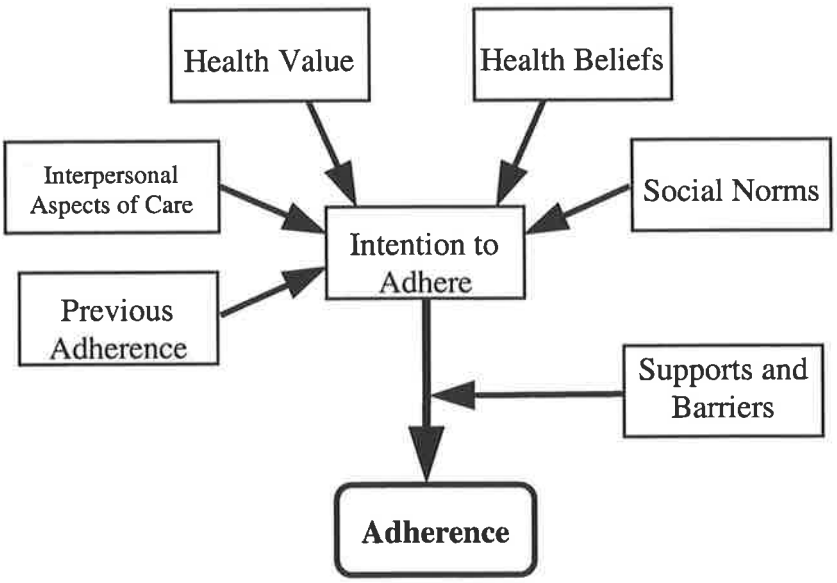


Figure 1.5 The Six Factor Model of Adherence.

TABLES AND FIGURES CITED IN CHAPTER 3.

Sensorlink System Serial #S301372-01
PATIENT DEVICE DATA 28-Aug-95

Date	Time	mM
27-Aug-95	18:34	11.4
26-Aug-95	11:46	12.0
26-Aug-95	09:22	12.0
24-Aug-95	16:52	12.7
23-Aug-95	18:31	15.3
22-Aug-95	18:15	5.9
22-Aug-95	07:27	4.6
21-Aug-95	07:29	3.6
20-Aug-95	18:01	10.2
20-Aug-95	08:00	2.7
19-Aug-95	18:28	14.5
19-Aug-95	08:06	13.2
18-Aug-95	17:54	10.9
17-Aug-95	16:46	14.1
16-Aug-95	18:30	14.8
16-Aug-95	07:41	9.8
15-Aug-95	16:17	15.8
15-Aug-95	07:53	6.9
14-Aug-95	19:07	18.2
14-Aug-95	07:39	12.5
13-Aug-95	18:29	10.0
12-Aug-95	17:59	12.0
12-Aug-95	08:02	13.1
10-Aug-95	17:24	23.9
09-Aug-95	18:18	14.7
08-Aug-95	16:54	12.0
07-Aug-95	18:17	13.9
07-Aug-95	07:35	11.2
06-Aug-95	18:49	18.1
06-Aug-95	09:19	3.4
05-Aug-95	18:17	28.7
05-Aug-95	08:27	6.6
04-Aug-95	18:31	5.8
04-Aug-95	07:39	15.6
03-Aug-95	21:44	5.3
03-Aug-95	17:04	16.5
03-Aug-95	07:36	5.6
02-Aug-95	18:32	18.3
29-Jul-95	08:13	11.5

Figure 3.1: Sample data downloaded from Blood Glucose Monitors.

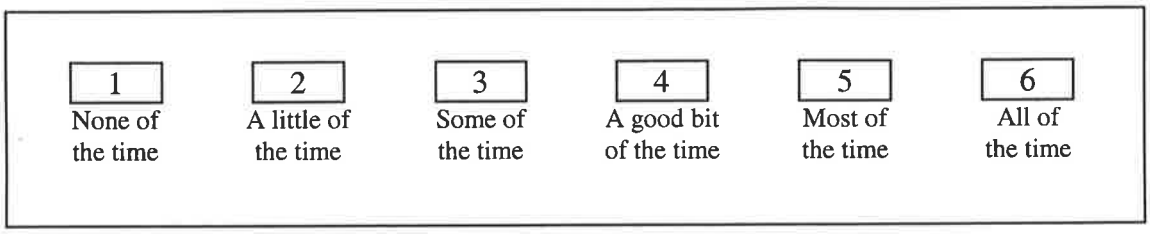


Figure 3.2: Scoring format of the Diabetes Specific Adherence Scale.

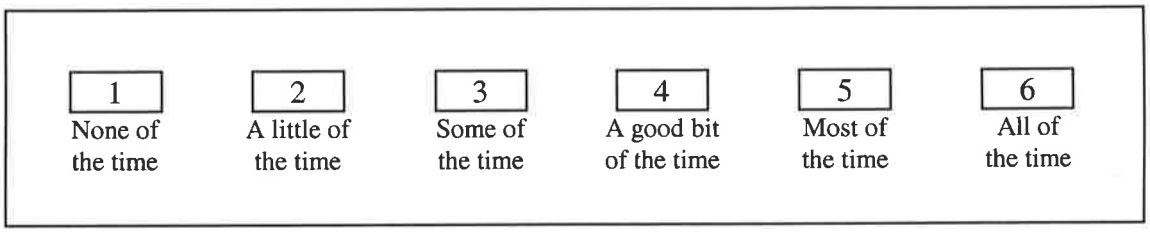


Figure 3.3: Scoring format of the General Adherence Scale.

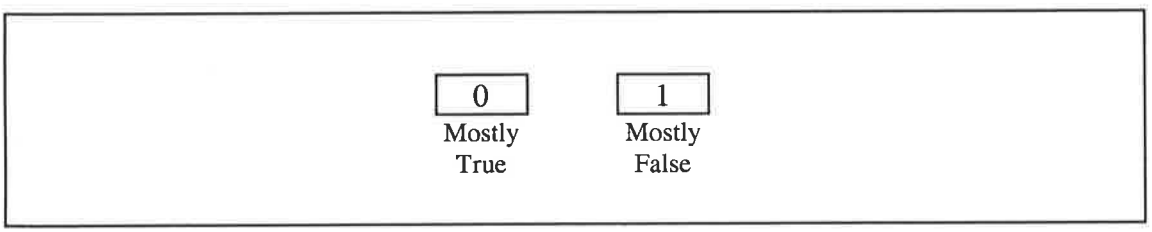


Figure 3.4: Scoring format for the Conflict Behaviour Questionnaire.

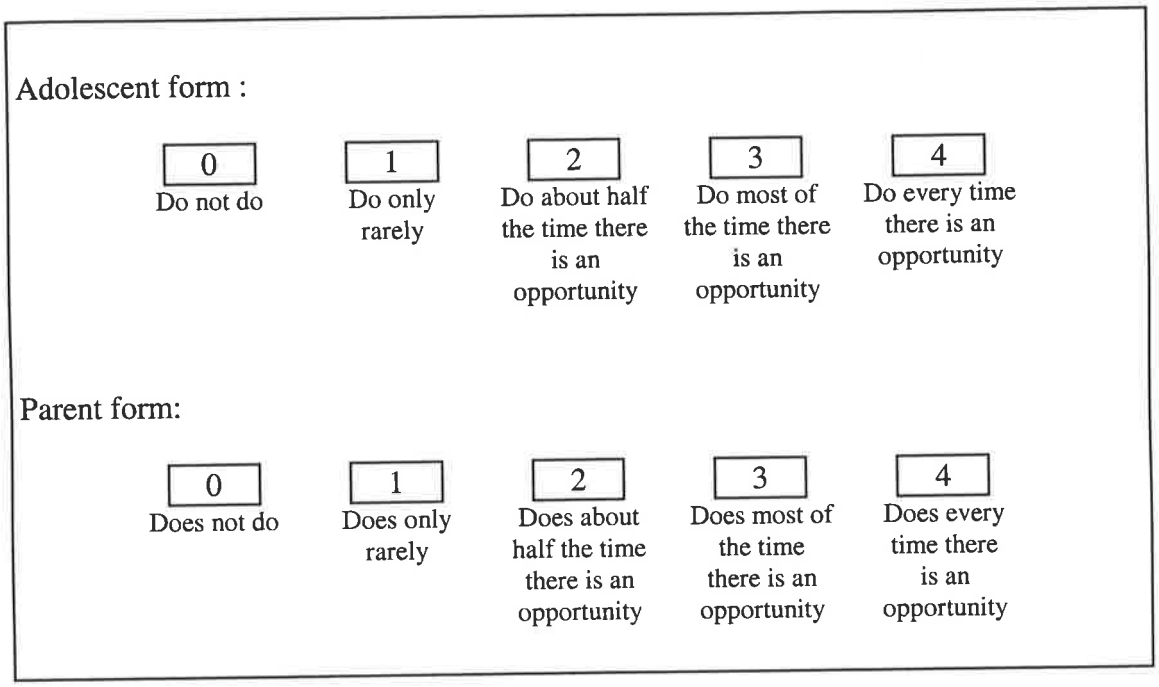


Figure 3.5: Scoring format for first three subscales of the Autonomous Functioning Checklist, by adolescent and parents.

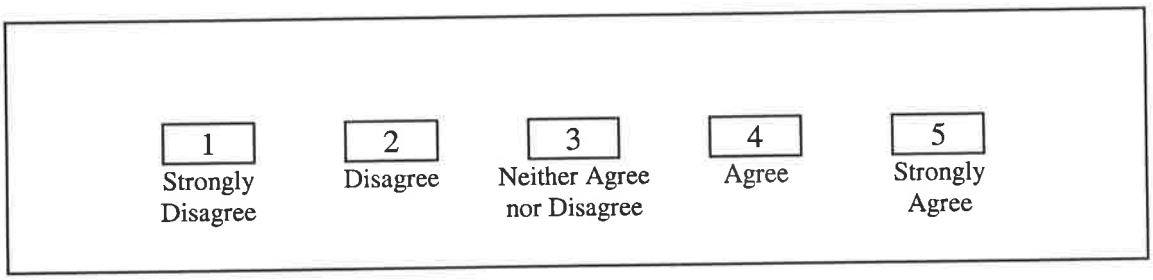


Figure 3.6: Response format for the Adherence Determinants Questionnaire and the Health Value Scale.

Table 3.1: Psychometric properties of the Adherence Determinants Questionnaire, Health Value Scale, and Social Desirability Response Set (DiMatteo, Hays, et al. 1993).

Scale	No. of Items	Range	Alpha Reliability	Homogeneity
Interpersonal Aspects of Care	8	8 — 40	0.84	0.40
Perceived Utility	8	8 — 40	0.76	0.28
Perceived Severity	4	4 — 20	0.65	0.31
Perceived Susceptibility	4	4 — 20	0.69	0.36
Subjective Norms	3	-18 — +18	0.85	0.66
Intentions to Adhere	4	4 — 20	0.84	0.56
Supports / Barriers	4	4 — 20	0.65	0.31
Health Value Scale	6	6 — 30	0.77	0.45

Table 3.2: Alpha reliabilities of Adherence Determinants Questionnaire scales in DiMatteo, Hays, et al. (1993) and the present study.

Scale	Alpha reliabilities.		
	DiMatteo, et al. (1993)	Adolescent reports	Parent reports
Interpersonal Aspects of Care	0.84	0.79	0.83
Perceived Utility	0.76	0.77	0.81
Perceived Severity	0.65	0.63	0.42
Perceived Susceptibility	0.69	0.71	0.70
Subjective Norms	0.85	0.73	0.69
Intentions to Adhere	0.84	0.86	0.87
Supports / Barriers	0.65	0.70	0.56

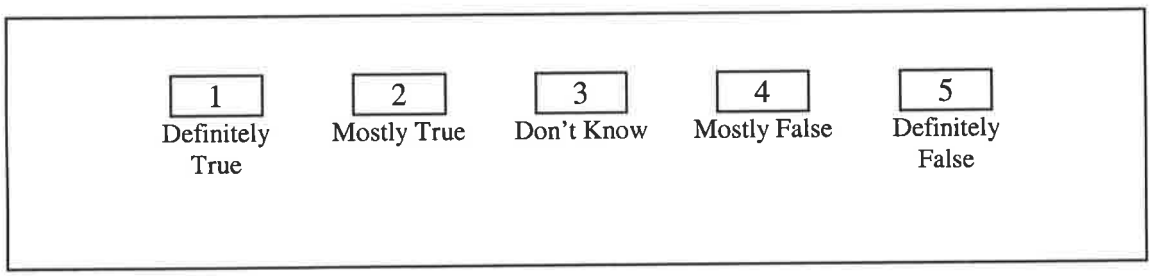


Figure 3.7: Response format for the Socially Desirable Response Set.

Table 3.3: Statistical methodologies employed in the thesis.

Statistics Employed	Variables examined	Rationale
Data Handling		
BGM data coding	Downloaded BGM data	Quantify previous 4 weeks of BGM in terms of (a) number of days of appropriate BGM, and (b) total number of tests.
Basic Statistics		
Means, *SD*s, maxima, minima, 95% confidence intervals	Demographic data; all variables	Examine characteristics of the sample, examine distributional properties of the data.
Exploratory Statistics		
Correlations	Adherence measures, conflict and autonomy measures, metabolic control variables	To determine the relationship between adherence measures, and between adherence measures and conflict, autonomy and metabolic control measures.
Repeated Measures ANOVA	Daily BGM adherence	To determine whether BGM adherence levels varied over time.
Advanced Statistics		
Trend Analysis	Daily BGM adherence	To examine the nature of the BGM adherence variance over time.
Hierarchical Multiple Regression Analyses	All variables	To examine the predictive power of the Six-Factor Model of Adherence. To examine the change in predictive power of the SFMA by the addition of parent-adolescent conflict and adolescent autonomy variables.
Stepwise Multiple Regression Analyses	All variables	To determine the best prediction of adherence and metabolic control from the predictor variables in this thesis.

TABLES CITED IN CHAPTER 4.

Table 4.1: Demographic characteristics of sample adolescents.

	N = 135
Adolescent Gender (n [%])	
Male	60 (44.4 %)
Female	75 (55.6 %)
Adolescent Age (Mean years ± *SD*)	14.9 ± 1.8
Adolescent Age Strata (n [%])	
12 year olds	20 (14.8 %)
13 year olds	24 (17.8 %)
14 year olds	25 (18.5 %)
15 year olds	17 (12.6 %)
16 year olds	25 (18.5 %)
17 year olds	24 (17.8 %)
IDDM Duration (Mean years ± *SD*)	6.0 ± 3.2
Parent Age (Mean ± *SD*)	42.9 ± 5.4
Family Structure (n [%])	
Two Parent	110 (81.5 %)
Single Mother	23 (17.0 %)
Single Father	2 (1.5 %)

Table 4.2: Age and gender distributions of adolescents (n).

	12 year old	13 year old	14 year old	15 year old	16 year old	17 year old
Male	8	12	12	5	12	11
Female	12	12	13	12	13	13

Table 4.3: Occupational prestige and educational attainment of sample parents.

	Fathers† (n = 102)	Mothers‡ (n = 133)
Occupational Prestige (n [%])*		
High (1.0 — 2.9)	12 (10.7 %)	2 (1.5 %)
Middle (3.0 — 4.9)	66 (58.9 %)	40 (30.1 %)
Low (5.0 — 7.9)	17 (15.2 %)	24 (18.0 %)
Home Duties	1 (0.9 %)	55 (41.4 %)
Student / Unemployed / Retired / Pensioner	11 (9.8 %)	6 (4.5 %)
Unclassifiable / Missing	5 (4.5 %)	6 (4.5 %)
Not present	23	2
Educational Attainment (n [%])		
Tertiary qualifications	14 (12.5 %)	18 (13.5 %)
Technical, trade or TAFE certificate	30 (26.8 %)	17 (12.8 %)
Completed High School	12 (10.7 %)	28 (21.0 %)
Some years of High School	50 (44.6 %)	64 (48.1 %)
Completed Primary School	4 (3.6 %)	5 (3.8 %)
Some years of Primary School	0 (0.0 %)	0 (0.0 %)
Missing	2 (1.8 %)	1 (0.8 %)
Not present	23	2

* Daniel (1983).
† 23 fathers were not present in the households.
‡ 2 mothers were not present in the households.

Table 4.4: Demographic information and adherence measures for adolescents from whom BGM data was, and was not, collected.

Measure	Sample with BGM data ($n = 75$)	Sample without BGM data ($n = 60$)	t	df	p
Adolescent Gender (n)					
Male	34 (45.3%)	26 (43.3%)			
Female	41 (54.7%)	34 (56.7%)	1.67*	1	0.2
Adolescent Age (mean years ± *SD* (95% CI))	14.9 ± 1.9 (14.4 to 15.3)	15.0 ± 1.8 (14.6 to 15.5)	-0.43	133	0.7
IDDM Duration (mean years ± *SD* (95% CI))	6.7 ± 3.4 (6.0 to 7.5)	5.2 ± 2.8 (4.4 to 5.9)	2.90	132	0.004
HbA1c result (mean ± *SD* (95% CI))	10.5 ± 1.5 (10.2 to 10.9)	8.5 ± 1.5 (8.1 to 8.8)	7.92	132	< 0.001
Adolescent GAS score (mean ± *SD* (95% CI))	22.5 ± 4.8 (21.4 to 23.6)	25.3 ± 4.0 (24.3 to 26.4)	-3.58	129	< 0.001
Adolescent DSAS score (mean ± *SD* (95% CI))	37.3 ± 6.1 (35.9 to 38.7)	39.3 ± 6.7 (37.6 to 41.0)	-1.83	133	0.07
Parent GAS score (mean ± *SD* (95% CI))	22.0 ± 4.9 (20.8 to 23.1)	25.3 ± 4.2 (24.2 to 26.4)	-4.18	132	< 0.001
Parent DSAS score (mean ± *SD* (95% CI))	37.0 ± 6.5 (35.5 to 38.5)	39.1 ± 8.1 (37.0 to 41.2)	-1.64	132	0.1

* Chi-square analysis

Table 4.5: Obtained means (± *SD*s) for the General Adherence Scale, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	5 — 30	7 — 30	11 — 30	23.8 ± 4.7	23.4 ± 4.8
Male (n = 60)	5 — 30	15 — 30	11 — 30	24.3 ± 4.3	23.6 ± 4.8
Female (n = 75)	5 — 30	7 — 30	12 — 30	23.4 ± 4.9	23.3 ± 4.9
12 Year Old (n = 20)	5 — 30	7 — 30	16 — 30	24.6 ± 4.8	24.6 ± 4.1
13 Year Old (n = 24)	5 — 30	15 — 30	14 — 30	23.7 ± 5.3	24.2 ± 5.0
14 Year Old (n = 25)	5 — 30	13 — 30	11 — 30	23.8 ± 4.3	23.5 ± 4.6
15 Year Old (n = 17)	5 — 30	16 — 28	15 — 30	22.1 ± 4.2	22.2 ± 4.5
16 Year Old (n = 25)	5 — 30	12 — 30	12 — 30	24.4 ± 4.9	23.4 ± 5.7
17 Year Old (n = 24)	5 — 30	15 — 30	12 — 28	23.8 ± 4.6	22.4 ± 4.8

Table 4.6: Obtained means (± *SD*s) for the Diabetes Specific Adherence Scale, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	9 — 54	14 — 52	18 — 51	38.2 ± 6.4	37.9 ± 7.3
Male (n = 60)	9 — 54	26 — 52	25 — 50	38.7 ± 5.6	38.4 ± 6.7
Female (n = 75)	9 — 54	14 — 50	18 — 51	37.8 ± 7.0	37.6 ± 7.7
12 Year Old (n = 20)	9 — 54	22 — 49	24 — 50	40.8 ± 5.6	40.1 ± 6.4
13 Year Old (n = 24)	9 — 54	14 — 52	26 — 49	38.5 ± 7.6	37.3 ± 6.0
14 Year Old (n = 25)	9 — 54	25 — 50	18 — 48	39.0 ± 5.8	37.5 ± 7.9
15 Year Old (n = 17)	9 — 54	25 — 46	23 — 46	36.4 ± 6.0	35.2 ± 6.5
16 Year Old (n = 25)	9 — 54	26 — 49	18 — 51	36.5 ± 5.8	39.4 ± 8.0
17 Year Old (n = 24)	9 — 54	26 — 50	21 — 49	37.7 ± 7.0	37.8 ± 8.2

Table 4.7: Mean (± *SD*) and range of frequencies of Blood Glucose Monitoring and days of appropriate Blood Glucose Monitoring, according to adolescent gender and age.

	Frequency of Blood Glucose Monitoring		
	Possible Range	Observed Range	Mean ± *SD*
Total Sample (n = 75)	0 — 125	0 — 125	37.1 ± 28.5
Male (n = 34)	0 — 125	0 — 125	34.8 ± 31.2
Female (n = 41)	0 — 125	0 — 102	38.9 ± 26.3
12 Year Old (n = 12)	0 — 125	22 — 125	59.2 ± 24.9
13 Year Old (n = 14)	0 — 125	0 — 102	37.4 ± 26.9
14 Year Old (n = 11)	0 — 125	6 — 94	36.6 ± 28.7
15 Year Old (n = 12)	0 — 125	4 — 114	42.4 ± 36.6
16 Year Old (n = 13)	0 — 125	4 — 81	24.0 ± 21.0
17 Year Old (n = 13)	0 — 125	0 — 59	24.7 ± 20.9

Table 4.8: Mean (± *SD*) and range of Days of Appropriate Blood Glucose Monitoring, according to adolescent gender and age.

	Appropriate Days of BGM*		
	Possible Range	Observed Range	Mean ± *SD*
Total Sample (n = 75)	0 — 28	0 — 28	11.9 ± 10.3
Male (n = 34)	0 — 28	0 — 28	10.8 ± 10.6
Female (n = 41)	0 — 28	0 — 28	12.9 ± 10.1
12 Year Old (n = 12)	0 — 28	7 — 27	19.4 ± 6.1
13 Year Old (n = 14)	0 — 28	0 — 28	12.1 ± 9.9
14 Year Old (n = 11)	0 — 28	1 — 28	13.1 ± 12.4
15 Year Old (n = 12)	0 — 28	1 — 28	14.2 ± 12.0
16 Year Old (n = 13)	0 — 28	0 — 27	6.2 ± 7.7
17 Year Old (n = 13)	0 — 28	0 — 25	7.5 ± 8.6

*** Appropriate Days of BGM:** Appropriate days of blood glucose monitoring in the previous month were defined as those days in which two or more blood glucose tests were performed.

Table 4.9: Obtained means (± *SD*s) for the Conflict Behaviour Questionnaire, with scoring ranges.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n = 127*)	0 — 20	0 — 17	0 — 20	5.7 ± 3.7	5.2 ± 5.2
Male (n = 58)	0 — 20	0 — 17	1 — 17	5.2 ± 3.4	5.3 ± 5.6
Female (n = 69)	0 — 20	0 — 20	0 — 20	6.1 ± 3.9	5.1 ± 4.9
12 Year Old (n = 18)	0 — 20	2 — 15	0 — 13	4.6 ± 3.6	4.1 ± 4.1
13 Year Old (n = 23)	0 — 20	1 — 17	0 — 20	5.2 ± 4.3	4.1 ± 6.1
14 Year Old (n = 24)	0 — 20	0 — 14	0 — 17	6.3 ± 3.5	7.1 ± 4.1
15 Year Old (n = 16)	0 — 20	2 — 17	0 — 20	5.1 ± 3.8	5.5 ± 6.6
16 Year Old (n = 23)	0 — 20	2 — 15	0 — 19	6.2 ± 3.3	5.6 ± 6.0
17 Year Old (n = 23)	0 — 20	1 — 16	0 — 13	6.3 ± 3.7	4.7 ± 3.9

* for 12 cases scores could not be computed because of missing adolescent or parent scores.

Table 4.10: Obtained means (± *SD*s) for the Combined Conflict Behaviour Questionnaire, with scoring ranges.

Sample	Range	Observed Range	Mean ± *SD*
Total sample (n = 127*)	0 — 40	1 — 37	10.9 ± 7.4
Male (n = 58)	0 — 40	2 — 37	10.4 ± 7.9
Female (n = 69)	0 — 40	1 — 26	11.3 ± 7.0
12 Year Old (n = 18)	0 — 40	3 — 25	8.7 ± 6.6
13 Year Old (n = 23)	0 — 40	1 — 37	9.3 ± 10.1
14 Year Old (n = 24)	0 — 40	3 — 26	13.4 ± 6.3
15 Year Old (n = 16)	0 — 40	2 — 23	10.6 ± 7.5
16 Year Old (n = 23)	0 — 40	2 — 27	11.7 ± 7.1
17 Year Old (n = 23)	0 — 40	3 — 25	10.9 ± 6.1

* for 12 cases combined scores could not be computed because of missing adolescent or parent scores.

Table 4.11: Normative data for the 20 item CBQ (Source: Foster & Robin, 1988).

	Means from normative samples of families	
	Clinical level of conflict	Nonclinical level of conflict
Mother report	12.4 ± 5.0	2.4 ± 2.8
Father report	10.5 ±5.0	3.2 ± 3.0
Adolescent report (of mother)	8.4 ± 6.0	2.0 ± 3.1
Adolescent report (of father)	7.6 ± 5.4	1.6 ± 1.6

Table 4.12: Obtained means (± *SD*s) for the Autonomous Functioning Checklist, with scoring ranges (n = 135).

AFC subscale	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Self- & Family Care	0 — 88	8 — 76	5 — 83	33.2 ± 12.7	30.3 ± 12.2
Management Activity	0 — 80	18 — 76	15 — 76	50.3 ± 13.0	49.0 ± 13.9
Recreational Activity	0 — 64	8 — 57	9 — 50	27.8 ± 9.8	26.8 ± 8.6
Social / Vocational Act.	0 — 20	0 — 18	2 — 17	10.0 ± 3.3	8.7 ± 3.6

Table 4.13: Obtained means (± *SD*s) for the Autonomous Functioning Checklist, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	0 — 252	59 — 187	39 — 190	122.3 ± 29.6	116.0 ± 30.0
Male (n = 60)	0 — 252	59 — 181	39 — 187	115.5 ± 30.3	112.7 ± 29.9
Female (n = 75)	0 — 252	71 — 187	68 — 190	128.3 ± 27.8	118.9 ± 30.0
12 Year Old (n = 20)	0 — 252	59 — 159	39 — 172	99.3 ± 26.5	97.1 ± 33.9
13 Year Old (n = 24)	0 — 252	60 — 174	55 — 151	112.2 ± 31.7	106.2 ± 24.6
14 Year Old (n = 25)	0 — 252	67 — 187	81— 145	129.4 ± 30.9	108.7 ± 19.9
15 Year Old (n = 17)	0 — 252	86 — 169	72 — 164	125.6 ± 26.9	120.9 ± 25.3
16 Year Old (n = 25)	0 — 252	76 — 166	64 — 185	124.6 ± 24.3	119.2 ± 29.6
17 Year Old (n = 24)	0 — 252	101 — 180	77 — 190	138.7 ± 22.6	141.1 ± 27.8

Table 4.14: Obtained means (± *SD*s) for the Autonomous Functioning Checklist subscale Self- and Family-Care, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	0 — 88	8 — 76	5 — 83	33.2 ± 12.7	30.3 ± 12.2
Male (n = 60)	0 — 88	9 — 68	5 — 83	32.2 ± 11.8	30.6 ± 12.1
Female (n = 75)	0 — 88	8 — 76	8 — 60	34.1 ± 13.4	30.2 ± 12.4
12 Year Old (n = 20)	0 — 88	12 — 76	5 — 58	29.4 ± 15.2	23.7 ± 12.5
13 Year Old (n = 24)	0 — 88	13 — 59	15 — 49	30.4 ± 13.1	27.7 ± 8.1
14 Year Old (n = 25)	0 — 88	13 — 57	8 — 55	36.4 ± 11.4	29.4 ± 9.6
15 Year Old (n = 17)	0 — 88	8 — 59	15 — 58	31.8 ± 13.2	32.6 ± 10.5
16 Year Old (n = 25)	0 — 88	9 — 49	15 — 58	30.6 ± 10.1	28.0 ± 10.1
17 Year Old (n = 24)	0 — 88	25 — 68	18 — 83	39.6 ± 11.5	40.4 ± 15.2

Table 4.15: Obtained means (± *SD*s) for the Autonomous Functioning Checklist subscale Management Activity, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	0 — 80	18 — 76	15 — 76	50.3 ± 13.0	49.0 ± 13.9
Male (n = 60)	0 — 80	18 — 75	15 — 73	46.9 ± 13.3	47.6 ± 13.6
Female (n = 75)	0 — 80	29 — 76	24 — 76	53.2 ± 12.1	50.0 ± 14.0
12 Year Old (n = 20)	0 — 80	21 — 55	16 — 59	36.2 ± 10.6	38.8 ± 13.9
13 Year Old (n = 24)	0 — 80	18 — 61	15 — 63	43.6 ± 11.2	43.8 ± 12.2
14 Year Old (n = 25)	0 — 80	28 — 73	34 — 65	51.6 ± 12.9	45.9 ± 9.8
15 Year Old (n = 17)	0 — 80	33 — 70	29 — 71	53.8 ± 10.0	52.5 ± 11.4
16 Year Old (n = 25)	0 — 80	36 — 71	23 — 72	55.0 ± 8.9	51.1 ± 13.2
17 Year Old (n = 24)	0 — 80	39 — 76	26 — 76	59.2 ± 10.4	60.9 ± 12.2

Table 4.16: Obtained means (± *SD*s) for the Autonomous Functioning Checklist subscale Recreational Activity, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	0 — 64	8 — 57	9 — 50	27.8 ± 9.8	26.8 ± 8.6
Male (n = 60)	0 — 64	8 — 57	9 — 50	26.6 ± 10.5	26.2 ± 8.6
Female (n = 75)	0 — 64	11 — 56	10 — 48	28.8 ± 9.1	27.3 ± 8.6
12 Year Old (n = 20)	0 — 64	8 — 43	9 — 46	23.5 ± 8.5	25.3 ± 9.5
13 Year Old (n = 24)	0 — 64	11 — 46	11 — 48	28.3 ± 11.0	25.9 ± 9.4
14 Year Old (n = 25)	0 — 64	18 — 57	18 — 38	30.9 ± 10.5	25.6 ± 5.8
15 Year Old (n = 17)	0 — 64	16 — 43	16 — 46	28.4 ± 8.8	27.3 ± 8.5
16 Year Old (n = 25)	0 — 64	12 — 49	10 — 46	27.7 ± 10.8	27.5 ± 9.4
17 Year Old (n = 24)	0 — 64	19 — 53	18 — 50	27.7 ± 7.7	29.4 ± 8.6

Table 4.17: Obtained means (± *SD*s) for the Autonomous Functioning Checklist subscale Social and Vocational Activity, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	0 — 20	0 — 18	2 — 17	10.0 ± 3.3	8.7 ± 3.6
Male (n = 60)	0 — 20	2 — 18	2 — 17	9.9 ± 3.5	8.2 ± 3.5
Female (n = 75)	0 — 20	0 — 17	2 — 17	10.1 ± 3.1	9.1 ± 3.7
12 Year Old (n = 20)	0 — 20	3 — 12	3 — 15	8.7 ± 2.6	7.9 ± 3.5
13 Year Old (n = 24)	0 — 20	2 — 14	2 — 17	9.0 ± 3.3	7.5 ± 3.6
14 Year Old (n = 25)	0 — 20	2 — 15	2 — 13	9.4 ± 3.3	7.6 ± 3.1
15 Year Old (n = 17)	0 — 20	4 — 13	3 — 15	9.8 ± 2.7	8.1 ± 3.1
16 Year Old (n = 25)	0 — 20	0 — 18	4 — 16	11.2 ± 3.6	10.0 ± 3.2
17 Year Old (n = 24)	0 — 20	6 — 17	3 — 17	11.7 ± 2.7	10.9 ± 4.0

Table 4.18: Normative mean scores (± *SD*s) from parents according to age and sex of adolescents for each subscale (Source: Sigafoos, et al. 1988).

Subscale	12 year old	13 year old	14 year old	15 year old	16 year old	17 year old
Self- & family-care						
Female	25.0 ± 10.4	29.6 ± 9.6	33.5 ± 11.3	36.0 ± 10.6	36.3 ± 11.7	41.2 ± 12.0
Male	24.9 ± 7.8	27.7 ± 8.6	29.1 ± 11.2	34.6 ± 9.7	31.2 ± 10.3	37.3 ± 6.9
Management						
Female	45.4 ± 10.7	52.1 ± 9.1	55.0 ± 10.1	60.7 ± 9.9	60.6 ± 9.9	64.1 ± 8.8
Male	43.9 ± 10.2	52.4 ± 11.6	50.6 ± 12.7	58.3 ± 7.5	60.3 ± 9.6	56.8 ± 13.7
Recreation						
Female	22.8 ± 7.0	26.8 ± 7.2	28.4 ± 9.6	27.2 ± 7.8	28.9 ± 7.3	26.8 ± 8.1
Male	21.5 ± 8.2	25.5 ± 9.5	23.8 ± 9.5	26.3 ± 9.5	23.6 ± 9.3	24.6 ± 9.5
Social / Vocational						
Female	7.0 ± 2.6	10.0 ± 2.7	11.4 ± 2.2	11.8 ± 3.4	13.6 ± 4.8	13.1 ± 3.2
Male	8.0 ± 3.2	9.4 ± 2.7	9.8 ± 3.4	10.8 ± 3.7	10.4 ± 3.5	11.3 ± 4.1

Table 4.19: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire, with scoring ranges (n = 135).

		Observed Range		Mean ± *SD*	
Adherence Determinants Questionnaire scale	Possible Range	Adolescent	Parent	Adolescent	Parent
Interpersonal Care	8 — 40	19 — 40	22 — 40	31.4 ± 4.2	32.9 ± 4.1
Perceived Utility	8 — 40	22 — 40	18 — 40	32.5 ± 4.1	33.4 ± 4.2
Perceived Severity	4 — 20	4 — 17	4 — 18	8.5 ± 2.6	10.3 ± 2.4
Perceived Susceptibility	4 — 20	6 — 20	8 — 20	13.8 ± 3.1	14.7 ± 2.5
Subjective Norms	-18 — 18	-12 — 2	-18 — 3	-1.3 ± 2.2	-1.8 ± 3.0
Intentions to Adhere	4 — 20	5 — 20	6 — 20	16.6 ± 2.4	16.1 ± 2.8
Supports / Barriers	4 — 20	8 — 20	8 — 20	14.6 ± 2.6	14.3 ± 2.3

Table 4.20: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire scale Interpersonal Aspects of Care, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	8 — 40	19 — 40	22 — 40	31.4 ± 4.2	32.9 ± 4.1
Male (n = 60)	8 — 40	24 — 40	25 — 40	32.2 ± 4.5	32.9 ± 3.9
Female (n = 75)	8 — 40	19 — 40	22 — 40	30.8 ± 3.9	32.9 ± 4.3
12 Year Old (n = 20)	8 — 40	24 — 38	25 — 40	30.0 ± 4.2	32.9 ± 3.9
13 Year Old (n = 24)	8 — 40	19 — 39	26 — 40	31.5 ± 5.0	32.2 ± 4.1
14 Year Old (n = 25)	8 — 40	23 — 40	25 — 40	31.6 ± 4.4	34.2 ± 4.2
15 Year Old (n = 17)	8 — 40	25 — 38	26 — 40	31.3 ± 3.2	33.1 ± 3.6
16 Year Old (n = 25)	8 — 40	26 — 39	22 — 40	31.5 ± 3.7	32.6 ± 4.8
17 Year Old (n = 24)	8 — 40	24 — 40	25 — 39	32.1 ± 4.3	32.5 ± 3.9

Table 4.21: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire scale Perceived Utility, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	8 — 40	22 — 40	18 — 40	32.5 ± 4.1	33.4 ± 4.2
Male (n = 60)	8 — 40	22 — 40	22 — 40	32.6 ± 4.2	33.3 ± 3.8
Female (n = 75)	8 — 40	23 — 40	18 — 40	32.4 ± 4.0	33.6 ± 4.5
12 Year Old (n = 20)	8 — 40	25 — 38	28 — 40	32.5 ± 3.7	33.7 ± 3.6
13 Year Old (n = 24)	8 — 40	23 — 40	27 — 40	31.6 ± 4.6	33.6 ± 4.0
14 Year Old (n = 25)	8 — 40	26 — 40	25 — 40	33.5 ± 3.8	33.2 ± 3.8
15 Year Old (n = 17)	8 — 40	24 — 39	24 — 38	32.0 ± 3.7	33.0 ± 4.6
16 Year Old (n = 25)	8 — 40	25 — 40	18 — 40	32.8 ± 3.9	33.7 ± 5.4
17 Year Old (n = 24)	8 — 40	22 — 40	22 — 40	32.5 ± 4.6	33.5 ± 4.2

Table 4.22: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire scale Perceived Severity, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	4 — 20	4 — 17	4 — 18	8.5 ± 2.6	10.3 ± 2.4
Male (n = 60)	4 — 20	4 — 16	6 — 18	8.5 ± 2.5	10.9 ± 2.3
Female (n = 75)	4 — 20	4 — 17	4 — 16	8.5 ± 2.7	9.8 ± 2.4
12 Year Old (n = 20)	4 — 20	6 — 17	5 — 14	8.7 ± 2.4	9.7 ± 2.4
13 Year Old (n = 24)	4 — 20	4 — 14	5 — 16	8.7 ± 2.9	10.3 ± 2.3
14 Year Old (n = 25)	4 — 20	4 — 14	4 — 16	8.3 ± 2.4	10.1 ± 2.4
15 Year Old (n = 17)	4 — 20	5 — 14	5 — 16	8.7 ± 2.6	10.0 ± 2.9
16 Year Old (n = 25)	4 — 20	4 — 11	6 — 18	7.8 ± 1.9	10.5 ± 2.4
17 Year Old (n = 24)	4 — 20	4 — 16	7 — 16	9.0 ± 3.0	11.1 ± 2.1

Table 4.23: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire scale Perceived Susceptibility, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	4 — 20	6 — 20	8 — 20	13.8 ± 3.1	14.7 ± 2.5
Male (n = 60)	4 — 20	7 — 20	8 — 20	14.0 ± 3.1	14.5 ± 2.6
Female (n = 75)	4 — 20	6 — 20	8 — 20	13.7 ± 3.0	14.9 ± 2.4
12 Year Old (n = 20)	4 — 20	8 — 18	11 — 20	13.4 ± 2.9	15.1 ± 2.1
13 Year Old (n = 24)	4 — 20	7 — 20	8 — 20	13.0 ± 3.5	14.1 ± 3.1
14 Year Old (n = 25)	4 — 20	9 — 19	11 — 20	13.7 ± 2.5	15.0 ± 2.6
15 Year Old (n = 17)	4 — 20	9 — 20	10 — 20	14.8 ± 3.0	14.4 ± 2.8
16 Year Old (n = 25)	4 — 20	8 — 20	10 — 20	14.6 ± 3.3	14.6 ± 2.5
17 Year Old (n = 24)	4 — 20	6 — 20	11 — 20	13.9 ± 3.0	14.9 ± 2.0

Table 4.24: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire scale Subjective Norms, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	-18 — 18	-12 — 2	-18 — 3	-1.3 ± 2.2	-1.8 ± 3.0
Male (n = 60)	-18 — 18	-11 — 1	-12 — 1	-0.9 ± 1.9	-1.8 ± 2.6
Female (n = 75)	-18 — 18	-12 — 2	-18 — 3	-1.6 ± 2.3	-1.9 ± 3.3
12 Year Old (n = 20)	-18 — 18	-6 — 2	-8 — 2	-1.3 ± 2.1	-0.8 ± 1.9
13 Year Old (n = 24)	-18 — 18	-12 — 1	-12 — 3	-1.5 ± 3.1	-1.5 ± 3.4
14 Year Old (n = 25)	-18 — 18	-4 — 0	-6 — 1	-0.5 ± 1.0	-1.4 ± 1.7
15 Year Old (n = 17)	-18 — 18	-5 — 0	-7 — 0	-2.1 ± 1.7	-1.9 ± 2.3
16 Year Old (n = 25)	-18 — 18	-5 — 0	-8 — 0	-1.0 ± 1.4	-2.3 ± 2.8
17 Year Old (n = 24)	-18 — 18	-11 — 0	-18— 0	-1.8 ± 2.7	-2.9 ± 4.5

Table 4.25: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire scale Intentions to Adhere, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	4 — 20	5 — 20	6 — 20	16.6 ± 2.4	16.1 ± 2.8
Male (n = 60)	4 — 20	5 — 20	6 — 20	16.6 ± 2.7	15.8 ± 3.1
Female (n = 75)	4 — 20	11 — 20	7 — 20	16.6 ± 2.2	16.4 ± 2.5
12 Year Old (n = 20)	4 — 20	14 — 20	14 — 20	17.6 ± 1.8	16.7 ± 1.9
13 Year Old (n = 24)	4 — 20	5 — 20	6 — 20	16.0 ± 3.4	16.0 ± 3.4
14 Year Old (n = 25)	4 — 20	12 — 20	9 — 20	16.7 ± 2.3	15.4 ± 3.0
15 Year Old (n = 17)	4 — 20	12 — 19	10 — 20	16.1 ± 1.8	16.4 ± 2.9
16 Year Old (n = 25)	4 — 20	14 — 20	7 — 20	17.1 ± 1.9	16.4 ± 2.9
17 Year Old (n = 24)	4 — 20	11 — 20	8 — 20	16.1 ± 2.4	16.2 ± 2.5

Table 4.26: Obtained means (± *SD*s) for the Adherence Determinants Questionnaire scale Supports / Barriers, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	4 — 20	8 — 20	8 — 20	14.6 ± 2.6	14.3 ± 2.3
Male (n = 60)	4 — 20	11 — 20	8 — 19	14.9 ± 2.4	14.0 ± 2.4
Female (n = 75)	4 — 20	8 — 20	10 — 20	14.3 ± 2.7	14.5 ± 2.3
12 Year Old (n = 20)	4 — 20	10 — 19	10 — 17	14.1 ± 2.5	13.9 ± 2.1
13 Year Old (n = 24)	4 — 20	9 — 20	10 — 20	14.6 ± 2.7	14.4 ± 2.4
14 Year Old (n = 25)	4 — 20	8 — 19	10 — 17	14.3 ± 2.8	13.8 ± 2.1
15 Year Old (n = 17)	4 — 20	11 — 17	10 — 18	14.0 ± 1.7	14.6 ± 2.3
16 Year Old (n = 25)	4 — 20	10 — 20	10 — 19	14.9 ± 2.5	14.7 ± 2.4
17 Year Old (n = 24)	4 — 20	8 — 20	8 — 20	15.2 ± 3.1	14.5 ± 2.6

Table 4.27: Means (± *SD*s) from studies using the Adherence Determinants Questionnaire (Source: DiMatteo, Hays, et al. 1993).

Adherence Determinants Questionnaire scale:	Study				
	Cancer (N=115)	Pap Smear (N=51)	Rehab. (N=131)	Head/Neck (N=91)	Diet (N=82)
Interpersonal Asp. Care	33.0 ± 4.5	29.7 ± 6.5	34.9 ± 4.4	32.9 ± 4.2	34.7 ± 4.4
Perceived Utility	33.8 ± 3.7	32.8 ± 4.3	33.5 ± 3.9	33.3 ± 4.7	34.5 ± 4.2
Perceived Severity	11.1 ± 2.9	12.3 ± 3.2	11.0 ± 2.2	15.2 ± 3.1	15.0 ± 2.6
Perceived Susceptibility	11.0 ± 2.9	11.3 ± 3.0	10.4 ± 3.2	10.8 ± 2.8	9.6 ± 2.5
Subjective Norms	4.2 ± 5.2	5.3 ± 5.0	4.4 ± 4.9	7.3 ± 6.2	2.0 ± 3.4
Intentions to Adhere	17.5 ± 2.4	17.7 ± 2.5	18.1 ± 2.2	17.7 ± 3.3	17.4 ± 2.2
Supports / Barriers	14.8 ± 2.7	14.3 ± 3.4	16.4 ± 2.7	15.3 ± 3.2	13.7 ± 2.9

Table 4.28: Obtained means (± *SD*s) for the Health Value Scale, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n = 135)	4 — 20	5 — 20	8 — 20	14.7 ± 2.7	15.0 ± 2.9
Male (n = 60)	4 — 20	5 — 20	8 — 20	14.5 ± 2.8	15.2 ± 3.0
Female (n = 75)	4 — 20	7 — 20	9 — 20	14.8 ± 2.6	14.8 ± 2.8
12 Year Old (n = 20)	4 — 20	12 — 20	10 — 19	15.8 ± 2.1	14.7 ± 2.5
13 Year Old (n = 24)	4 — 20	5 — 20	8 — 20	13.8 ± 3.2	15.0 ± 3.3
14 Year Old (n = 25)	4 — 20	7 — 20	11 — 20	14.6 ± 3.0	15.3 ± 2.4
15 Year Old (n = 17)	4 — 20	11 — 17	10 — 18	14.8 ± 2.0	14.5 ± 2.4
16 Year Old (n = 25)	4 — 20	9 — 20	9 — 20	14.8 ± 2.8	14.9 ± 3.3
17 Year Old (n = 24)	4 — 20	10 — 18	8 — 20	14.4 ± 2.5	15.5 ± 3.3

Table 4.29: Means (± *SD*s) from studies using the Health Value Scale (Sources: DiMatteo, Hays, et al. 1993; Lau, et al. 1986).

Study	Sample	Scoring Range	N	Mean ± *SD*
Lau, et al. (1986)	11-16 year old girls	4 - 20*	97	13.4 ± 3.0
Lau, et al. (1986)	Parents of 11-16 yr olds girls	4 - 20*	95	16.2 ± 2.9
Lau, et al. (1986)	Ulcer clinic	4 - 28†	74	22.5 ± 5.2
Lau, et al. (1986)	University students	4 - 28†	1026	20.3 ± 4.4
Lau, et al. (1986)	Parents of Uni. students	4 - 28†	940	23.0 ± 4.2
DiMatteo, Hays, et al. (1993)	Cancer Prevention	6 - 30‡	115	23.7 ± 5.0
DiMatteo, Hays, et al. (1993)	Pap Smear	6 - 30‡	51	25.6 ± 4.4
DiMatteo, Hays, et al. (1993)	Rehabilitation	6 - 30‡	131	23.1 ± 5.3
DiMatteo, Hays, et al. (1993)	Head / Neck	6 - 30‡	91	26.2 ± 4.1
DiMatteo, Hays, et al. (1993)	Diet	6 - 30‡	82	22.3 ± 5.5

* Using 4 items; 5 point Likert format.
† Using 4 items; 7 point Likert format.
‡ Using 6 items; 5 point Likert format.

Table 4.30: Obtained means (± *SD*s) for the Diabetes Knowledge Questionnaire, with scoring ranges according to adolescent gender and age.

Sample	Possible Range	Observed Range		Mean ± *SD*	
		Adolescent	Parent	Adolescent	Parent
Total sample (n = 135)	0 — 15	3 — 15	1 — 15	11.2 ± 2.2	12.6 ± 2.0
Male (n = 60)	0 — 15	4 — 15	6 — 15	11.2 ± 2.0	13.1 ± 1.4
Female (n = 75)	0 — 15	3 — 15	1 — 15	11.2 ± 2.3	12.1 ± 2.3
12 Year Old (n = 20)	0 — 15	4 — 14	1 — 15	10.8 ± 2.5	12.4 ± 2.9
13 Year Old (n = 24)	0 — 15	3 — 15	10 — 15	10.5 ± 2.8	13.0 ± 1.4
14 Year Old (n = 25)	0 — 15	6 — 14	4 — 15	11.0 ± 2.3	12.4 ± 2.5
15 Year Old (n = 17)	0 — 15	8 — 14	10 — 14	11.6 ± 1.5	12.2 ± 1.3
16 Year Old (n = 25)	0 — 15	7 — 14	10 — 15	11.7 ± 1.6	12.7 ± 1.2
17 Year Old (n = 24)	0 — 15	8 — 15	6 — 15	11.9 ± 1.7	12.7 ± 2.2

Table 4.31: Mean (± *SD*) HbA_{1c} assay levels, according to adolescent gender and age.

Sample	Possible Range	Observed Range	Mean ± *SD*
Total sample (n = 135)	2.5 — 14.0	5.8 — 14.0	9.6 ± 1.8
Male (n = 60)	2.5 — 14.0	6.8 — 14.0	9.9 ± 1.7
Female (n = 75)	2.5 — 14.0	5.8 — 14.0	9.4 ± 1.9
12 Year Old (n = 20)	2.5 — 14.0	6.7 — 14.0	9.7 ± 1.8
13 Year Old (n = 24)	2.5 — 14.0	7.3 — 11.5	9.8 ± 1.3
14 Year Old (n = 25)	2.5 — 14.0	6.7 — 13.5	9.5 ± 1.8
15 Year Old (n = 17)	2.5 — 14.0	6.2 — 12.4	9.7 ± 2.1
16 Year Old (n = 25)	2.5 — 14.0	5.8 — 14.0	9.9 ± 2.2
17 Year Old (n = 24)	2.5 — 14.0	5.8 — 13.0	9.1 ± 1.7

Table 4.32: Pearson correlation coefficiants (and *p* values) between questionnaire measures and Social Desirability Responding amongst adolescents and parents.

	Adolescent		Parent	
Measure	*r*	*p*	*r*	*p*
Diabetes Specific Adherence	0.19	0.03	-0.11	
General Adherence	0.13		-0.05	
Autonomous Functioning Checklist				
Self- & Family Care	0.23	0.01	0.15	
Management Activity	0.27	0.002	0.24	0.01
Recreational Activity	0.19	0.04	0.24	0.01
Social & Vocational Activity	0.26	0.002	0.15	
Conflict Behaviour Questionnaire	-0.18		0.01	
Adherence Determinants Questionnaire				
Interpersonal Aspects of Care	0.18	0.04	0.02	
Perceived Utility	0.29	0.001	0.00	
Perceived Severity	-0.22	0.01	0.03	
Perceived Susceptibility	-0.02		-0.08	
Subjective Norms	-0.17		0.10	
Intentions	0.27	0.002	0.04	
Supports / Barriers	0.21	0.02	0.08	
Health Value	0.26	0.003	0.07	

TABLES AND FIGURES CITED IN CHAPTER 5.

Table 5.1: Scoring distributions of measures of adherence (n = 135).

	Scoring range	Mean ± *SD* (95% Confidence Interval)
Adolescent reports		
GAS	5 - 30	23.8 ± 4.7 (23.0 to 24.6)
DSAS	9 - 54	38.2 ± 6.4 (37.1 to 39.3)
Parent reports		
GAS	5 - 30	23.4 ± 4.8 (22.6 to 24.2)
DSAS	9 - 54	37.9 ± 7.3 (36.7 to 39.2)
Blood Glucose Monitoring*	0 - 28	11.9 ± 10.3 (9.6 to 14.3)

* n = 75.

Table 5.2: Pearson correlations (with p values*) between questionnaire measures of adherence (n = 135).

	Adolescent DSAS	Adolescent GAS	Parent DSAS	Parent GAS
Adolescent DSAS	--	0.57	0.56	0.38
Adolescent GAS		--	0.28 (0.001)	0.47
Parent DSAS			--	0.46
Parent GAS				--

* unless otherwise stated, $p < 0.001$

Table 5.3: Scoring distributions of measures of adherence before and after 0 - 100 linear transformation (n = 135).

	Original data		Transformed data	
	Scoring range	Mean ± *SD* (95% CI)	Scoring range	Mean ± *SD* (95% CI)
Adolescent reports				
GAS	5 - 30	23.8 ± 4.7 (23.0 to 24.6)	0 - 100	75.1 ± 18.8 (71.8 to 78.4)
DSAS	9 - 54	38.2 ± 6.4 (37.1 to 39.3)	0 - 100	64.89 ± 14.3 (62.4 to 67.3)
Parent reports				
GAS	5 - 30	23.4 ± 4.8 (22.6 to 24.2)	0 - 100	73.6 ± 19.4 (70.3 to 77.0)
DSAS	9 - 54	37.9 ± 7.3 (36.7 to 39.2)	0 - 100	64.3 ± 16.2 (61.6 to 67.1)
Blood Glucose Monitoring*	0 - 28	11.9 ± 10.3 (9.6 to 14.3)	0 - 100	42.6 ± 36.8 (34.1 to 51.0)

* n = 75.

Table 5.4: Wilcoxon Signed-Ranks tests for measures of adherence (n = 135).

First measure	Second measure	Z	*p*
Adolescent DSAS	Adolescent GAS	- 6.35	< 0.0001
Parent DSAS	Parent GAS	- 5.32	< 0.0001
Adolescent GAS	Parent GAS	- 0.86	0.39
Adolescent DSAS	Parent DSAS	- 0.24	0.81

Table 5.5: Pearson correlations (with p values*) between questionnaire and behavioural measures of adherence (n = 75).

	Adolescent DSAS	Adolescent GAS	Parent DSAS	Parent GAS	BGM
Adolescent DSAS	--	0.54	0.54	0.39 (0.001)	0.53
Adolescent GAS		--	0.22 (0.06)	0.38 (0.001)	0.29 (0.01)
Parent DSAS			--	0.49	0.51
Parent GAS				--	0.40
BGM					--

* unless otherwise stated, $p < 0.001$

Table 5.6: Pearson correlations between measures of adherence and adolescents' age.

	Adolescent DSAS (n = 135)	Adolescent GAS (n = 135)	Parent DSAS (n = 135)	Parent GAS (n = 135)	BGM (n = 75)
Adolescent age	- 0.18 (p = 0.04)	-0.02 (p = 0.8)	- 0.03 (p = 0.7)	- 0.14 (p = 0.1)	- 0.36 (p = 0.001)

Table 5.7: Obtained means (± *SD*s) for the General Adherence Scale, with scoring ranges by adolescent age.

Sample	Possible Range	Observed Range		Mean ± *SD* (95% Confidence Interval)	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	5 — 30	7 — 30	11 — 30	23.8 ± 4.7 (23.0 to 24.6)	23.4 ± 4.8 (22.6 to 24.2)
12 Year Old (n = 20)	5 — 30	7 — 30	16 — 30	24.6 ± 4.8 (22.3 to 26.8)	24.6 ± 4.1 (22.6 to 26.6)
13 Year Old (n = 24)	5 — 30	15 — 30	14 — 30	23.7 ± 5.2 (21.5 to 25.9)	24.2 ± 5.0 (22.1 to 26.3)
14 Year Old (n = 25)	5 — 30	13 — 30	11 — 30	23.8 ± 4.3 (21.9 to 25.6)	23.5 ± 4.6 (21.6 to 25.4)
15 Year Old (n = 17)	5 — 30	16 — 28	15 — 30	22.1 ± 4.2 (19.9 to 24.2)	22.2 ± 4.5 (19.9 to 24.6)
16 Year Old (n = 25)	5 — 30	12 — 30	12 — 30	24.4 ± 4.9 (22.3 to 26.5)	23.4 ± 5.7 (21.1 to 25.8)
17 Year Old (n = 24)	5 — 30	15 — 30	12 — 28	23.8 ± 4.6 (21.9 to 25.8)	22.4 ± 4.8 (20.4 to 24.5)

Table 5.8: Obtained means (± *SD*s) for the Diabetes Specific Adherence Scale, with scoring ranges by adolescent age.

Sample	Possible Range	Observed Range		Mean ± *SD* (95% Confidence Interval)	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	9 — 54	14 — 52	18 — 51	38.2 ± 6.4 (37.1 to 39.3)	37.9 ± 7.3 (36.7 to 39.2)
12 Year Old (n = 20)	9 — 54	22 — 49	24 — 50	40.8 ± 5.6 (38.2 to 43.4)	40.1 ± 6.4 (37.0 to 43.1)
13 Year Old (n = 24)	9 — 54	14 — 52	26 — 49	38.5 ± 7.6 (35.3 to 41.7)	37.3 ± 6.0 (34.8 to 39.9)
14 Year Old (n = 25)	9 — 54	25 — 50	18 — 48	39.0 ± 5.8 (36.6 to 41.5)	37.5 ± 7.9 (34.1 to 40.8)
15 Year Old (n = 17)	9 — 54	25 — 46	23 — 46	36.4 ± 6.0 (33.3 to 39.5)	35.2 ± 6.5 (31.9 to 38.5)
16 Year Old (n = 25)	9 — 54	26 — 49	18 — 51	36.5 ± 5.8 (34.1 to 38.9)	39.4 ± 8.0 (36.1 to 42.7)
17 Year Old (n = 24)	9 — 54	26 — 50	21 — 49	37.7 ± 7.0 (34.7 to 40.7)	37.8 ± 8.1 (34.3 to 41.2)

Table 5.9: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the General Adherence Scale according to adolescent age.

Adolescent Age	*n*	*(n - 3)*	*r*	*z*	Weighted *z* = *(n - 3)z*	Weighted Square = $(n - 3)z^2$
12 year old	20	17	0.304	0.310	5.270	1.634
13 year old	24	21	0.486	0.536	11.256	6.033
14 year old	25	22	0.516	0.576	12.672	7.299
15 year old	17	14	0.293	0.299	4.186	1.252
16 year old	25	22	0.665	0.811	17.842	14.470
17 year old	24	21	0.388	0.412	8.652	3.565
Total	135	117			59.878	34.253

Table 5.10: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Diabetes Specific Adherence Scale according to adolescent age.

Adolescent Age	*n*	*(n - 3)*	*r*	*z*	Weighted *z* = *(n - 3)z*	Weighted Square = $(n - 3)z^2$
12 year old	20	17	0.171	0.172	2.924	0.503
13 year old	24	21	0.356	0.377	7.917	2.985
14 year old	25	22	0.514	0.563	12.386	6.973
15 year old	17	14	0.700	0.867	12.138	10.524
16 year old	25	22	0.676	0.829	18.238	15.119
17 year old	24	21	0.877	1.376	28.896	39.761
Total	135	117			82.499	75.865

Table 5.11: Summary of results of tests of differences between correlations of parent-adolescent agreement on the Diabetes Specific Adherence Scale according to adolescents' age strata.

	12 year olds	13 year olds	14 year olds	15 year olds	16 year olds	17 year olds
12 year old adolescents	--	n.s.	n.s.	n.s.	$p < 0.05$	$p < 0.01$
13 year old adolescents		--	n.s.	n.s.	n.s.	$p < 0.01$
14 year old adolescents			--	n.s.	n.s.	$p < 0.01$
15 year old adolescents				--	n.s.	n.s.
16 year old adolescents					--	n.s.
17 year old adolescents						--

Table 5.12: Mean (± *SD*) blood glucose monitoring adherence by adolescent age.

Sample	Possible Range	Observed Range	Mean ± *SD* (95% Confidence Interval)
Total BGM sample (n = 75)	0 — 28	0 — 28	11.9 ± 10.3 (9.6 to 14.3)
12 Year Old (n = 12)	0 — 28	7 — 27	19.4 ± 6.1 (15.5 to 23.3)
13 Year Old (n = 14)	0 — 28	0 — 28	12.1 ± 9.9 (6.4 to 17.8)
14 Year Old (n = 11)	0 — 28	1 — 28	13.1 ± 12.4 (4.7 to 21.4)
15 Year Old (n = 12)	0 — 28	1 — 28	14.2 ± 12.0 (6.6 to 21.8)
16 Year Old (n = 13)	0 — 28	0 — 27	6.2 ± 7.7 (1.6 to 10.9)
17 Year Old (n = 13)	0 — 28	0 — 25	7.5 ± 8.6 (2.2 to 12.7)

Figure 5.1: Distribution of Appropriate Days of Blood Glucose Monitoring according to adolescents' age.

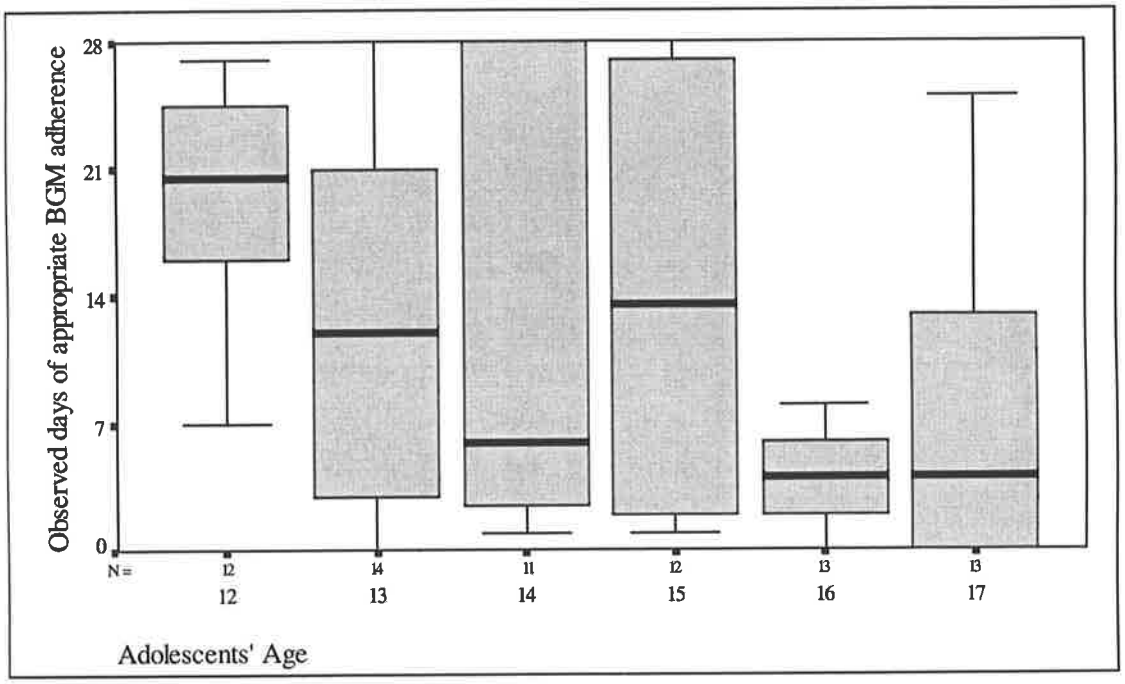


Table 5.13: Pearson correlation coefficients (and *p* values) between adolescent and parent completed adherence measures and Social Desirability Responding, according to adolescent age strata.

	Social Desirability Responding		
	Young adolescents (12-13 year olds) ($n = 44$)	Middle adolescents (14-15 year olds) ($n = 42$)	Older adolescents (16-17 year olds) ($n = 49$)
Adolescent GAS	0.28 ($p = 0.07$)	0.26 ($p = 0.1$)	0.36 ($p = 0.01$)
Adolescent DSAS	0.24 ($p = 0.1$)	0.26 ($p = 0.1$)	0.45 ($p = 0.001$)
Parent GAS	0.48 ($p = 0.001$)	0.19 ($p = 0.2$)	0.12 ($p = 0.4$)
Parent DSAS	0.17 ($p = 0.3$)	0.18 ($p = 0.3$)	- 0.03 ($p = 0.8$)

Table 5.14: Obtained means (± *SD*s) for the General Adherence Scale, with scoring ranges by adolescent gender.

Sample	Possible Range	Observed Range		Mean ± *SD* (95% Confidence Interval)	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	5 — 30	7 — 30	11 — 30	23.8 ± 4.7 (23.0 to 24.6)	23.4 ± 4.8 (22.6 to 24.2)
Male (n = 60)	5 — 30	15 — 30	11 — 30	24.3 ± 4.3 (23.2 to 25.5)	23.6 ± 4.8 (22.3 to 24.9)
Female (n = 75)	5 — 30	7 — 30	12 — 30	23.4 ± 4.9 (22.2 to 24.5)	23.3 ± 4.9 (22.1 to 24.4)

Table 5.15: Obtained means (± *SD*s) for the Diabetes Specific Adherence Scale, with scoring ranges by adolescent gender.

Sample	Possible Range	Observed Range		Mean ± *SD* (95% Confidence Interval)	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	9 — 54	14 — 52	18 — 51	38.2 ± 6.4 (37.1 to 39.3)	37.9 ± 7.3 (36.7 to 39.2)
Male (n = 60)	9 — 54	26 — 52	25 — 50	38.7 ± 5.6 (37.2 to 40.1)	38.4 ± 6.7 (36.7 to 40.2)
Female (n = 75)	9 — 54	14 — 50	18 — 51	37.8 ± 7.0 (36.2 to 39.4)	37.6 ± 7.7 (35.8 to 39.4)

Table 5.16: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the General Adherence Scale according to adolescent gender.

Adolescent gender	*n*	*(n - 3)*	*r*	*z*	$1/(n-3)$
Male	60	57	0.600	0.693	0.018
Female	75	72	0.383	0.523	0.014
			D =	0.170	Sum = 0.032

Table 5.17: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Diabetes Specific Adherence Scale according to adolescent gender.

Adolescent gender	*n*	*(n - 3)*	*r*	*z*		$1/(n-3)$
Male	60	57	0.674	0.811		0.018
Female	75	72	0.495	0.549		0.014
				D = 0.262	Sum =	0.032

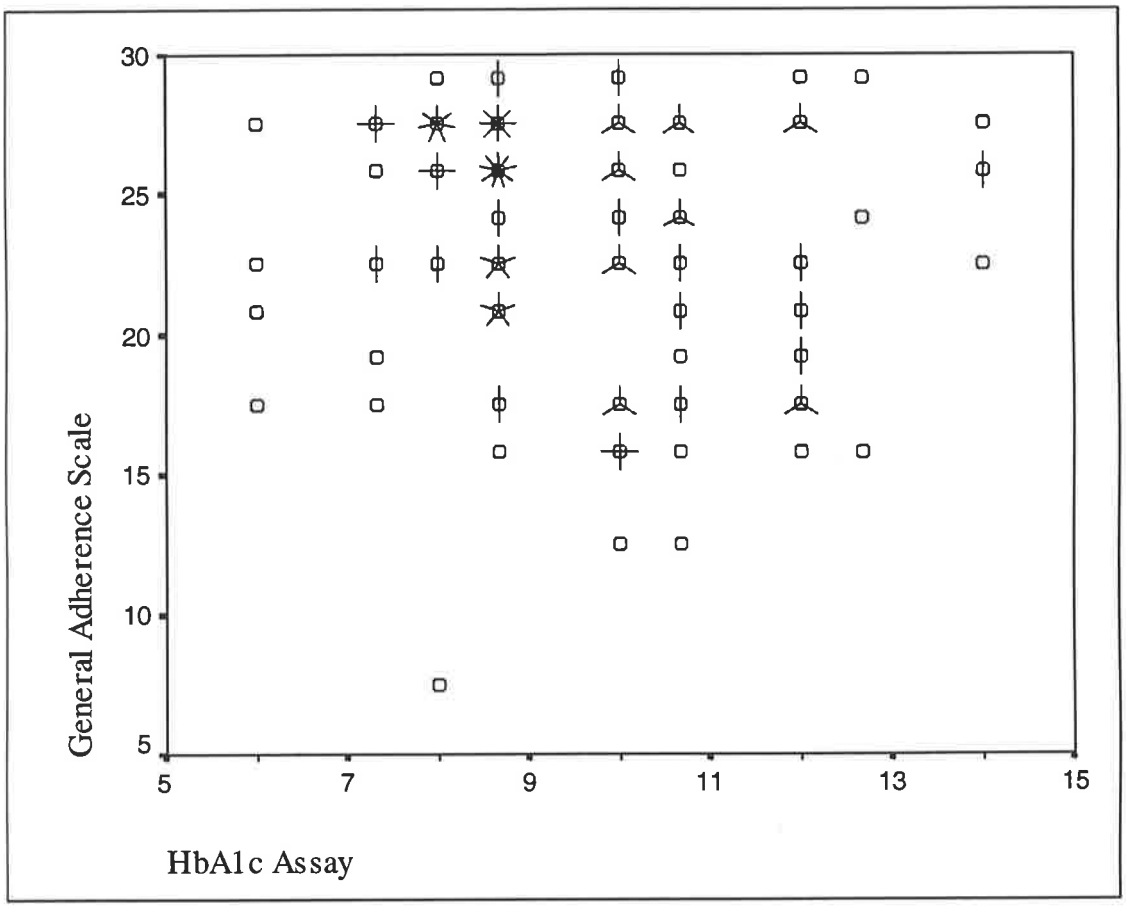
Table 5.18: Mean (± *SD*) and range of Days of Appropriate Blood Glucose Monitoring Adherence, by adolescent gender.

	Appropriate Days of BGM Adherence		
	Possible Range	Observed Range	Mean ± *SD* (95% Confidence Interval)
Total Sample (n = 75)	0 — 28	0 — 28	11.9 ± 10.3 (9.6 to 14.3)
Male (n = 34)	0 — 28	0 — 28	10.8 ± 10.6 (7.1 to 14.5)
Female (n = 41)	0 — 28	0 — 28	12.9 ± 10.1 (9.7 to 16.1)

Table 5.19: Pearson correlations between adolescents' health status (HbA_{1c}) and adolescent and parent scores on the General Adherence Scale and Diabetes Specific Adherence Scale, and observed Blood Glucose Monitoring adherence.

	Adolescent		Parent reports		Blood glucose monitoring (n = 75)
	GAS (n = 135)	DSAS (n = 135)	GAS (n = 135)	DSAS (n = 135)	
HbA_{1c} level	- 0.17 (p = 0.06)	- 0.11 (p = 0.2)	-0.30 (p = 0.001)	- 0.21 (p = 0.02)	- 0.20 (p = 0.08)

Figure 5.2: Scatterplot of adolescent scores on the General Adherence Scale against HbA_{1c} assay values, as integers.



Note: Single cases are represented by circles, multiple cases are represented by *sunflowers*, the number of cases is indicated by the number of *petals* on each sunflower (Cleveland & McGill, 1984).

Table 5.20: Multivariate analysis of variance of questionnaire measures of adherence in relation to adolescent age and gender (n = 135).

Effect	Dependent Variable	F ratio	df	p
Adolescent Age	Adolescent DSAS	1.26	5, 117	0.29
	Adolescent GAS	0.70	5, 117	0.63
	Parent DSAS	1.02	5, 117	0.41
	Parent GAS	0.55	5, 117	0.74
	Multivariate DV	0.85	20, 379.05	0.52
Adolescent Gender	Adolescent DSAS	0.77	5, 117	0.38
	Adolescent GAS	1.07	5, 117	0.30
	Parent DSAS	0.64	5, 117	0.42
	Parent GAS	0.12	5, 117	0.73
	Multivariate DV	0.98	20, 379.05	0.81
Adolescent Age by Adolescent Gender Interaction	Adolescent DSAS	2.07	5, 117	0.07
	Adolescent GAS	1.16	5, 117	0.33
	Parent DSAS	0.94	5, 117	0.46
	Parent GAS	1.53	5, 117	0.19
	Multivariate DV	1.43	20, 379.05	0.11

Table 5.21: Two-way Analysis of Variance of Blood Glucose Monitoring by Adolescent Age and Gender (n = 71).

Source of Variation	SS	df	MS	F	p
Main Effects	16593.99	6	2765.67	2.236	0.052
Adolescent Age	13955.21	5	2791.04	2.257	0.060
Adolescent Gender	548.17	1	548.17	0.443	0.508
2-Way Interactions	7261.10	5	1452.22	1.174	0.333
Explained	24082.91	11	2189.36	1.770	0.080
Residual	72962.94	59	1236.66		
Total	97045.85	70	1236.37		

Table 5.22: Obtained means (± *SD*s) for the General Adherence Scale, with scoring ranges by parental work status.

Sample	Possible Range	Observed Range		Mean ± *SD* (95% Confidence Intervals)	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	5 — 30	7 — 30	11 — 30	23.8 ± 4.7 (23.0 to 24.6)	23.4 ± 4.8 (22.6 to 24.2)
At home (n = 64)	5 — 30	7 — 30	11 — 30	23.7 ± 4.9 (22.5 to 25.0)	23.2 ± 5.0 (22.0 to 24.5)
Not at home (n = 70)	5 — 30	12 — 30	12 — 30	24.0 ± 4.4 (22.9 to 25.0)	23.5 ± 4.8 (22.4 to 24.7)

Table 5.23: Obtained means (± *SD*s) for the Diabetes Specific Adherence Scale, with scoring ranges by parental work status.

Sample	Possible Range	Observed Range		Mean ± *SD* (95% Confidence Intervals)	
		Adolescent	Parent	Adolescent	Parent
Total sample (n=135)	9 — 54	14 — 52	18 — 51	38.2 ± 6.4 (37.1 to 39.3)	37.9 ± 7.3 (36.7 to 39.2)
At home (n = 64)	9 — 54	14 — 49	18 — 51	38.5 ± 6.6 (36.9 to 40.2)	38.3 ± 7.1 (36.5 to 40.1)
Not at home (n = 70)	9 — 54	25 — 52	18 — 50	37.8 ± 6.3 (36.3 to 39.3)	37.6 ± 7.5 (35.8 to 39.4)

Table 5.24: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the General Adherence Scale according to parental work status.

Parent work status	*n*	*(n - 3)*	*r*	*z*		$1/(n-3)$
At home	64	61	0.356	0.377		0.016
Not at home	70	67	0.625	0.741		0.015
				D = 0.364	Sum =	0.031

Table 5.25: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Diabetes Specific Adherence Scale according to parental work status.

Parent work status	*n*	*(n - 3)*	*r*	*z*		$1/(n-3)$
At home	64	61	0.370	0.388		0.016
Not at home	70	67	0.734	0.929		0.015
				D = 0.541	Sum =	0.031

Table 5.26: Mean (± *SD*) and range of Days of Appropriate Blood Glucose Monitoring Adherence, by parental work status.

	Appropriate Days of BGM Adherence		
	Possible Range	Observed Range	Mean ± *SD* (95% Confidence Intervals)
Total Sample (n = 75)	0 — 28	0 — 28	11.9 ± 10.3 (9.6 to 14.3)
At home (n = 35)	0 — 28	0 — 28	13.7 ± 10.5 (10.1 to 17.3)
Not at home (n = 40)	0 — 28	0 — 28	10.3 ± 10.0 (7.1 to 13.5)

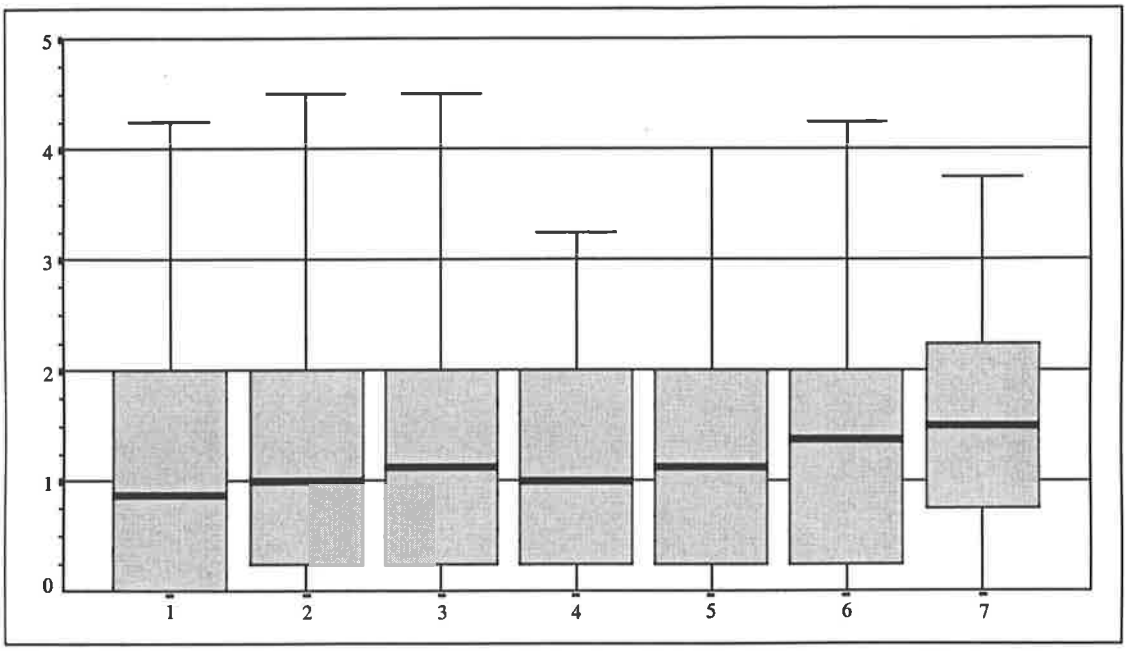


Figure 5.3: Number of tests performed per day over 4-day blocks, spanning the 28 days prior to assessment (n = 74).

Table 5.27: Repeated Measures Analysis of Variance of Variance of Blood Glucose Monitoring data, using 4-day observational blocks.

Source of variation	SS	df	MS	F
Between subjects	6227.06	73	85.30	
Within Subjects	3000.29	438		
Blocks	217.09	6	36.18	5.62
Residual	2783.20	432	6.44	

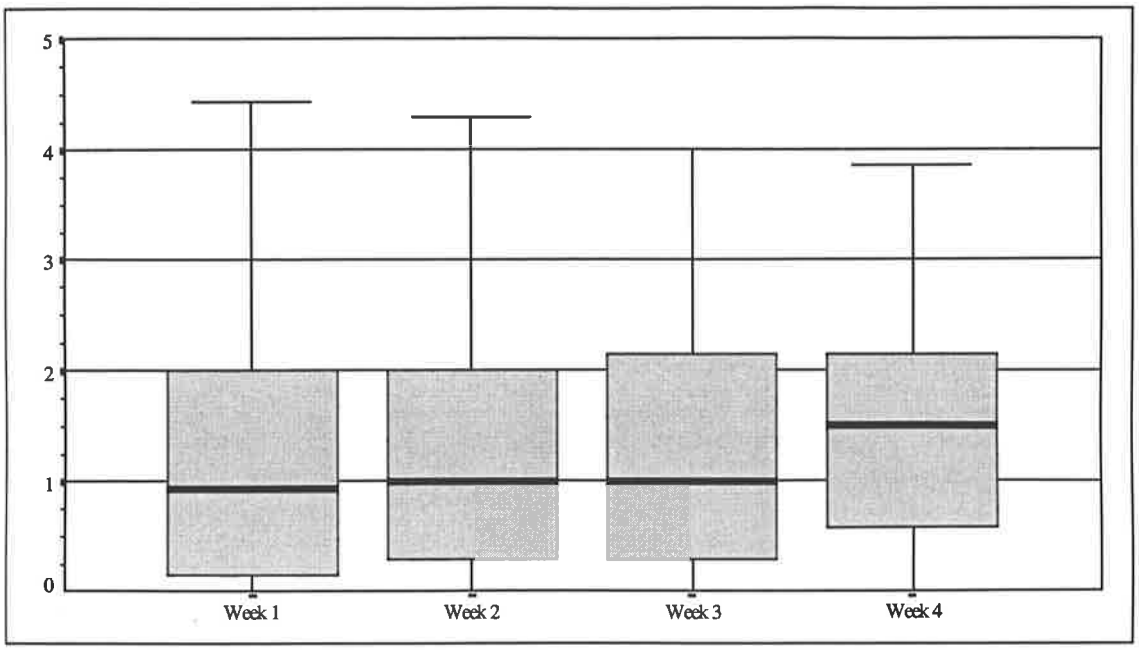


Figure 5.4: Number of tests performed per day over 7-day blocks, spanning the 28 days prior to assessment (n = 74).

Table 5.28: Repeated Measures Analysis of Variance of Blood Glucose Monitoring data, using 7-day observational blocks.

Source of variation	SS	df	MS	F
Between subjects	10784.82	73	147.73	
Within Subjects	3136.50	219		
Blocks	348.42	3	116.14	9.00
Residual	2788.08	216	12.91	

Table 5.29: Tests for trends in Blood Glucose Monitoring data, using 4-day observational blocks.

	Blocks	1	2	3	4	5	6	7	Σc^2	C	MS
	Block totals:	344	358	373	377	395	431	495			
Linear		-3	-2	-1	0	1	2	3	28	621	186.12
Quadratic		5	0	-3	-4	-3	0	5	84	383	23.60
											209.72

Table 5.30: Tests for trends in Blood Glucose Monitoring data, using 7-day observational blocks.

	Blocks	1	2	3	4	Σc^2	C	MS
	Block totals:	605	664	686	824			
Linear		-3	-1	1	3	20	679	311.51
Quadratic		1	-1	-1	1	4	79	21.08
								332.59

Table 5.31: Pearson correlations (and *p* values*) between adolescent and parent reports of Blood Glucose Monitoring adherence (DSAS item 2), and observed Blood Glucose Monitoring adherence over different time frames (*n* = 74).

	Blocks 1-7 last 28 days	Blocks 3-7 last 20 days	Blocks 5-7 last 12 days	Blocks 6,7 last 8 days	Block 7 last 4 days
DSAS item 2					
Adolescent report	0.66	0.65	0.61	0.60	0.54
Parent report	0.53	0.54	0.50	0.46	0.39

* Unless otherwise indicated, $p < 0.001$

Table 5.32: Number of appropriate days of BGM adherence over different time frames, according to reports of high and low levels of BGM adherence by adolescents.

Number of observed days of appropriate BGM in interval:	Adolescent reported BGM adherence		$t^{\ddagger}$
	Low* ($n = 27$)	High† ($n = 48$)	
Past 28 days (Mean ± *SD* (95% CI))	3.9 ± 5.7 (1.6 to 6.2)	16.4 ± 9.6 (13.6 to 19.2)	-7.07
Past 20 days (Mean ± *SD* (95% CI))	2.9 ± 4.3 (1.2 to 4.6)	12.1 ± 7.0 (10.1 to 14.1)	-7.06
Past 12 days (Mean ± *SD* (95% CI))	2.07 ± 3.0 (0.9 to 3.3)	7.4 ± 4.3 (6.2 to 8.6)	-6.33
Past 8 days (Mean ± *SD* (95% CI))	1.6 ± 2.0 (0.7 to 2.4)	5.1 ± 2.8 (4.3 to 5.9)	-6.24
Past 4 days (Mean ± *SD* (95% CI))	0.9 ± 1.2 (0.4 to 1.4)	2.5 ± 1.5 (2.1 to 3.0)	-5.00

* **Low:** responses on the DSAS item assessing BGM, rating adherence as 1 (none of the time), 2 (a little of the time), or 3 (some of the time).

† **High:** responses on the DSAS item assessing BGM, rating adherence as 4 (a good bit of the time), 5 (most of the time), or 6 (all of the time).

‡ Unless otherwise stated, $p < 0.001$.

Table 5.33: Number of appropriate days of BGM adherence over different time frames, according to reports of high and low levels of BGM adherence by parents.

Number of observed days of appropriate BGM in interval:	Parent reported BGM adherence		$t^{\ddagger}$
	Low* (n = 25)	High† (n = 50)	
Past 28 days (Mean ± *SD* (95% CI))	5.4 ± 7.4 (2.3 to 8.4)	15.2 ± 10.0 (12.4 to 18.0)	-4.81
Past 20 days (Mean ± *SD* (95% CI))	3.9 ± 5.4 (1.6 to 6.1)	11.2 ± 7.3 (9.2 to 13.3)	-4.91
Past 12 days (Mean ± *SD* (95% CI))	2.8 ± 3.8 (1.2 to 4.3)	6.8 ± 4.4 (5.6 to 8.1)	-3.95
Past 8 days (Mean ± *SD* (95% CI))	2.2 ± 2.8 (1.1 to 3.4)	4.6 ± 2.9 (3.8 to 5.4)	-3.35 (p = 0.001)
Past 4 days (Mean ± *SD* (95% CI))	1.3 ± 1.5 (0.7 to 1.9)	2.3 ± 1.6 (1.8 to 2.7)	-2.51 (p = 0.01)

* **Low:** responses on the DSAS item assessing BGM, rating adherence as 1 (none of the time), 2 (a little of the time), or 3 (some of the time).

† **High:** responses on the DSAS item assessing BGM, rating adherence as 4 (a good bit of the time), 5 (most of the time), or 6 (all of the time).

‡ Unless otherwise stated, $p < 0.001$.

Table 5.34: Number of appropriate days of BGM adherence over different time frames, according to reports of high, moderate and low levels of BGM adherence by adolescents.

Number of observed days of appropriate BGM in interval:	Adolescent reported BGM adherence			$F^{\S}$ (2,72)
	Low* ($n = 16$)	Moderate† ($n = 18$)	High‡ ($n = 41$)	
Past 28 days (Mean ± *SD* (95% CI))	2.3 ± 3.4 (0.5 to 4.0)	7.6 ± 8.3 (3.5 to 11.7)	17.6 ± 9.2 (14.7 to 20.5)	24.12
Past 20 days (Mean ± *SD* (95% CI))	1.7 ± 3.0 (0.1 to 3.3)	5.6 ± 6.0 (2.6 to 8.5)	13.0 ± 6.7 (10.9 to 15.1)	24.49
Past 12 days (Mean ± *SD* (95% CI))	1.4 ± 2.3 (0.1 to 2.6)	3.7 ± 4.0 (1.7 to 5.7)	7.9 ± 4.1 (6.6 to 9.1)	19.66
Past 8 days (Mean ± *SD* (95% CI))	1.0 ± 1.4 (0.2 to 1.8)	2.8 ± 2.9 (1.4 to 4.3)	5.3 ± 2.7 (4.5 to 6.2)	18.93
Past 4 days (Mean ± *SD* (95% CI))	0.6 ± 1.0 (0.1 to 1.1)	1.6 ± 1.6 (0.8 to 2.4)	2.6 ± 1.4 (2.2 to 3.1)	12.38

* **Low:** responses on the DSAS item assessing BGM, rating adherence as 1 (none of the time) or 2 (a little of the time).
† **Moderate:** responses on the DSAS item assessing BGM, rating adherence as 3 (some of the time), or 4 (a good bit of the time).
‡ **High:** responses on the DSAS item assessing BGM, rating adherence as 5 (most of the time), or 6 (all of the time).
§ Unless otherwise stated, $p < 0.001$

Table 5.35: Number of appropriate days of BGM adherence over different time frames, according to reports of high, moderate and low levels of BGM adherence by parents.

Number of observed days of appropriate BGM in interval:	Parent reported BGM adherence			$F^{\S}$ (2,72)
	Low* (n = 16)	Moderate† (n = 15)	High‡ (n = 44)	
Past 28 days (Mean ± *SD* (95˘ % CI))	4.6 ± 7.7 (0.5 to 8.6)	6.9 ± 6.6 (3.3 to 10.6)	16.3 ± 10.0 (13.3 to 19.3)	13.01
Past 20 days (Mean ± *SD* (95% CI))	2.9 ± 5.2 (0.1 to 5.7)	5.8 ± 5.3 (2.8 to 8.8)	11.9 ± 7.3 (9.7 to 14.2)	12.90
Past 12 days (Mean ± *SD* (95% CI))	1.9 ± 3.4 (0.1 to 3.7)	4.3 ± 3.9 (2.2 to 6.5)	7.2 ± 4.4 (5.8 to 8.5)	10.48
Past 8 days (Mean ± *SD* (95% CI))	1.5 ± 2.3 (0.3 to 2.7)	3.3 ± 3.0 (1.6 to 4.9)	4.8 ± 2.9 (4.0 to 5.7)	8.80
Past 4 days (Mean ± *SD* (95% CI))	0.9 ± 1.2 (0.3 to 1.6)	1.6 ± 1.7 (0.6 to 2.6)	2.5 ± 1.5 (2.0 to 2.9)	6.48 (p = 0.003)

* **Low:** responses on the DSAS item assessing BGM, rating adherence as 1 (none of the time) or 2 (a little of the time).
† **Moderate:** responses on the DSAS item assessing BGM, rating adherence as 3 (some of the time), or 4 (a good bit of the time).
‡ **High:** responses on the DSAS item assessing BGM, rating adherence as 5 (most of the time), or 6 (all of the time).
§ Unless otherwise stated, $p < 0.001$

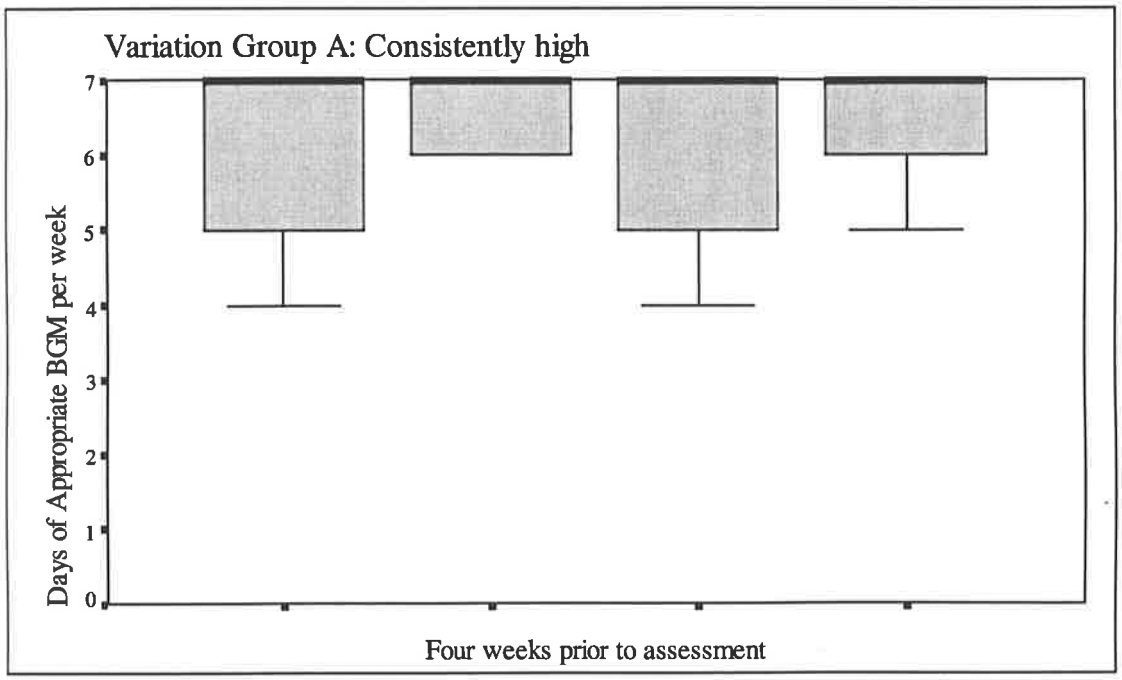


Figure 5.5: Mean number of days of appropriate blood glucose monitoring each week over the four weeks prior to assessment for Group A (Consistently High) cases (n = 22).

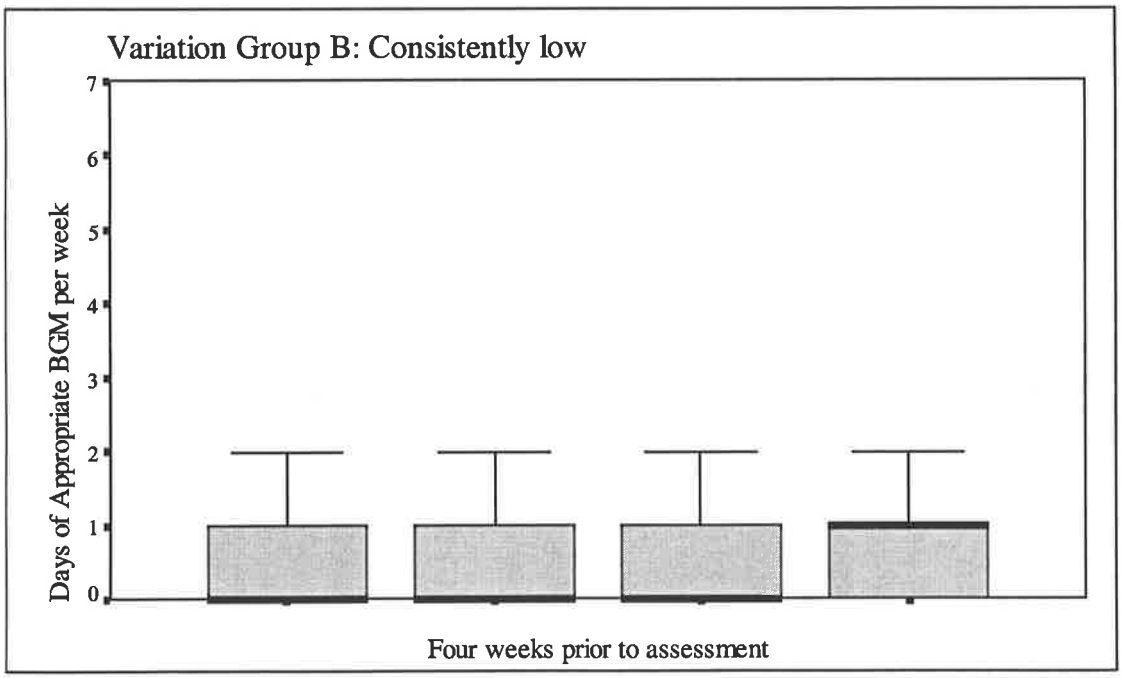


Figure 5.6: Mean number of days of appropriate blood glucose monitoring each week over the four weeks prior to assessment for Group B (Consistently Low) cases (n = 33).

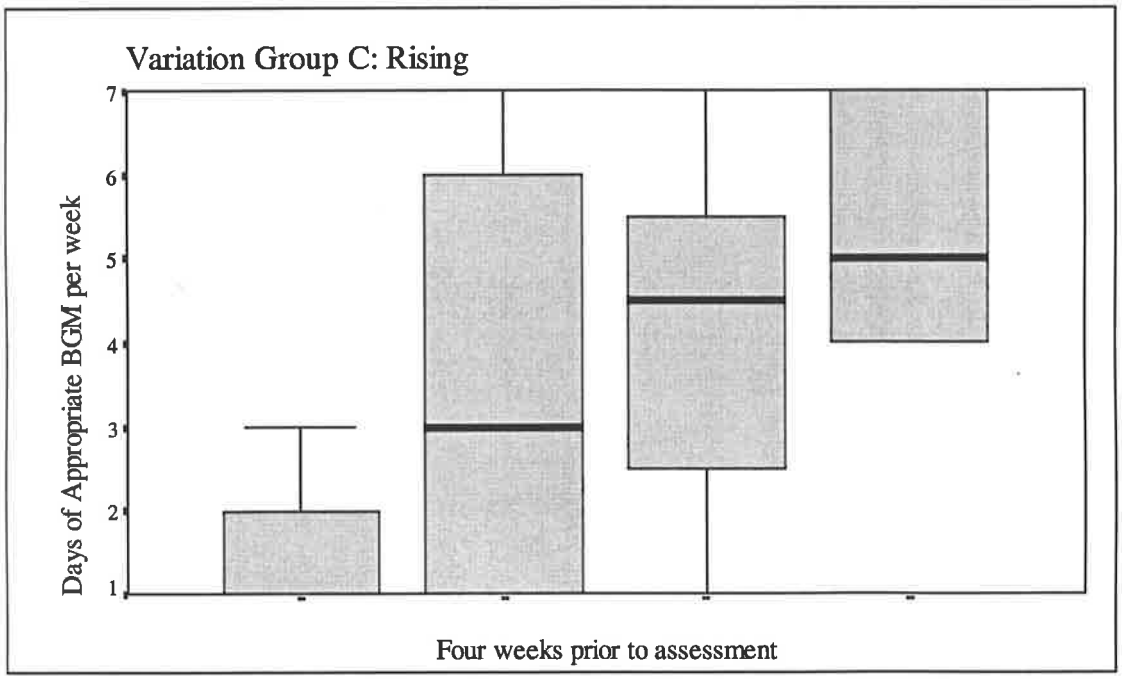


Figure 5.7: Mean number of days of appropriate blood glucose monitoring each week over the four weeks prior to assessment for Group C (Rising) cases (n = 12).

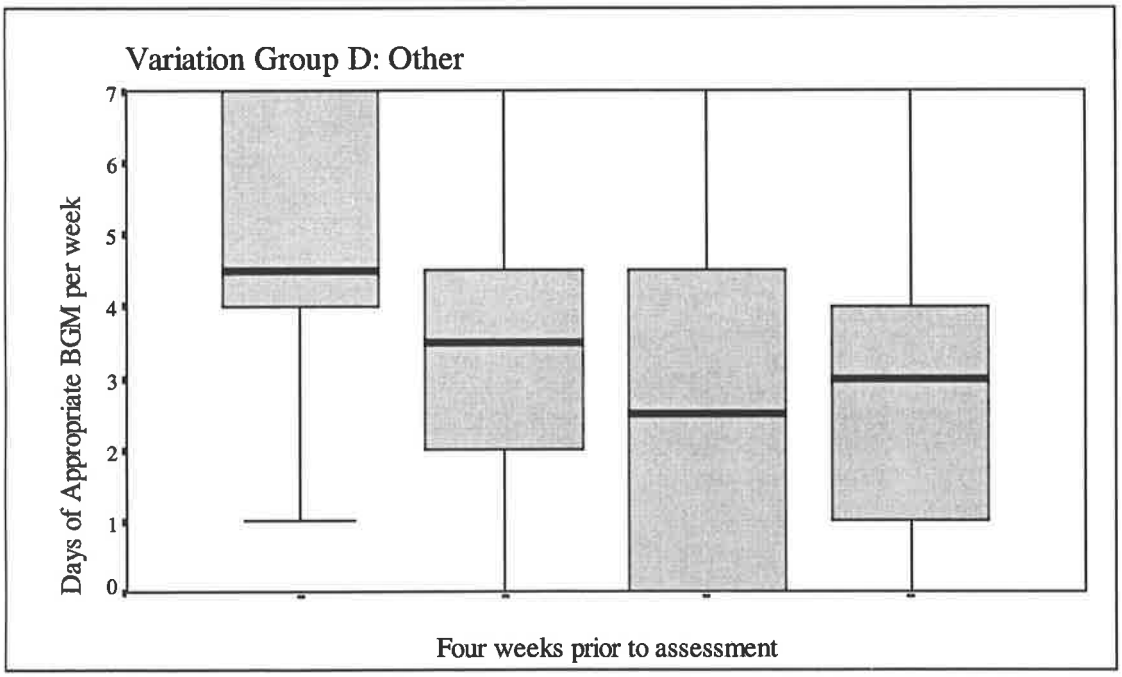


Figure 5.8: Mean number of days of appropriate blood glucose monitoring each week over the four weeks prior to assessment for Group D (Other) cases (n = 8).

Table 5.36: Analysis of Variance of blood glucose monitoring variance over time in relation to groups rated with Consistently High, Consistently Low, or Rising blood glucose monitoring adherence.

Source	SS	df	MS	F
Variance Group	1708.20	2	854.10	265.74
Time	72.24	3	24.75	25.98
Variance Group by Time	86.11	6	14.35	15.06
TOTAL	1868.55	12		

Note: Unless otherwise stated, $p < 0.001$

Table 5.37: Reported general (GAS), diabetes specific (DSAS) and blood glucose monitoring (DSAS item 2) adherence by adolescents and parents, according to variation pattern in observed blood glucose monitoring.

		Adolescent reports			Parent Reports		
	n	GAS	DSAS	DSAS item 2	GAS	DSAS	DSAS item 2
Consistently High*	22	24.1 ± 5.8 (21.5 to 26.6)	40.7 ± 7.0 (37.6 to 43.8)	5.5 ± 0.8 (5.2 to 5.9)	24.3 ± 3.8 (22.6 to 26.0)	41.0 ± 4.8 (38.8 to 43.1)	5.5 ± 0.9 (5.1 to 5.9)
Consistently Low†	33	20.7 ± 4.0 (19.2 to 22.2)	34.1 ± 4.6 (32.4 to 35.8)	3.2 ± 1.6 (2.6 to 3.7)	19.6 ± 4.7 (17.8 to 21.4)	33.6 ± 6.5 (31.2 to 36.0)	3.5 ± 1.7 (2.9 to 4.1)
Rising‡	12	23.7 ± 4.7 (20.7 to 26.7)	38.3 ± 5.7 (34.7 to 41.9)	4.9 ± 1.3 (4.1 to 5.7)	22.4 ± 3.5 (20.2 to 24.6)	38.9 ± 3.3 (36.8 to 41.0)	4.8 ± 1.3 (4.0 to 5.6)
Other§	8	23.0 ± 3.5 (20.0 to 26.0)	38.4 ± 4.6 (34.5 to 42.2)	4.4 ± 1.6 (3.0 to 5.7)	23.5 ± 6.5 (18.1 to 28.9)	36.8 ± 8.5 (29.7 to 43.8)	3.8 ± 2.1 (2.0 to 5.5)

* **Consistently High:** Four or more days of appropriate BGM adherence in each of the four weeks prior to assessment.
† **Consistently Low:** Less than four days of appropriate BGM adherence in each of the four weeks prior to assessment.
‡ **Rising:** Patterns of increasing BGM adherence over the four weeks prior to assessment.
§ **Other:** Variations in BGM adherence not covered by the abovementioned ratings.

Table 5.38: Analysis of Variance of adolescent reports of adherence conflict in relation to blood glucose monitoring adherence groups.

Source	SS	df	MS	F*
Adolescent GAS				
Between BGM Adherence Groups	165.40	2	82.70	3.59† (p=0.03)
Within BGM Adherence Groups	1406.35	61	23.05	
TOTAL	1571.75	63		
Adolescent DSAS				
Between BGM Adherence Groups	547.43	2	273.72	8.47†
Within BGM Adherence Groups	2067.08	64	32.30	
TOTAL	2614.51	66		
Adolescent DSAS item 2				
Between BGM Adherence Groups	79.88	2	39.94	22.57†‡
Within BGM Adherence Groups	113.28	64	1.77	
TOTAL	193.16	66		

* Unless otherwise stated, $p < 0.001$

† Post hoc comparisons: Signficant difference detected between Consistently High and Consistently Low BGM adherence groups, using Tukey's HSD.

‡ Post hoc comparisons: Signficant difference detected between Consistently Low and Rising BGM adherence groups, using Tukey's HSD.

Table 5.39: Analysis of Variance of parent reports of adherence conflict in relation to blood glucose monitoring adherence groups.

Source	SS	df	MS	F*
Parent GAS				
Between BGM Adherence Groups	264.66	2	132.33	7.28† (p=0.001)
Within BGM Adherence Groups	1163.52	64	18.18	
TOTAL	1428.18	66		
Parent DSAS				
Between BGM Adherence Groups	721.85	2	360.92	12.20†‡
Within BGM Adherence Groups	1892.78	64	29.57	
TOTAL	2614.63	66		
Parent DSAS item 2				
Between BGM Adherence Groups	54.31	2	27.15	13.23†‡
Within BGM Adherence Groups	131.36	64	2.05	
TOTAL	185.67	66		

* Unless otherwise stated, $p < 0.001$

† Post hoc comparisons: Signficant difference detected between Consistently High and Consistently Low BGM adherence groups, using Tukey's HSD.

‡ Post hoc comparisons: Signficant difference detected between Consistently Low and Rising BGM adherence groups, using Tukey's HSD.

Table 5.40: Distributions of HbA_{1c} assay results according to blood glucose monitoring adherence group.

HbA_{1c}	Blood Glucose Monitoring Adherence Group			
	Consistently High (n = 22)	Consistently Low (n = 33)	Rising (n = 12)	Other (n = 8)
Mean ± *SD* (95% CI)	10.0 ± 1.5 (9.3 to 10.7)	10.7 ± 1.5 (10.2 to 11.2)	11.0 ± 1.5 (10.0 to 11.9)	10.5 ± 1.6 (9.1 to 11.8)

FIGURES CITED IN CHAPTER 6.

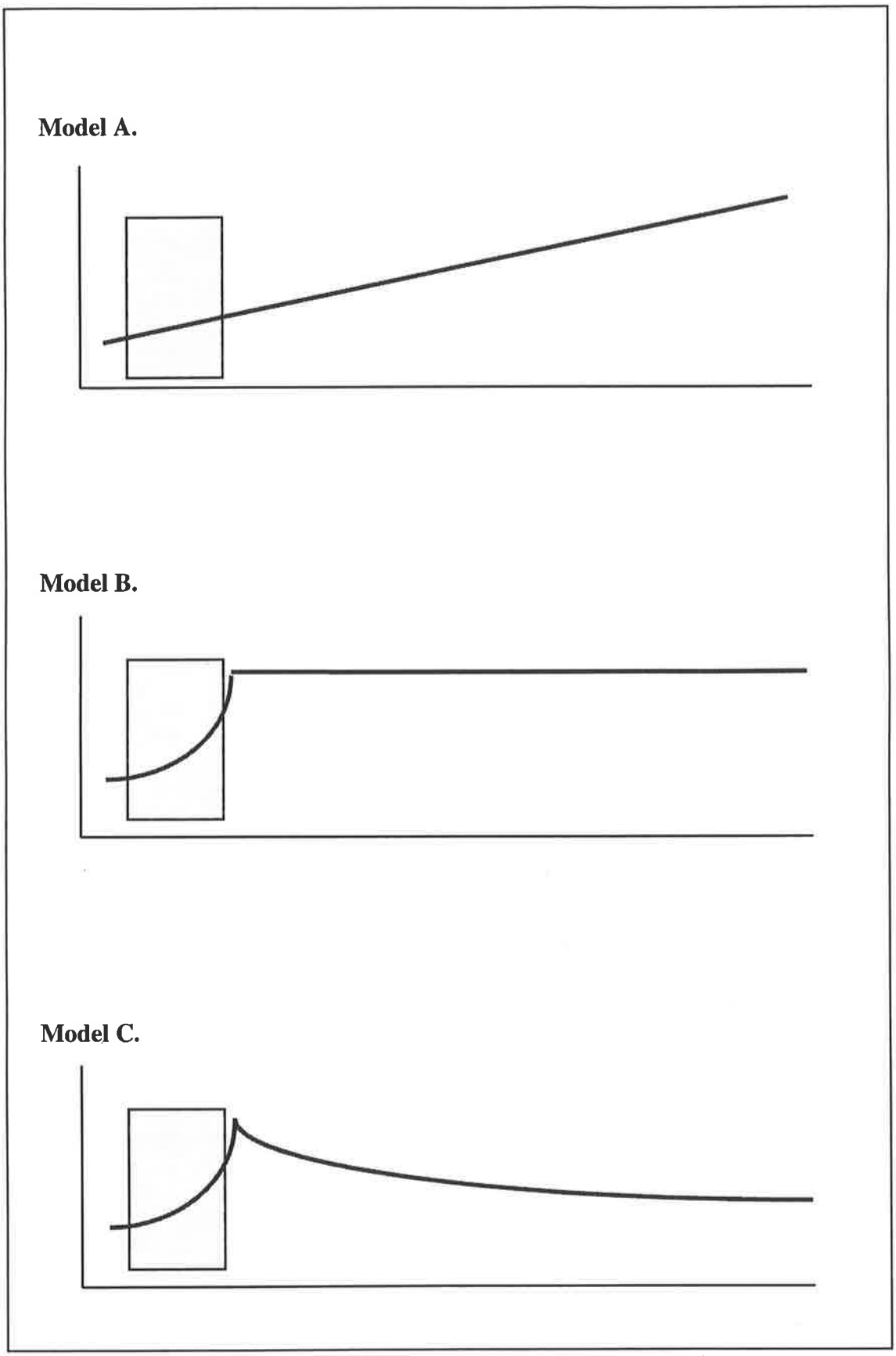


Figure 6.1: Models A, B, and C of variation in adherence levels over time.

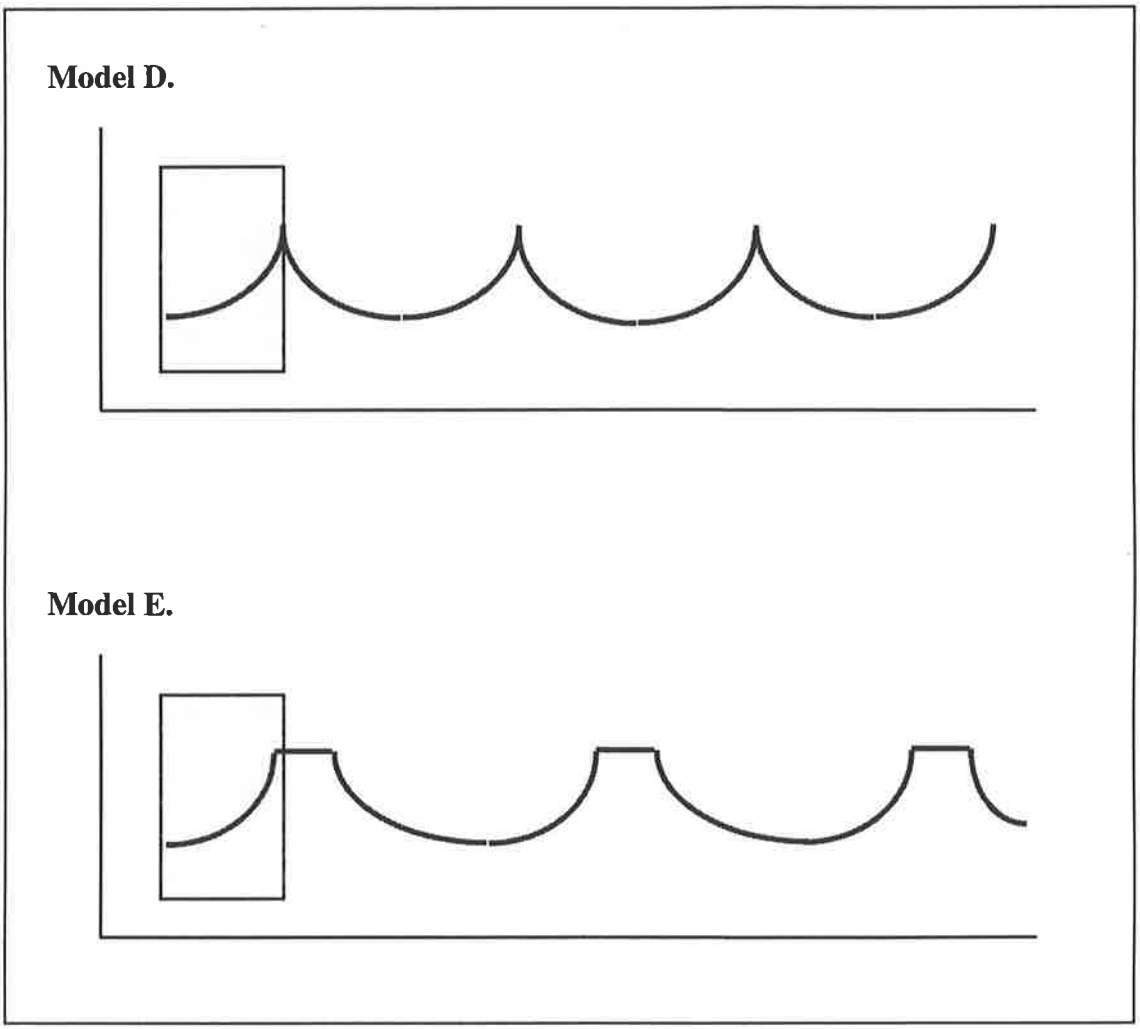


Figure 6.2: Models D and E of variation in adherence levels over time.

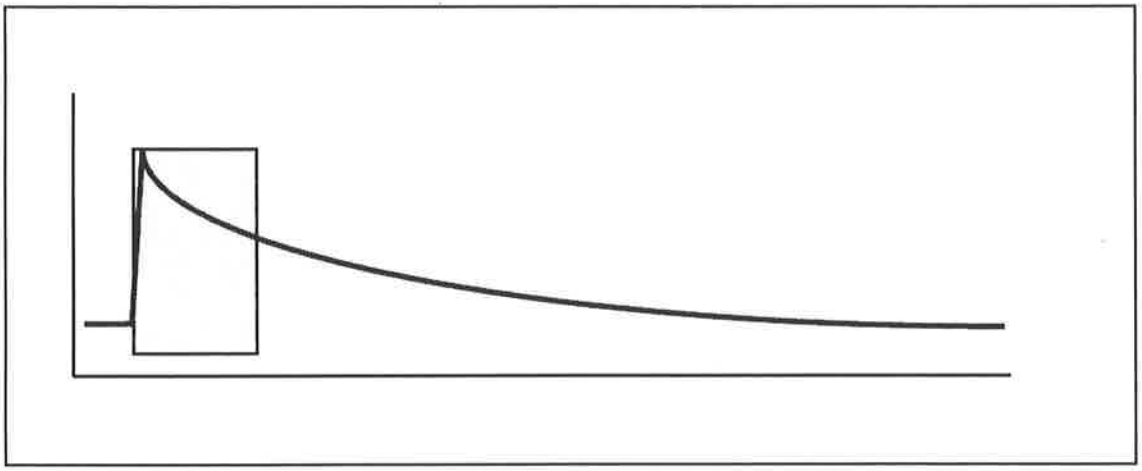


Figure 6.3: Model of variation in adherence level over time based upon novelty effect.

TABLES CITED IN CHAPTER 7.

Table 7.1: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores.

	n	Adolescent	Parent	Combined score
Total sample	127			
Mean ± *SD* (95% CI)		5.8 ± 3.7 (5.1 to 6.4)	5.2 ± 5.1 (4.3 to 6.1)	10.9 ± 7.4 (9.6 to 12.2)
Observed range		0 - 17	0 - 20	1 - 37

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.2: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to adolescent age.

	n	Adolescent	Parent	Combined score
12 year old adolescents	18			
Mean ± *SD*		4.6 ± 3.6	4.1 ± 4.1	8.7 ± 6.6
(95% CI)		(2.8 to 6.4)	(2.1 to 6.1)	(5.4 to 12.0)
Observed range		2 - 15	0 - 13	3 - 25
13 year old adolescents	23			
Mean ± *SD*		5.2 ± 4.3	4.1 ± 6.1	9.3 ± 10.1
(95% CI)		(3.3 to 7.0)	(1.5 to 6.7)	(4.9 to 13.6)
Observed range		1 - 17	0 - 20	1 - 37
14 year old adolescents	24			
Mean ± *SD*		6.3 ± 3.5	7.1 ± 4.1	13.4 ± 6.3
(95% CI)		(4.8 to 7.8)	(5.4 to 8.9)	(10.8 to 16.1)
Observed range		0 - 14	0 - 17	3 - 26
15 year old adolescents	16			
Mean ± *SD*		5.1 ± 3.8	5.5 ± 6.6	10.6 ± 7.5
(95% CI)		(3.1 to 7.1)	(2.0 to 9.0)	(6.6 to 14.6)
Observed range		2 - 17	0 - 20	2 - 23
16 year old adolescents	23			
Mean ± *SD*		6.2 ± 3.3	5.5 ± 6.0	11.7 ± 7.1
(95% CI)		(4.8 to 7.7)	(2.9 to 8.1)	(8.7 to 14.8)
Observed range		2 - 15	0 - 19	2 - 27
17 year old adolescents	23			
Mean ± *SD*		6.3 ± 3.7	4.7 ± 3.9	10.9 ± 6.1
(95% CI)		(4.7 to 7.9)	(3.0 to 6.3)	(8.3 to 13.6)
Observed range		1 - 16	0 - 13	3 - 25

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.3: Pearson correlations between adolescent, parent, and combined reports of parent-adolescent conflict, and adolescents' age (n = 127).

	Adolescent CBQ	Parent CBQ	Combined CBQ
Adolescent age	0.14 (p = 0.1)	0.04 (p = 0.7)	0.11 (p = 0.2)

Table 7.4: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to adolescent gender.

	n	Adolescent	Parent	Combined score
Male adolescents	58			
Mean ± *SD* (95% CI)		5.2 ± 3.4 (4.3 to 6.0)	5.4 ± 5.5 (3.9 to 6.8)	10.4 ± 7.9 (8.3 to 12.5)
Observed range		0 - 17	0 - 20	2 - 37
Female adolescents	69			
Mean ± *SD* (95% CI)		6.2 ± 3.9 (5.3 to 7.1)	5.0 ± 4.8 (3.9 to 6.1)	11.3 ± 7.0 (9.6 to 13.0)
Observed range		1 - 17	0 - 20	1 - 26

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.5: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to parents' age.

Sample	*n*	Adolescent	Parent	Combined score
Parents under 40 years old	28			
Mean ± *SD*		4.9 ± 2.4	5.2 ± 4.8	10.0 ± 6.0
(95% CI)		(3.9 to 5.8)	(3.4 to 7.1)	(7.7 to 12.4)
Observed range		2 - 10	0 - 19	3 - 26
Parents 40 to 45 years old	64			
Mean ± *SD*		6.0 ± 4.1	5.0 ± 5.2	10.9 ± 8.1
(95% CI)		(4.9 to 7.0)	(3.7 to 6.3)	(8.9 to 12.9)
Observed range		0 - 17	0 - 20	1 - 37
Parents over 45 years old	35			
Mean ± *SD*		6.1 ± 3.7	5.4 ± 5.5	11.6 ± 7.4
(95% CI)		(4.9 to 7.3)	(3.6 to 7.3)	(9.0 to 14.1)
Observed range		1 - 17	0 - 20	2 - 36

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.6: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to responding parent.

	n	Adolescent	Parent	Combined score
Mother - Adolescent	110			
Mean ± *SD* (95% CI)		5.7 ± 3.8 (5.0 to 6.4)	5.1 ± 5.2 (4.1 to 6.1)	10.8 ± 7.5 (9.4 to 12.2)
Observed range		0 - 17	0 - 20	2 - 37
Father - Adolescent	17			
Mean ± *SD* (95% CI)		5.5 ± 2.7 (4.1 to 6.9)	5.9 ± 5.5 (3.1 to 8.8)	11.5 ± 7.2 (7.8 to 15.2)
Observed range		1 - 10	0 - 18	1 - 27

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.7: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to adolescent gender and responding parent.

Sample	*n*	Adolescent	Parent	Combined score
Mother - Male adolescent	53			
Mean ± *SD*		5.0 ± 3.5	4.9 ± 5.4	9.9 ± 7.8
(95% CI)		(4.1 to 6.0)	(3.4 to 6.4)	(7.8 to 12.1)
Observed range		0 - 17	0 - 20	2 - 37
Mother - Female adolescent	57			
Mean ± *SD*		6.3 ± 4.1	5.3 ± 5.0	11.6 ± 7.2
(95% CI)		(5.3 to 7.4)	(4.0 to 6.6)	(9.7 to 13.5)
Observed range		2 - 17	0 - 20	2 - 26
Father - Male adolescent	5			
Mean ± *SD*		6.4 ± 2.4	9.4 ± 6.5	15.8 ± 7.8
(95% CI)		(3.4 to 9.4)	(1.3 to 17.5)	(6.1 to 25.5)
Observed range		3 - 9	2 - 18	7 - 27
Father - Female adolescent	12			
Mean ± *SD*		5.2 ± 2.9	4.5 ± 4.5	9.7 ± 6.5
(95% CI)		(3.3 to 7.0)	(1.6 to 7.4)	(5.6 to 13.8)
Observed range		1 - 10	0 - 11	1 - 20

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.8: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to adolescent age and responding parent, 12 to 14 year old adolescents.

		Mother - Adolescent				Father - Adolescent		
	n	Adolescent	Parent	Combined score	*n*	Adolescent	Parent	Combined score
12 year old adolescents	17				1			
Mean ± *SD* (95% CI)		4.6 ± 3.8 (2.7 to 6.5)	4.4 ± 4.0 (2.3 to 6.4)	8.9 ± 6.7 (5.5 to 12.4)		-	-	-
Observed range		2 - 15	0 - 13	3 - 25		-	-	-
13 year old adolescents	17				6			
Mean ± *SD* (95% CI)		5.4 ± 4.8 (2.9 to 7.8)	4.4 ± 6.8 (0.9 to 7.9)	9.7 ± 11.4 (3.9 to 15.6)		4.7 ± 2.7 (1.9 to 7.5)	3.3 ± 3.4 (-0.3 to 6.9)	8.0 ± 5.7 (2.1 to 13.9)
Observed range		2 - 17	0 - 20	2 - 37		1 - 8	0 - 9	1 - 15
14 year old adolescents	21				3			
Mean ± *SD* (95% CI)		6.4 ± 3.5 (4.8 to 8.0)	6.7 ± 4.2 (4.7 to 8.6)	13.0 ± 6.6 (10.1 to 16.0)		5.7 ± 3.8 (-3.7 to 15.1)	10.3 ± 0.6 (8.8 to 11.8)	16.0 ± 3.6 (7.0 to 25.0)
Observed range		0 - 14	0 - 17	3 - 26		3 - 10	10 - 11	13 - 20

Table 7.9: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to adolescent age and responding parent, 15 to 17 year old adolescents.

		Adolescent-mother				Adolescent-father		
	n	Adolescent	Parent	Combined score	*n*	Adolescent	Parent	Combined score
15 year old adolescents	14				2			
Mean ± *SD* (95% CI)		4.8 ± 3.9 (2.6 to 7.0)	6.1 ± 6.8 (2.2 to 10.1)	10.9 ± 7.9 (6.3 to 15.5)		7.5 ± 2.1 (-11.6 to 26.6)	1.0 ± 1.4 (-11.7 to 13.7)	8.5 ± 3.5 (-23.3 to 40.3)
Observed range		2 - 17	0 - 20	2 - 23		6 - 9	0 - 2	6 - 11
16 year old adolescents	22				1			
Mean ± *SD* (95% CI)		6.1 ± 3.3 (4.6 to 7.6)	5.0 ± 5.4 (2.6 to 7.4)	11.0 ± 6.5 (8.2 to 13.9)		-	-	-
Observed range		2 - 15	0 - 19	2 - 26		-	-	-
17 year old adolescents	19				4			
Mean ± *SD* (95% CI)		6.5 ± 3.8 (4.7 to 8.4)	4.1 ± 3.5 (2.4 to 5.7)	10.6 ± 5.9 (7.8 to 13.4)		5.0 ± 2.9 (0.3 to 9.7)	7.5 ± 5.3 (-0.9 to 15.9)	12.5 ± 8.1 (-0.4 to 25.4)
Observed range		1 - 16	0 - 11	3 - 25		2 - 8	3 - 13	5 - 20

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.10: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to parental work status.

	n	Adolescent	Parent	Combined score
Parent at home	60			
Mean ± *SD*		5.7 ± 3.5	5.0 ± 5.1	10.6 ± 7.1
(95% CI)		(4.8 to 6.6)	(3.7 to 6.3)	(8.8 to 12.4)
Observed range		1 - 17	0 - 20	2 - 36
Parent outside the home	67			
Mean ± *SD*		5.8 ± 3.9	5.4 ± 5.3	11.2 ± 7.8
(95% CI)		(4.9 to 6.8)	(4.1 to 6.6)	(9.3 to 13.2)
Observed range		0 - 17	0 - 20	1 - 37

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.11: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to responding parent and parent's work status.

Sample	*n*	Mean ± *SD* (95% Confidence Interval) Adolescent	Parent	Combined score
Mother - At home	55			
Mean ± *SD* (95% CI)		5.6 ± 3.6 (4.6 to 6.5)	5.2 ± 5.1 (3.8 to 6.5)	10.7 ± 7.1 (8.8 to 12.7)
Observed range		1 - 17	0 - 20	2 - 36
Mother - Outside the home	55			
Mean ± *SD* (95% CI)		5.9 ± 4.1 (4.7 to 7.0)	5.1 ± 5.3 (3.7 to 6.5)	11.0 ± 8.0 (8.8 to 13.1)
Observed range		0 - 17	0 - 20	2 - 37
Father - At home	5			
Mean ± *SD* (95% CI)		6.2 ± 3.0 (2.4 to 10.0)	2.8 ± 4.4 (-2.6 to 8.2)	9.0 ± 7.1 (0.1 to 17.9)
Observed range		2 - 10	0 - 10	2 - 20
Father - Outside the home	12			
Mean ± *SD* (95% CI)		5.3 ± 2.7 (3.5 to 7.0)	7.3 ± 5.5 (3.7 to 10.8)	12.5 ± 7.3 (7.9 to 17.1)
Observed range		1 - 9	0 - 18	1 - 27

Table 7.12: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to household structure.

	n	Adolescent	Parent	Combined score
Single Parent	23			
Mean ± *SD* (95% CI)		5.9 ± 4.2 (4.1 to 7.6)	6.1 ± 5.6 (3.7 to 8.4)	11.6 ± 8.3 (8.0 to 15.1)
Observed range		2 - 17	0 - 20	2 - 36
Dual Parent	104			
Mean ± *SD* (95% CI)		5.7 ± 3.6 (5.0 to 6.4)	5.0 ± 5.0 (4.0 to 5.9)	10.7 ± 7.3 (9.3 to 12.2)
Observed range		0 - 17	0 - 20	1 - 37

Note: The higher the score, the greater the reported parent-adolescent conflict, scoring ranges 0-20 (adolescent and parent) and 0-40 (combined score).

Table 7.13: Pearson correlations between adolescent, parent, and combined reports of parent-adolescent conflict, and adolescent and parent completed measures of adherence (n = 127).

	Adolescent Report		Parent Report	
	GAS	DSAS	GAS	DSAS
Adolescent CBQ	-0.30 (p = 0.001)	-0.26 (p = 0.003)	-0.33	-0.25 (p = 0.005)
Parent CBQ	-0.26 (p = 0.003)	-0.09 (p = 0.3)	-0.35	-0.20 (p = 0.02)
Combined CBQ	-0.33	-0.20 (p = 0.02)	-0.40	-0.27 (p = 0.002)

Note: unless otherwise stated, $p < 0.001$

Table 7.14: Pearson correlations between observed Blood Glucose Monitoring adherence and reports of Parent-Adolescent Conflict (n = 70).

	Adolescent CBQ	Parent CBQ	Combined CBQ
Observed BGM adherence	- 0.22 (p = 0.06)	- 0.05 (p = 0.7)	- 0.18 (p = 0.1)

Table 7.15: Pearson correlations between observed Blood Glucose Monitoring adherence over different time frames, and reports of Parent-Adolescent Conflict (n = 70).

	Observed Blood Glucose Monitoring Adherence				
	Last 28 days	Last 20 days	Last 12 days	Last 8 days	Last 4 days
Adolescent CBQ	- 0.22 (p = 0.06)	-0.24 (p = 0.045)	-0.20 (p = 0.09)	-0.20 (p = 0.09)	-0.22 (p = 0.07)
Parent CBQ	- 0.05 (p = 0.7)	-0.06 (p = 0.6)	-0.08 (p = 0.5)	-0.13 (p = 0.3)	-0.13 (p = 0.3)
Combined CBQ	- 0.18 (p = 0.1)	-0.20 (p = 0.09)	-0.20 (p = 0.1)	-0.23 (p = 0.05)	-0.23 (p = 0.05)

Table 7.16: Distribution of scores on the Conflict Behaviour Questionnaire by adolescents and parents, and combined scores, according to blood glucose monitoring adherence group.

	Blood Glucose Monitoring Adherence Group			
Conflict Behaviour Questionnaire form	Consistently High (n = 21)	Consistently Low (n = 31)	Rising (n = 10)	Other (n = 8)
Adolescent (Mean ± *SD* (95% CI))	5.0 ± 3.3 (3.5 to 6.4)	6.7 ± 4.5 (5.1 to 8.4)	5.7 ± 2.7 (3.8 to 7.6)	6.3 ± 3.5 (3.3 to 9.2)
Parent (Mean ± *SD* (95% CI))	4.6 ± 4.6 (2.5 to 6.7)	6.4 ± 6.1 (4.1 to 8.6)	5.2 ± 4.6 (1.9 to 8.5)	5.0 ± 4.9 (0.9 to 9.1)
Combined (Mean ± *SD* (95% CI))	9.5 ± 6.7 (6.5 to 12.6)	13.1 ± 8.4 (10.0 to 16.2)	10.9 ± 6.0 (6.6 to 15.2)	11.3 ± 8.1 (4.4 to 18.1)

Table 7.17: Analysis of Variance of reports of parent-adolescent conflict in relation to blood glucose monitoring adherence groups.

Source	SS	df	MS	F
Adolescent CBQ				
Between BGM Adherence Groups	34.75	3	11.58	0.78
Within BGM Adherence Groups	994.13	67	14.84	
TOTAL	1028.87	70		
Parent CBQ				
Between BGM Adherence Groups	30.35	3	10.12	0.35
Within BGM Adherence Groups	1999.94	70	28.57	
TOTAL	2030.28	73		
Combined CBQ				
Between BGM Adherence Groups	165.15	3	55.05	0.96
Within BGM Adherence Groups	3804.35	66	57.64	
TOTAL	3969.50	69		

Table 7.18: Analysis of Variance of reports of parent-adolescent conflict in relation to blood glucose monitoring adherence groups, with combined "Rising" and "Other" groups.

Source	SS	df	MS	F
Adolescent CBQ				
Between BGM Adherence Groups	33.40	2	16.70	1.14
Within BGM Adherence Groups	995.47	68	14.63	
TOTAL	1028.87	70		
Parent CBQ				
Between BGM Adherence Groups	28.71	2	14.36	0.50
Within BGM Adherence Groups	2001.57	71	28.19	
TOTAL	2030.28	73		
Combined CBQ				
Between BGM Adherence Groups	164.61	2	82.30	1.45
Within BGM Adherence Groups	3804.89	67	56.79	
TOTAL	3969.50	69		

Table 7.19: Correlations between reports of parent-adolescent conflict and adherence according to adolescents' age: 12, 13 and 14 year olds.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
12 year olds (n = 18)	Adolescent	-0.34 (p = 0.2)	-0.36 (p = 0.1)	0.15 (p = 0.6)	0.13 (p = 0.6)
	Parent	-0.58 (p = 0.01)	-0.41 (p = 0.08)	-0.23 (p = 0.4)	0.00 (p = 1.0)
	Combined	-0.44 (p = 0.07)	-0.42 (p = 0.09)	0.14 (p = 0.6)	0.07 (p = 0.8)
13 year olds (n = 23)	Adolescent	-0.45 (p = 0.03)	-0.19 (p = 0.4)	-0.74	-0.57 (p = 0.004)
	Parent	-0.37 (p = 0.07)	-0.12 (p = 0.6)	-0.68	-0.52 (p = 0.01)
	Combined	-0.42 (p = 0.049)	-0.15 (p = 0.5)	-0.73	-0.55 (p = 0.006)
14 year olds (n = 24)	Adolescent	-0.37 (p = 0.09)	-0.43 (p = 0.04)	-0.31 (p = 0.14)	-0.35 (p = 0.10)
	Parent	-0.53 (p = 0.009)	-0.21 (p = 0.3)	-0.32 (p = 0.1)	-0.14 (p = 0.5)
	Combined	-0.54 (p = 0.009)	-0.39 (p = 0.06)	-0.37 (p = 0.07)	-0.27 (p = 0.2)

Note: Unless otherwise stated, $p < 0.001$

Table 7.20: Correlations between reports of parent-adolescent conflict and adherence according to adolescents' age: 15, 16 and 17 year olds.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
15 year olds (n = 16)	Adolescent	-0.29 (p = 0.3)	0.12 (p = 0.7)	-0.21 (p = 0.4)	-0.31 (p = 0.2)
	Parent	-0.02 (p = 0.95)	0.03 (p = 0.9)	-0.26 (p = 0.3)	0.07 (p = 0.8)
	Combined	-0.14 (p = 0.6)	0.005 (p = 0.99)	-0.30 (p = 0.3)	-0.14 (p = 0.6)
16 year olds (n = 23)	Adolescent	-0.41 (p = 0.06)	-0.33 (p = 0.1)	-0.19 (p = 0.4)	0.03 (p = 0.9)
	Parent	-0.009 (p = 0.97)	0.09 (p = 0.7)	-0.18 (p = 0.4)	-0.27 (p = 0.2)
	Combined	-0.21 (p = 0.4)	-0.10 (p = 0.7)	-0.22 (p = 0.3)	-0.21 (p = 0.3)
17 year olds (n = 23)	Adolescent	-0.04 (p = 0.9)	-0.26 (p = 0.2)	-0.39 (p = 0.06)	-0.40 (p = 0.05)
	Parent	-0.30 (p = 0.2)	-0.14 (p = 0.5)	-0.48 (p = 0.02)	-0.27 (p = 0.2)
	Combined	-0.24 (p = 0.3)	-0.22 (p = 0.3)	-0.52 (p = 0.01)	-0.39 (p = 0.07)

Note: Unless otherwise stated, $p < 0.001$

Table 7.21: Correlations between reports of parent-adolescent conflict and adherence according to adolescents' age: 12 and 13 year olds versus 14 and 15 year olds and 16 and 17 year olds.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
12 & 13 year olds ($n = 41$)	Adolescent	-0.41 ($p = 0.007$)	-0.25 ($p = 0.1$)	-0.44 ($p = 0.004$)	-0.27 ($p = 0.09$)
	Parent	-0.39 ($p = 0.009$)	-0.16 ($p = 0.3$)	-0.53	-0.29 ($p = 0.06$)
	Combined	-0.41 ($p = 0.008$)	-0.20 ($p = 0.2$)	-0.50 ($p = 0.001$)	-0.32 ($p = 0.04$)
14 & 15 year olds ($n = 40$)	Adolescent	-0.28 ($p = 0.08$)	-0.18 ($p = 0.3$)	-0.24 ($p = 0.1$)	-0.31 ($p = 0.06$)
	Parent	-0.22 ($p = 0.2$)	-0.04 ($p = 0.8$)	-0.25 ($p = 0.1$)	-0.01 ($p = 0.9$)
	Combined	-0.31 ($p = 0.06$)	-0.18 ($p = 0.3$)	-0.29 ($p = 0.07$)	-0.19 ($p = 0.2$)
16 & 17 year olds ($n = 46$)	Adolescent	-0.21 ($p = 0.2$)	-0.29 ($p = 0.048$)	-0.29 ($p = 0.047$)	-0.20 ($p = 0.2$)
	Parent	-0.13 ($p = 0.4$)	-0.02 ($p = 0.9$)	-0.27 ($p = 0.07$)	-0.26 ($p = 0.07$)
	Combined	-0.22 ($p = 0.2$)	-0.17 ($p = 0.3$)	-0.34 ($p = 0.02$)	-0.29 ($p = 0.05$)

Note: Unless otherwise stated, $p < 0.001$

Table 7.22: Correlations between reports of parent-adolescent conflict and adherence according to adolescents' age: 12 to 14 year olds versus 15 to 17 year olds.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
12 to 14 year olds (n = 65)	Adolescent	-0.40 (p = 0.001)	-0.30 (p = 0.01)	-0.41 (p = 0.001)	-0.30 (p = 0.01)
	Parent	-0.44	-0.19 (p = 0.1)	-0.47	-0.24 (p = 0.047)
	Combined	-0.45	-0.26 (p = 0.04)	-0.47	-0.30 (p = 0.02)
15 to 17 year olds (n = 62)	Adolescent	-0.19 (p = 0.2)	-0.19 (p = 0.1)	-0.25 (p = 0.04)	-0.19 (p = 0.1)
	Parent	-0.10 (p = 0.45)	-0.01 (p = 0.96)	-0.26 (p = 0.04)	-0.17 (p = 0.2)
	Combined	-0.19 (p = 0.2)	-0.12 (p = 0.3)	-0.32 (p = 0.01)	-0.24 (p = 0.06)

Note: Unless otherwise stated, $p < 0.001$

Table 7.23: Correlations between reports of parent-adolescent conflict and adherence according to adolescents' gender.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
Male adolescents (n = 58)	Adolescent	-0.29 (p = 0.03)	-0.30 (p = 0.02)	-0.35 (p = 0.009)	-0.38 (p = 0.003)
	Parent	-0.34 (p = 0.01)	-0.11 (p = 0.4)	-0.44 (p = 0.001)	-0.29 (p = 0.02)
	Combined	-0.35 (p = 0.009)	-0.22 (p = 0.1)	-0.44 (p = 0.001)	-0.37 (p = 0.004)
Female adolescents (n = 69)	Adolescent	-0.29 (p = 0.01)	-0.23 (p = 0.05)	-0.32 (p = 0.006)	-0.15 (p = 0.2)
	Parent	-0.21 (p = 0.09)	-0.08 (p = 0.5)	-0.28 (p = 0.02)	-0.14 (p = 0.3)
	Combined	-0.31 (p = 0.01)	-0.19 (p = 0.1)	-0.35 (p = 0.003)	-0.18 (p = 0.1)

Note: Unless otherwise stated, $p < 0.001$

Table 7.24: Correlations between reports of parent-adolescent conflict and adherence according to parents' age.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
Under 40 years old (n = 28)	Adolescent	-0.52 (p = 0.006)	-0.34 (p = 0.07)	-0.18 (p = 0.4)	-0.16 (p = 0.4)
	Parent	-0.45 (p = 0.02)	-0.33 (p = 0.08)	-0.45 (p = 0.02)	-0.08 (p = 0.7)
	Combined	-0. 51 (p = 0.008)	-0.34 (p = 0.08)	-0.44 (p = 0.02)	-0.13 (p = 0.5)
40 - 45 years old (n = 64)	Adolescent	-0.30 (p = 0.02)	-0.23 (p = 0.06)	-0.36 (p = 0.004)	-0.36 (p = 0.003)
	Parent	-0.34 (p = 0.006)	-0.08 (p = 0.5)	-0.46	-0.27 (p = 0.03)
	Combined	-0.37 (p = 0.004)	-0.18 (p = 0.2)	-0.46	-0.36 (p = 0.003)
Over 45 years old (n = 35)	Adolescent	-0.23 (p = 0.2)	-0.24 (p = 0.2)	-0.35 (p = 0.03)	-0.14 (p = 0.4)
	Parent	-0. 06 (p = 0.7)	0.02 (p = 0.9)	-0.11 (p = 0.5)	-0.20 (p = 0.2)
	Combined	-0.18 (p = 0.3)	-0.14 (p = 0.4)	-0.23 (p = 0.2)	-0.24 (p = 0.2)

Note: Unless otherwise stated, $p < 0.001$

Table 7.25: Correlations between reports of parent-adolescent conflict and adherence according to parents' gender.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
Mothers (n = 110)	Adolescent	-0.34	-0.34	-0.34	-0.26 (p = 0.006)
	Parent	-0.28 (p = 0.003)	-0.15 (p = 0.1)	-0.36	-0.21 (p = 0.02)
	Combined	-0.36	-0.29 (p = 0.002)	-0.40	-0.29 (p = 0.002)
Fathers (n = 17)	Adolescent	-0.03 (p = 0.9)	0.23 (p = 0.5)	-0.27 (p = 0.3)	-0.14 (p = 0.6)
	Parent	-0.18 (p = 0.5)	0.17 (p = 0.5)	-0.32 (p = 0.2)	-0.13 (p = 0.6)
	Combined	-0.14 (p = 0.6)	0.21 (p = 0.4)	-0.34 (p = 0.2)	-0.15 (p = 0.6)

Note: Unless otherwise stated, $p < 0.001$

Table 7.26: Correlations between reports of parent-adolescent conflict and adherence according to parental work status.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
At home (n = 60)	Adolescent	-0.21 (p = 0.1)	-0.10 (p = 0.4)	-0.29 (p = 0.02)	-0.13 (p = 0.3)
	Parent	-0.39 (p = 0.002)	-0.08 (p = 0.5)	-0.46	-0.15 (p = 0.2)
	Combined	-0.37 (p = 0.004)	-0.13 (p = 0.3)	-0.46	-0.21 (p = 0.1)
Outside the home (n = 67)	Adolescent	-0.41 (p = 0.001)	-0.40 (p = 0.001)	-0.37 (p = 0.002)	-0.34 (p = 0.006)
	Parent	-0.17 (p = 0.2)	-0.09 (p = 0.5)	-0.25 (p = 0.04)	-0.25 (p = 0.04)
	Combined	-0.32 (p = 0.01)	-0.25 (p = 0.04)	-0.34 (p = 0.005)	-0.32 (p = 0.009)

Note: Unless otherwise stated, $p < 0.001$

Table 7.27: Correlations between reports of parent-adolescent conflict and adherence according to family structure.

		Adolescent reports		Parent reports	
Sample	CBQ scale	GAS	DSAS	GAS	DSAS
Dual parents (n = 104)	Adolescent	-0.23 (p = 0.02)	-0.25 (p = 0.009)	-0.31 (p = 0.001)	-0.23 (p = 0.02)
	Parent	-0.16 (p = 0.1)	-0.06 (p = 0.5)	-0.37	-0.17 (p = 0.08)
	Combined	-0.24 (p = 0.02)	-0.18 (p = 0.07)	-0.41	-0.24 (p = 0.02)
Single parents (n = 23)	Adolescent	-0.50 (p = 0.01)	-0.30 (p = 0.2)	-0.43 (p = 0.04)	-0.31 (p = 0.1)
	Parent	-0.62 (p = 0.002)	-0.26 (p = 0.2)	-0.24 (p = 0.3)	-0.28 (p = 0.2)
	Combined	-0.68 (p = 0.001)	-0.33 (p = 0.1)	-0.35 (p = 0.1)	-0.39 (p = 0.07)

Note: Unless otherwise stated, $p < 0.001$

Table 7.28: Pearson correlations between reports of parent-adolescent conflict and adolescents' health status (HbA_{1c}).

	Adolescent (n = 127)	Parent (n = 127)	Combined score (n = 127)
HbA_{1c}	0.23 (p = 0.009)	0.16 (p = 0.06)	0.25 (p = 0.005)

Table 7.29: Hierarchical stepwise multiple regression analyses of HbA1c against adolescent and parent completed measures of adherence and parent-adolescent conflict.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Equation 1. Adolescent GAS and CBQ					
Step 1 Adolescent GAS	-0.182	0.033	0.033	4.19	0.04
Step 2 Adolescent CBQ	0.205	0.071	0.038	5.00	0.03
Equation 2. Adolescent DSAS and CBQ					
Step 1 Adolescent DSAS	-0.112	0.013	0.013	1.62	0.2
Regression halted after *Step 1*.					
Equation 3. Parent GAS and CBQ					
Step 1 Parent GAS	-0.323	0.105	0.105	14.94	0.0002
Step 2 Parent CBQ	0.056	0.107	0.003	0.40	0.5
Equation 4. Parent DSAS and CBQ					
Step 1 Parent DSAS	-0.231	0.053	0.053	7.23	0.0001
Step 2 Parent CBQ	0.139	0.072	0.018	2.52	0.1
Equation 5. Adolescent GAS and Combined CBQ					
Step 1 Adolescent GAS	-0.200	0.040	0.040	5.01	0.03
Step 2 Combined CBQ	0.197	0.075	0.035	4.48	0.04
Equation 6. Adolescent DSAS and Combined CBQ					
Step 1 Adolescent DSAS	-0.143	0.021	0.021	2.60	0.1
Regression halted after *Step 1*.					
Equation 7. Parent GAS and Combined CBQ					
Step 1 Parent GAS	-0.351	0.124	0.124	17.34	0.0001
Step 2 Combined CBQ	0.132	0.138	0.015	2.08	0.2
Equation 8. Parent DSAS and Combined CBQ					
Step 1 Parent DSAS	-0.243	0.059	0.059	7.70	0.006
Step 2 Combined CBQ	0.207	0.099	0.040	5.37	0.02

* F test on R^2 change.

TABLES CITED IN CHAPTER 9.

Table 9.1: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents.

	n	Adolescent	Parent
Total sample	135		
Mean ± *SD* (95% Confidence Interval)		122.1 ± 29.6 (116.9 to 127.3)	114.8 ± 30.1 (109.7 to 120.0)
Observed range		59 - 187	39 - 190

Note: Higher scores indicate greater autonomy, scoring range 0 - 252.

Table 9.2: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents.

Subscale	*n*	Adolescent	Parent
Self- & Family-Care	135		
Mean ± *SD*		33.2 ± 12.7	30.3 ± 12.2
(95% Confidence Interval)		(31.0 to 35.4)	(28.2 to 32.4)
Observed range*		8 - 76	5 - 83
Management Activity:	135		
Mean ± *SD*		50.3 ± 13.0	48.9 ± 13.9
(95% Confidence Interval)		(48.1 to 52.6)	(46.6 to 51.3)
Observed range†		18 - 76	15 - 76
Recreational Activity	135		
Mean ± *SD*		27.8 ± 9.7	26.8 ± 8.6
(95% Confidence Interval)		(26.2 to 29.5)	(25.4 to 28.3)
Observed range‡		8 - 57	9 - 50
Social / Vocational Activity	135		
Mean ± *SD*		10.0 ± 3.2	8.7 ± 3.6
(95% Confidence Interval)		(9.4 to 10.6)	(8.1 to 9.3)
Observed range§		0 - 18	2 - 17

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88.
† Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80.
‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64.
§ Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

Table 9.3: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents, according to adolescent age.

	n	Adolescent	Parent
12 year old adolescents	20		
Mean ± *SD*		99.3 ± 26.5	97.1 ± 33.9
(95% CI)		(86.2 to 112.5)	(80.3 to 113.9)
Observed range		59 - 159	39 - 172
13 year old adolescents	24		
Mean ± *SD*		112.2 ± 31.7	106.2 ± 24.6
(95% CI)		(98.5 to 125.9)	(95.5 to 116.8)
Observed range		60 - 174	55 - 151
14 year old adolescents	25		
Mean ± *SD*		129.4 ± 30.9	108.7 ± 19.9
(95% CI)		(116.0 to 142.7)	(100.1 to 117.3)
Observed range		67 - 187	81 - 145
15 year old adolescents	17		
Mean ± *SD*		125.6 ± 26.9	120.9 ± 25.3
(95% CI)		(111.3 to 139.9)	(107.5 to 134.4)
Observed range		86 - 169	72 - 164
16 year old adolescents	25		
Mean ± *SD*		124.6 ± 24.3	119.2 ± 29.6
(95% CI)		(114.1 to 135.1)	(106.4 to 132.0)
Observed range		76 - 166	64 - 185
17 year old adolescents	24		
Mean ± *SD*		138.7 ± 22.6	141.1 ± 27.8
(95% CI)		(128.9 to 148.4)	(129.0 to 153.1)
Observed range		101 - 180	77 - 190

Note: The higher the score, the greater the reported adolescent autonomy, scoring range 0-252.

Table 9.4: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to adolescent age: 12 year olds to 14 year olds.

	Self- & Family-Care		Management Activity		Recreational Activity		Social / Vocational Activity	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
12 year old adolescents (n = 20)								
Mean ± *SD* (95% CI)	29.4 ± 15.2 (22.3 to 36.5)	23.7 ± 12.5 (17.8 to 29.6)	36.2 ± 10.6 (30.9 to 41.5)	38.3 ± 14.4 (31.1 to 45.4)	23.5 ± 8.5 (19.5 to 27.5)	25.3 ± 9.5 (20.8 to 29.7)	8.7 ± 2.6 (7.4 to 9.9)	7.9 ± 3.5 (6.3 to 9.5)
Observed range	12 - 76	5 - 58	21 - 55	16 - 59	8 - 43	9 - 46	3 - 12	3 - 15
13 year old adolescents (n = 24)								
Mean ± *SD* (95% CI)	30.4 ± 13.1 (24.8 to 36.1)	27.7 ± 8.3 (24.1 to 31.3)	43.6 ± 11.2 (38.9 to 48.3)	43.8 ± 12.2 (38.7 to 49.0)	28.3 ± 11.0 (23.7 to 33.0)	25.9 ± 9.4 (21.9 to 29.8)	9.0 ± 3.3 (7.6 to 10.4)	7.5 ± 3.6 (5.9 to 9.0)
Observed range	13 - 59	15 - 49	18 - 61	15 - 63	11 - 46	11 - 48	2 - 14	2 - 17
14 year old adolescents (n = 25)								
Mean ± *SD* (95% CI)	36.4 ± 11.4 (31.7 to 41.1)	29.4 ± 9.6 (25.4 to 33.3)	51.6 ± 12.9 (46.2 to 57.1)	45.8 ± 10.0 (41.5 to 50.0)	30.9 ± 10.5 (26.3 to 35.4)	26.0 ± 5.8 (23.5 to 28.5)	9.4 ± 3.3 (8.0 to 10.8)	7.7 ± 3.1 (6.3 to 9.0)
Observed range	13 - 57	8 - 55	28 - 73	34 - 65	18 - 57	18 - 38	2 - 15	2 - 13

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88. † Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80. ‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64. § Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

Table 9.5: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to adolescent age: 15 year olds to 17 year olds.

	Self- & Family-Care		Management Activity		Recreational Activity		Social / Vocational Activity	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
15 year old adolescents (n = 17)								
Mean ± *SD* (95% CI)	33.2 ± 12.3 (26.6 to 39.8)	32.6 ± 10.5 (27.0 to 38.2)	53.8 ± 10.0 (48.7 to 60.0)	52.5 ± 11.4 (46.7 to 58.4)	28.4 ± 8.8 (23.9 to 32.9)	27.3 ± 8.5 (22.9 to 31.7)	9.8 ± 2.7 (8.4 to 11.2)	8.1 ± 3.1 (6.5 to 9.6)
Observed range	8 - 59	15 - 58	33 - 70	29 - 71	16 - 43	16 - 46	4 - 13	3 - 15
16 year old adolescents (n = 25)								
Mean ± *SD* (95% CI)	30.6 ± 10.0 (26.4 to 34.9)	28.3 ± 10.2 (24.0 to 32.5)	55.0 ± 8.9 (51.3 to 58.8)	51.8 ± 12.9 (46.4 to 57.3)	27.7 ± 10.8 (23.3 to 32.2)	27.5 ± 9.4 (23.6 to 31.4)	11.2 ± 3.6 (9.6 to 12.7)	10.0 ± 3.2 (8.7 to 11.4)
Observed range	9 - 49	15 - 58	36 - 71	23 - 72	12 - 49	10 - 46	0 - 18	4 - 16
17 year old adolescents (n = 24)								
Mean ± *SD* (95% CI)	39.6 ± 11.5 (34.6 to 44.6)	41.0 ± 15.3 (34.4 to 47.6)	59.2 ± 10.4 (54.8 to 63.6)	60.9 ± 12.2 (55.8 to 66.1)	27.7 ± 7.7 (24.5 to 30.9)	29.4 ± 8.6 (25.8 to 33.0)	11.7 ± 2.7 (10.6 to 12.8)	10.9 ± 4.0 (9.2 to 12.6)
Observed range	25 - 68	18 - 83	39 - 76	26 - 76	19 - 53	18 - 50	6 - 17	3 - 17

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88. † Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80. ‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64. § Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

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Table 9.6: Pearson correlations between adolescent and parent reports of adolescent autonomy, and adolescents' age (n = 135).

	Correlation with Adolescents' Age	
	Adolescent Reports	Parent Reports
Total AFC score	0.36	0.42
Self- & Family-Care	0.18 (p = 0.04)	0.32
Management Activity	0.55	0.45
Recreational Activity	0.07 (p = 0.4)	0.13 (p = 0.1)
Social / Vocational Activity	0.34	0.30

Note: unless otherwise stated, $p < 0.001$

Table 9.7: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents, according to adolescent gender.

	n	Adolescent	Parent
Male adolescents	60		
Mean ± SD (95% CI)		115.5 ± 30.3 (107.6 to 123.4)	112.7 ± 29.9 (104.9 to 120.5)
Observed range		59 - 181	39 - 187
Female adolescents	75		
Mean ± SD (95% CI)		128.3 ± 27.8 (121.5 to 135.1)	118.9 ± 30.0 (111.5 to 126.2)
Observed range		71 - 187	68 - 190

Table 9.8: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to adolescent gender.

	Self- & Family-Care		Management Activity		Recreational Activity		Social / Vocational Activity	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Female adolescents (n = 75)								
Mean ± *SD* (95% CI)	34.4 ± 13.2 (31.3 to 37.6)	30.3 ± 12.6 (27.4 to 33.3)	53.2 ± 12.1 (50.3 to 56.0)	50.4 ± 14.1 (47.1 to 53.7)	28.8 ± 9.1 (26.7 to 30.9)	27.4 ± 8.6 (25.4 to 29.4)	10.1 ± 3.1 (9.4 to 10.8)	9.1 ± 3.7 (8.3 to 10.0)
Observed range	8 - 76	8 - 60	29 - 76	24 - 76	11 - 56	10 - 48	0 - 17	2 - 17
Male adolescents (n = 60)								
Mean ± *SD* (95% CI)	32.2 ± 11.8 (29.1 to 35.2)	30.6 ± 12.1 (27.4 to 33.7)	46.9 ± 13.3 (53.4 to 50.3)	47.6 ± 13.7 (44.0 to 51.2)	26.6 ± 10.5 (23.9 to 29.3)	26.4 ± 8.6 (24.1 to 28.6)	9.9 ± 3.5 (9.0 to 10.8)	8.3 ± 3.6 (7.3 to 9.2)
Observed range	9 - 68	5 - 83	18 - 75	15 - 73	8 - 57	9 - 50	2 - 18	2 - 17

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88. † Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80. ‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64. § Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

Table 9.9: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents, according to parents' age.

	n	Adolescent	Parent
Parents under 40 years old	30		
Mean ± *SD* (95% CI)		116.6 ± 28.6 (105.3 to 127.9)	111.1 ± 28.5 (99.9 to 122.4)
Observed range		64 - 174	64 - 172
Parents 40 to 45 years old	66		
Mean ± *SD* (95% CI)		120.5 ± 30.9 (112.8 to 128.2)	114.9 ± 29.7 (107.4 to 122.3)
Observed range		59 - 187	39 - 187
Parents over 45 years old	39		
Mean ± *SD* (95% CI)		130.0 ± 27.1 (120.7 to 139.3)	121.7 ± 31.7 (110.8 to 132.6)
Observed range		60 - 171	55 - 190

Table 9.10: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to parents' age.

	Self- & Family-Care		Management Activity		Recreational Activity		Social / Vocational Activity	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Parents under 40 years old (n = 30)								
Mean ± *SD*	33.0 ± 14.2	29.0 ± 10.1	45.4 ± 13.0	44.8 ± 14.1	27.2 ± 9.2	26.9 ± 7.4	9.4 ± 2.7	8.8 ± 3.2
(95% CI)	(27.5 to 38.5)	(25.1 to 32.9)	(40.5 to 50.4)	(39.4 to 50.1)	(23.7 to 30.7)	(24.1 to 29.7)	(8.4 to 10.4)	(7.6 to 10.0)
Observed range	10 - 76	14 - 58	21 - 69	23 - 72	15 - 46	15 - 46	4 - 14	2 - 15
Parents 40 to 45 years old (n = 66)								
Mean ± *SD*	33.3 ± 12.6	30.3 ± 13.5	49.7 ± 12.2	48.7 ± 13.3	27.2 ± 10.4	26.3 ± 8.8	9.7 ± 3.3	8.6 ± 3.7
(95% CI)	(30.2 to 36.4)	(27.0 to 33.7)	(46.6 to 52.7)	(45.4 to 52.0)	(24.6 to 29.7)	(24.2 to 28.5)	(8.9 to 10.5)	(7.7 to 9.6)
Observed range	12 - 65	5 - 83	22 - 75	16 - 76	8 - 57	9 - 50	0 - 16	2 - 17
Parents over 45 years old (n = 39)								
Mean ± *SD*	34.0 ± 11.5	31.7 ± 11.9	55.2 ± 12.8	53.2 ± 14.2	29.4 ± 9.0	27.9 ± 9.1	11.1 ± 3.4	8.8 ± 3.9
(95% CI)	(30.1 to 37.8)	(27.7 to 35.7)	(51.0 to 59.4)	(48.6 to 57.9)	(26.5 to 32.4)	(24.9 to 31.0)	(10.0 to 12.2)	(7.5 to 10.1)
Observed range	8 - 68	15 - 58	18 - 76	15 - 75	13 - 49	10 - 46	2 - 18	3 - 17

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88. † Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80. ‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64. § Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

Table 9.11: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents, according to responding parent.

	n	Adolescent	Parent
Mother	118		
Mean ± *SD* (95% CI)		122.5 ± 29.4 (116.9 to 128.1)	117.1 ± 29.9 (111.4 to 122.8)
Observed range		59 - 187	39 - 190
Father	17		
Mean ± *SD* (95% CI)		121.0 ± 31.5 (104.8 to 137.2)	108.8 ± 30.5 (93.1 to 124.5)
Observed range		71 - 174	75 - 179

Table 9.12: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to responding parent.

	Self- & Family-Care		Management Activity		Recreational Activity		Social / Vocational Activity	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Mother (n = 118)								
Mean ± *SD*	33.7 ± 12.8	30.7 ± 12.3	50.1 ± 12.8	49.6 ± 13.8	27.7 ± 9.6	27.0 ± 8.8	10.1 ± 3.2	8.8 ± 3.7
(95% CI)	(31.3 to 36.1)	(28.4 to 33.0)	(47.7 to 52.5)	(47.0 to 52.1)	(26.0 to 29.5)	(25.4 to 28.6)	(9.5 to 10.6)	(8.1 to 9.5)
Observed range	8 - 76	5 - 83	18 - 75	15 - 76	8 - 57	9 - 50	0 - 18	2 - 17
Father (n = 17)								
Mean ± *SD*	31.3 ± 11.3	28.6 ± 12.6	51.8 ± 14.1	46.2 ± 15.2	28.5 ± 11.2	26.3 ± 7.3	9.6 ± 3.7	8.1 ± 3.5
(95% CI)	(25.7 to 36.9)	(22.4 to 34.9)	(44.5 to 59.0)	(38.4 to 54.0)	(22.7 to 34.2)	(22.5 to 30.1)	(7.7 to 11.5)	(6.3 to 9.9)
Observed range	13 - 59	14 - 58	29 - 76	25 - 73	11 - 46	11 - 40	3 - 17	2 - 17

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88. † Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80. ‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64. § Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

Table 9.13: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents, according to parental work status.

	n	Adolescent	Parent
Parent at home	64		
Mean ± *SD* (95% CI)		122.9 ± 30.7 (115.1 to 130.7)	114.8 ± 30.2 (107.1 to 122.4)
Observed range		59 - 181	46 - 190
Parent outside the home	70		
Mean ± *SD* (95% CI)		121.7 ± 28.7 (114.5 to 128.9)	117.1 ± 30.0 (39 to 187)
Observed range		67 - 187	39 - 187

Table 9.14: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to parental work status.

	Self- & Family-Care		Management Activity		Recreational Activity		Social / Vocational Activity	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Parent at home (n = 64)								
Mean ± *SD*	34.2 ± 13.6	30.8 ± 11.8	49.9 ± 14.3	48.1 ± 14.7	28.6 ± 9.2	26.6 ± 7.9	9.6 ± 3.1	8.6 ± 3.8
(95% CI)	(30.8 to 37.7)	(27.8 to 33.7)	(46.3 to 53.5)	(44.4 to 51.9)	(26.3 to 30.9)	(24.7 to 28.6)	(8.8 to 10.4)	(7.7 to 9.5)
Observed range	9 - 76	5 - 60	18 - 73	15 - 76	8 - 49	10 - 46	0 - 16	2 - 17
Parent outside the home (n = 70)								
Mean ± *SD*	32.6 ± 11.6	30.1 ± 12.8	50.9 ± 11.7	50.4 ± 13.1	27.3 ± 10.3	27.4 ± 9.2	10.5 ± 3.3	8.9 ± 3.5
(95% CI)	(29.8 to 35.4)	(27.0 to 33.2)	(48.0 to 53.7)	(47.2 to 53.6)	(24.8 to 29.8)	(25.1 to 29.6)	(9.7 to 11.3)	(8.1 to 9.8)
Observed range	8 - 59	8 - 83	28 - 76	16 - 73	13 - 57	9 - 50	2 - 18	3 - 17

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88. † Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80. ‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64. § Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

Table 9.15: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents, according to family structure.

	n	Adolescent	Parent
Dual Parent	110		
Mean ± *SD* (95% CI)		122.8 ± 28.9 (117.1 to 128.5)	118.1 ± 29.4 (112.3 to 123.9)
Observed range		59 - 187	39 -190
Single Parent	25		
Mean ± *SD* (95% CI)		120.4 ± 33.0 (106.8 to 134.0)	107.2 ± 31.3 (94.3 to 120.1)
Observed range		60 - 181	46 - 169

Table 9.16: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to parental work status.

	Self- & Family-Care		Management Activity		Recreational Activity		Social / Vocational Activity	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Dual parent (n = 110)								
Mean ± *SD* (95% CI)	32.3 ± 11.7 (30.1 to 34.6)	30.0 ± 11.6 (27.8 to 32.2)	51.2 ± 12.8 (48.7 to 53.6)	50.8 ± 13.4 (48.2 to 53.3)	28.1 ± 9.6 (26.3 to 30.0)	27.3 ± 8.8 (25.7 to 29.0)	10.2 ± 3.1 (9.6 to 10.8)	9.0 ± 3.7 (8.3 to 9.7)
Observed range	8 - 65	8 - 60	21 - 76	16 - 76	8 - 56	9 - 50	2 - 18	2 - 17
Single parent (n = 25)								
Mean ± *SD* (95% CI)	37.9 ± 15.2 (31.7 to 44.2)	32.3 ± 15.1 (26.0 to 38.5)	46.8 ± 13.2 (41.3 to 52.3)	42.3 ± 14.5 (36.3 to 48.3)	26.5 ± 10.5 (22.1 to 30.8)	25.1 ± 7.4 (22.1 to 28.2)	9.2 ± 3.7 (7.6 to 10.7)	7.5 ± 3.0 (6.3 to 8.8)
Observed range	13 - 76	5 - 83	18 - 73	15 - 69	13 - 57	11 - 46	0 - 15	2 - 13

* Self- & Family-Care: Higher scores indicate greater autonomy, scoring range 0 - 88. † Management Activity: Higher scores indicate greater autonomy, scoring range 0 - 80. ‡ Recreational Activity: Higher scores indicate greater autonomy, scoring range 0 - 64. § Social / Vocational Activity: Higher scores indicate greater autonomy, scoring range 0 - 20.

Table 9.17: Pearson correlations (with *p* values) between adolescent and parent reports of autonomy (total AFC scale) and adherence (*n* = 135).

	Adolescent Report		Parent Report	
	GAS	DSAS	GAS	DSAS
Adolescent AFC	0.14 ($p = 0.1$)	0.16 ($p = 0.07$)	0.01 ($p = 0.9$)	0.12 ($p = 0.2$)
Parent AFC	0.09 ($p = 0.3$)	0.12 ($p = 0.2$)	0.14 ($p = 0.1$)	0.10 ($p = 0.3$)

Note: unless otherwise stated, $p < 0.001$

Table 9.18: Pearson correlations (with *p* values) between adolescent and parent reports of autonomy (AFC subscales) and adherence (*n* = 135).

	Adolescent Report		Parent Report	
	GAS	DSAS	GAS	DSAS
Adolescent AFC reports				
Self- and Family-Care	-0.03 ($p = 0.7$)	0.08 ($p = 0.3$)	-0.04 ($p = 0.6$)	0.07 ($p = 0.5$)
Management Activity	0.13 ($p = 0.1$)	0.04 ($p = 0.6$)	0.03 ($p = 0.7$)	0.10 ($p = 0.3$)
Recreational Activity	0.21 ($p = 0.02$)	0.23 ($p = 0.007$)	0.00 ($p = 1.0$)	0.09 ($p = 0.3$)
Social / Vocational Activity	0.04 ($p = 0.7$)	0.11 ($p = 0.2$)	0.06 ($p = 0.5$)	0.10 ($p = 0.2$)
Parent AFC reports				
Self- and Family-Care	-0.03 ($p = 0.7$)	0.06 ($p = 0.5$)	0.07 ($p = 0.4$)	0.09 ($p = 0.3$)
Management Activity	0.16 ($p = 0.07$)	0.11 ($p = 0.2$)	0.18 ($p = 0.03$)	0.10 ($p = 0.3$)
Recreational Activity	0.15 ($p = 0.1$)	0.13 ($p = 0.1$)	0.09 ($p = 0.3$)	0.00 ($p = 1.0$)
Social / Vocational Activity	0.04 ($p = 0.7$)	0.06 ($p = 0.5$)	-0.02 ($p = 0.8$)	0.12 ($p = 0.2$)

Note: unless otherwise stated, $p < 0.001$

Table 9.19: Pearson correlations (with *p* values) between adolescent and parent reports of autonomy and observed blood glucose monitoring adherence (*n* = 75).

	Correlation of reports with observed BGM adherence	
	Adolescent reports	Parent Reports
Total AFC score	-0.04 ($p = 0.7$)	-0.20 ($p = 0.09$)
AFC Subscales:		
Self- & Family-Care	-0.05 ($p = 0.7$)	-0.26 ($p = 0.02$)
Management Activity	-0.03 ($p = 0.8$)	-0.10 ($p = 0.4$)
Recreational Activity	-0.04 ($p = 0.7$)	-0.11 ($p = 0.4$)
Social / Vocational Activity	-0.09 ($p = 0.5$)	-0.09 ($p = 0.5$)

Table 9.20: Pearson correlations between observed Blood Glucose Monitoring adherence over different time frames, and reports of Adolescent Autonomy (*n* = 74).

	Observed Blood Glucose Monitoring Adherence				
	Last 28 days	Last 20 days	Last 12 days	Last 8 days	Last 4 days
Adolescent AFC	-0.04 ($p = 0.7$)	-0.07 ($p = 0.6$)	-0.01 ($p = 0.97$)	-0.01 ($p = 0.91$)	-0.03 ($p = 0.8$)
Parent AFC	-0.20 ($p = 0.09$)	-0.22 ($p = 0.06$)	-0.18 ($p = 0.1$)	-0.17 ($p = 0.1$)	-0.21 ($p = 0.07$)

Table 9.21: Pearson correlations between observed Blood Glucose Monitoring adherence over different time frames, and reports of Adolescent Autonomy using subscales of the Autonomous Functioning Checklist (n = 74).

	Observed Blood Glucose Monitoring Adherence				
	Last 28 days	Last 20 days	Last 12 days	Last 8 days	Last 4 days
Adolescent AFC reports					
Self- and Family-Care	-0.05 (p = 0.7)	-0.07 (p = 0.6)	-0.04 (p = 0.8)	-0.04 (p = 0.7)	-0.05 (p = 0.7)
Adolescent AFC: Management Activity	-0.03 (p = 0.8)	-0.06 (p = 0.6)	0.00 (p = 1.0)	0.02 (p = 0.9)	0.00 (p = 1.0)
Adolescent AFC: Recreational Activity	-0.04 (p = 0.7)	-0.03 (p = 0.8)	-0.01 (p = 0.96)	-0.02 (p = 0.9)	-0.05 (p = 0.6)
Adolescent AFC: Social / Vocational Activity	-0.09 (p = 0.5)	-0.09 (p = 0.4)	-0.07 (p = 0.6)	-0.06 (p = 0.6)	-0.08 (p = 0.5)
Parent AFC reports					
Self- and Family-Care	-0.26 (p = 0.02)	-0.27 (p = 0.02)	-0.24 (p = 0.04)	-0.24 (p = 0.04)	-0.27 (p = 0.02)
Management Activity	-0.10 (p = 0.4)	-0.14 (p = 0.2)	-0.10 (p = 0.4)	-0.09 (p = 0.4)	-0.12 (p = 0.3)
Recreational Activity	-0.11 (p = 0.4)	-0.11 (p = 0.4)	-0.08 (p = 0.5)	-0.07 (p = 0.5)	-0.10 (p = 0.4)
Social / Vocational Activity	-0.09 (p = 0.5)	-0.12 (p = 0.3)	-0.10 (p = 0.4)	-0.12 (p = 0.3)	-0.14 (p = 0.2)

Table 9.22: Distribution of scores on the Autonomous Functioning Checklist by adolescents and parents, according to blood glucose monitoring adherence group.

	Blood Glucose Monitoring Adherence Group			
	Consistently High (n = 22)	Consistently Low (n = 33)	Rising (n = 12)	Other (n = 8)
Adolescent (Mean ± *SD* (95%CI))	122.8 ± 31.5 (108.4 to 137.1)	122.1 ± 23.3 (113.4 to 130.8)	113.9 ± 30.8 (94.3 to 133.5)	121.9 ± 25.9 (100.2 to 143.5)
Parent (Mean ± *SD* (95% CI))	107.5 ± 26.8 (95.3 to 119.7)	116.6 ± 30.6 (105.2 to 128.1)	103.3 ± 39.9 (77.9 to 128.6)	132.6 ± 39.2 (99.8 to 165.4)

Table 9.23: Distribution of scores on the Autonomous Functioning Checklist subscales by adolescents and parents, according to blood glucose monitoring adherence group.

	Blood Glucose Monitoring Adherence Group			
	Consistently High (n = 22)	Consistently Low (n = 33)	Rising (n = 12)	Other (n = 8)
Adolescent AFC reports (Mean ± *SD* (95% CI))				
Self- and Family-Care	35.3 ± 16.0 (28.1 to 42.6)	34.0 ± 12.0 (29.5 to 38.5)	25.9 ± 9.7 (19.7 to 32.1)	36.0 ± 11.6 (26.3 to 45.7)
Management Activity	50.2 ± 12.7 (44.4 to 56.0)	50.0 ± 9.9 (46.3 to 53.7)	47.3 ± 14.8 (38.0 to 56.7)	47.8 ± 15.1 (35.1 to 60.4)
Recreational Activity	27.3 ± 9.9 (22.8 to 31.8)	27.5 ± 7.7 (24.6 to 30.4)	30.1 ± 11.6 (22.7 to 37.5)	26.5 ± 6.0 (21.5 to 31.5)
Social / Vocational Activity	9.9 ± 3.3 (8.4 to 11.4)	10.6 ± 3.2 (9.4 to 11.8)	10.6 ± 3.2 (8.5 to 12.6)	11.6 ± 2.7 (9.3 to 13.9)
Parent AFC reports (Mean ± *SD* (95% CI))				
Self- and Family-Care	27.2 ± 10.6 (22.4 to 32.1)	32.6 ± 14.6 (27.1 to 38.1)	25.2 ± 13.9 (16.3 to 34.0)	35.3 ± 17.0 (21.1 to 49.4)
Management Activity	46.9 ± 13.7 (40.6 to 53.1)	47.5 ± 13.2 (42.6 to 52.5)	41.5 ± 17.4 (30.4 to 52.6)	55.1 ± 15.9 (41.8 to 68.4)
Recreational Activity	25.2 ± 7.2 (21.9 to 28.5)	27.9 ± 9.1 (24.5 to 31.3)	28.6 ± 8.1 (23.4 to 33.8)	30.4 ± 11.1 (21.1 to 39.6)
Social / Vocational Activity	8.2 ± 3.4 (6.7 to 9.7)	8.6 ± 3.4 (7.3 to 9.8)	8.0 ± 4.1 (5.4 to 10.6)	11.9 ± 3.9 (8.6 to 15.1)

Table 9.24: Pearson correlations between reports of autonomy and adolescents' metabolic control (HbA_{1c}).

	Correlation of reports with HbA_{1c} levels	
	Adolescent reports (n = 135)	Parent Reports (n = 135)
Total AFC score	- 0.01 (p = 0.9)	- 0.14 (p = 0.1)
AFC Subscales:		
Self- & Family-Care	0.02 (p = 0.9)	- 0.03 (p = 0.7)
Management Activity	-0.09 (p = 0.3)	- 0.25 (p = 0.003)
Recreational Activity	0.03 (p = 0.7)	- 0.03 (p = 0.7)
Social / Vocational Activity	0.15 (p = 0.08)	0.002 (p = 0.98)

TABLES CITED IN CHAPTER 11.

Table 11.1: Distribution of scores on the Adherence Determinants Questionnaire scales, by adolescents and parents.

Scale	*n*	Adolescent	Parent
Interpersonal Aspects of Care*	135		
Mean ± *SD* (95% Confidence Interval)		31.4 ± 4.2 (30.7 to 32.1)	32.9 ± 4.1 (32.2 to 33.6)
Observed range		19 - 40	22 - 40
Perceived Utility†	135		
Mean ± *SD* (95% Confidence Interval)		32.5 ± 4.0 (31.8 to 33.2)	33.4 ± 4.2 (32.7 to 34.2)
Observed range		22 - 40	18 - 40
Perceived Severity‡	135		
Mean ± *SD* (95% Confidence Interval)		8.5 ± 2.6 (8.0 to 8.9)	10.3 ± 2.4 (9.9 to 10.7)
Observed range		4 - 17	4 - 18
Perceived Susceptibility§	135		
Mean ± *SD* (95% Confidence Interval)		13.8 ± 3.1 (13.3 to 14.4)	14.7 ± 2.5 (14.3 to 15.1)
Observed range		6 - 20	8 - 20
Subjective Norms**	135		
Mean ± *SD* (95% Confidence Interval)		-1.3 ± 2.2 (-1.7 to -1.0)	-1.8 ± 3.0 (-2.3 to -1.3)
Observed range		(-12) - 2	(-18) - 3
Intentions to Adhere††	135		
Mean ± *SD* (95% Confidence Interval)		16.6 ± 2.4 (16.2 to 17.0)	16.1 ± 2.8 (15.7 to 16.6)
Observed range		5 - 20	6 - 20
Supports / Barriers‡‡	135		
Mean ± *SD* (95% Confidence Interval)		14.6 ± 2.6 (14.1 to 15.0)	14.3 ± 2.3 (13.9 to 14.7)
Observed range		8 - 20	8 - 20

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40.
† Perceived Utility: Higher scores indicate greater utility, scoring range 8-40.
‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20.
§ Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.
** Subjective Norms: Higher scores indicate greater normative support, scoring range -18—18.
†† Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20.
‡‡ Supports/Barriers: Higher scores indicate greater support for adherence, scoring range 4-20.

Table 11.2: Distribution of scores on the Health Value Scale by adolescents and parents.

	n	Adolescent	Parent
Health Value*	135		
Mean ± *SD*		14.7 ± 2.7	15.0 ± 2.9
(95% Confidence Interval)		(14.2 to 15.1)	(14.5 to 15.5)
Observed range		5 - 20	8 - 20
Diabetes Knowledge†	135		
Mean ± *SD*		11.2 ± 2.1	12.6 ± 2.0
(95% Confidence Interval)		(10.9 to 11.6)	(12.2 to 12.9)
Observed range		3 - 15	1 - 15

* Health Value: Higher scores indicate greater value of health, scoring range 4-20.
† Diabetes Knowledge: Higher scores indicate greater knowledge of diabetes treatment, scoring range 0-15.

Table 11.3: Distributions of scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the Adherence Determinants Questionnaire by adolescents and parents, according to adolescents' age: 12 to 14 year olds.

	Interpersonal Aspects of Care*		Perceived Utility†		Perceived Severity‡		Perceived Susceptibility§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
12 year old adolescents (n = 20)								
Mean ± *SD* (95% CI)	30.0 ± 4.2 (28.0 to 32.0)	32.9 ± 3.9 (31.0 to 34.7)	32.5 ± 3.7 (30.7 to 34.2)	33.7 ± 3.6 (32.0 to 35.3)	8.7 ± 2.4 (7.6 to 9.8)	9.7 ± 2.4 (8.6 to 10.8)	13.4 ± 2.9 (12.0 to 14.7)	15.1 ± 2.1 (14.1 to 16.1)
Observed range	24 - 38	25 - 40	25 - 38	28 - 40	6 - 17	5 - 14	8 - 18	11 - 20
13 year old adolescents (n = 24)								
Mean ± *SD* (95% CI)	31.5 ± 5.0 (29.4 to 33.7)	32.2 ± 4.1 (30.5 to 33.9)	31.6 ± 4.6 (29.7 to 33.6)	33.6 ± 4.0 (31.8 to 35.3)	8.7 ± 2.9 (7.5 to 9.9)	10.3 ± 2.3 (9.2 to 11.3)	13.0 ± 3.5 (11.5 to 14.5)	14.1 ± 3.1 (12.8 to 15.5)
Observed range	19 - 39	26 - 40	23 - 40	27 - 40	4 - 14	5 - 16	7 - 20	8 - 20
14 year old adolescents (n = 25)								
Mean ± *SD* (95% CI)	31.6 ± 4.4 (29.7 to 33.6)	34.2 ± 4.2 (32.5 to 35.9)	33.5 ± 3.8 (31.8 to 35.2)	33.2 ± 3.8 (31.6 to 34.7)	8.3 ± 2.8 (7.0 to 9.5)	10.1 ± 2.4 (9.2 to 11.1)	13.7 ± 2.5 (12.6 to 14.7)	15.0 ± 2.6 (13.9 to 16.1)
Observed range	23 - 40	25 - 40	26 - 40	25 - 40	4 - 14	4 - 16	9 - 19	11 - 20

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40. † Perceived Utility: Higher scores indicate greater utility, scoring range 8-40. ‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20. § Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.

Table 11.4: Distributions of scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the Adherence Determinants Questionnaire by adolescents and parents, according to adolescents' age: 15 to 17 year olds.

	Interpersonal Aspects of Care*		Perceived Utility†		Perceived Severity‡		Perceived Susceptibility§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
15 year old adolescents (n = 17)								
Mean ± *SD* (95% CI)	31.3 ± 3.2 (29.7 to 32.9)	33.1 ± 3.6 (31.3 to 35.0)	32.0 ± 3.7 (30.1 to 33.9)	33.0 ± 4.6 (30.6 to 35.4)	8.7 ± 2.5 (7.3 to 10.0)	10.0 ± 2.9 (8.5 to 11.5)	14.8 ± 3.0 (13.2 to 16.3)	14.4 ± 2.8 (13.0 to 15.9)
Observed range	25 - 38	26 - 40	24 - 39	24 - 38	5 - 14	5 - 16	9 - 20	10 - 20
16 year old adolescents (n = 25)								
Mean ± *SD* (95% CI)	31.5 ± 3.7 (30.0 to 33.0)	32.6 ± 4.8 (30.6 to 34.6)	32.8 ± 3.9 (31.2 to 34.4)	33.7 ± 5.4 (31.4 to 36.0)	7.8 ± 1.9 (7.0 to 8.6)	10.5 ± 2.4 (9.5 to 11.5)	14.6 ± 3.3 (13.2 to 15.9)	14.6 ± 2.5 (13.5 to 15.6)
Observed range	26 - 39	22 - 40	25 - 40	18 - 40	4 - 11	6 - 18	8 - 20	10 - 20
17 year old adolescents (n = 24)								
Mean ± *SD* (95% CI)	32.1 ± 4.3 (30.2 to 33.9)	32.5 ± 3.9 (30.8 to 34.1)	32.5 ± 4.6 (30.5 to 34.5)	33.5 ± 4.2 (31.7 to 35.3)	9.0 ± 3.0 (7.7 to 10.3)	11.1 ± 2.1 (10.2 to 12.0)	13.9 ± 3.0 (12.6 to 15.2)	14.9 ± 2.0 (14.0 to 15.7)
Observed range	24 - 40	28 - 39	22 - 40	22 - 40	4 - 16	7 - 16	6 - 20	11 - 18

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40. † Perceived Utility: Higher scores indicate greater utility, scoring range 8-40. ‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20. § Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.

Table 11.5: Distributions of scores on the Subjective Norms, Intentions to Adhere and Supports/Barriers scales of the Adherence Determinants Questionnaire and the Health Value Scale, by adolescents and parents, according to adolescents' age: 12 to 14 year olds.

	Subjective Norms*		Intentions to Adhere†		Supports / Barriers‡		Health Value§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
12 year old adolescents (n = 20)								
Mean ± *SD*	-1.3 ± 2.1	-0.8 ± 1.9	17.6 ± 1.8	16.7 ± 1.9	14.1 ± 2.5	13.9 ± 2.1	15.8 ± 2.1	14.7 ± 2.5
(95% CI)	(-2.3 to -0.3)	(-1.7 to 0.1)	(16.7 to 18.5)	(15.8 to 17.6)	(12.9 to 15.3)	(12.9 to 14.8)	(14.8 to 16.9)	(13.5 to 15.9)
Observed range	-6 - 2	-8 - 2	14 - 20	14 - 20	10 - 19	10 - 17	12 - 20	10 - 19
13 year old adolescents (n = 24)								
Mean ± *SD*	-1.5 ± 3.1	-1.5 ± 3.4	16.0 ± 3.4	16.0 ± 3.4	14.6 ± 2.7	14.3 ± 2.4	13.8 ± 3.2	15.0 ± 3.3
(95% CI)	(-2.8 to -0.2)	(-3.0 to -0.1)	(14.6 to 17.5)	(14.5 to 17.4)	(13.5 to 15.7)	(13.3 to 15.4)	(12.5 to 15.2)	(13.6 to 16.3)
Observed range	-12 - 1	-12 - 3	5 - 20	6 - 20	9 - 20	10 - 20	5 - 20	8 - 20
14 year old adolescents (n = 25)								
Mean ± *SD*	-0.5 ± 1.0	-1.4 ± 1.7	16.7 ± 2.3	15.4 ± 3.0	14.3 ± 2.7	13.8 ± 2.1	14.5 ± 3.0	15.3 ± 2.4
(95% CI)	(-1.0 to -0.1)	(-2.1 to -0.7)	(15.6 to 17.7)	(14.1 to 16.7)	(13.1 to 15.5)	(12.9 to 14.6)	(13.2 to 15.9)	(14.3 to 16.3)
Observed range	-4 - 0	-6 - 1	12 - 20	9 - 20	8 - 19	10 - 17	7 - 20	11 - 20

* Subjective Norms: Higher scores indicate greater normative support, scoring range -18 — 18. † Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20. ‡ Supports / Barriers: Higher scores indicate greater support for adherence, scoring range 4-20. § Health Value: Higher scores indicate greater value of health, scoring range 4-20.

Table 11.6: Distributions of scores on the Subjective Norms, Intentions to Adhere and Supports/Barriers scales of the Adherence Determinants Questionnaire and the Health Value Scale, by adolescents and parents, according to adolescents' age: 15 to 17 year olds.

	Subjective Norms*		Intentions to Adhere†		Supports / Barriers‡		Health Value§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
15 year old adolescents (n = 17)								
Mean ± *SD*	-2.1 ± 1.7	-1.9 ± 2.3	16.1 ± 1.8	16.4 ± 2.8	14.0 ± 1.7	14.6 ± 2.2	14.8 ± 2.0	14.5 ± 2.4
(95% CI)	(-3.0 to -1.1)	(-3.1 to -0.6)	(15.2 to 17.1)	(14.9 to 17.9)	(13.1 to 14.9)	(13.4 to 15.8)	(13.8 to 15.9)	(13.2 to 15.8)
Observed range	-5 - 0	-7 - 0	12 - 19	10 - 20	11 - 17	10 - 18	11 - 17	10 - 18
16 year old adolescents (n = 25)								
Mean ± *SD*	-1.0 ± 1.4	-2.3 ± 2.8	17.1 ± 1.9	16.4 ± 2.9	14.9 ± 2.5	14.7 ± 2.4	14.8 ± 2.7	14.9 ± 3.3
(95% CI)	(-1.5 to -0.4)	(-3.5 to -1.2)	(16.3 to 17.9)	(15.2 to 17.5)	(13.9 to 16.0)	(13.7 to 15.7)	(13.7 to 16.0)	(13.5 to 16.2)
Observed range	-5 - 0	-8 - 0	14 - 20	7 - 20	10 - 20	10 - 19	9 - 20	9 - 20
17 year old adolescents (n = 24)								
Mean ± *SD*	-1.8 ± 2.7	-2.9 ± 4.5	16.1 ± 2.4	16.2 ± 2.5	15.2 ± 3.1	14.5 ± 2.6	14.4 ± 2.4	15.5 ± 3.3
(95% CI)	(-3.0 to -0.7)	(-4.8 to -1.0)	(15.1 to 17.1)	(15.1 to 17.3)	(13.9 to 16.5)	(13.3 to 15.6)	(13.3 to 15.4)	(14.1 to 16.9)
Observed range	-11 - 0	-18 - 0	11 - 20	8 - 20	8 - 20	8 - 20	10 - 18	8 - 20

* Subjective Norms: Higher scores indicate greater normative support, scoring range -18 — 18. † Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20. ‡ Supports / Barriers: Higher scores indicate greater support for adherence, scoring range 4-20. § Health Value: Higher scores indicate greater value of health, scoring range 4-20.

Table 11.7: Distribution of scores on the Diabetes Knowledge Questionnaire by adolescents and parents, according to adolescents' age.

	Adolescent	Parent
12 year old adolescents (n = 20)		
Mean ± *SD*	10.8 ± 2.5	12.4 ± 2.9
(95% CI)	(9.6 to 12.0)	(11.0 to 13.8)
Observed range	4 - 14	1 - 15
13 year old adolescents (n = 24)		
Mean ± *SD*	10.5 ± 2.8	13.0 ± 1.4
(95% CI)	(9.3 to 11.7)	(12.4 to 13.6)
Observed range	3 - 15	10 - 15
14 year old adolescents (n = 25)		
Mean ± *SD*	11.0 ± 2.3	12.4 ± 2.5
(95% CI)	(10.0 to 11.9)	(11.3 to 13.4)
Observed range	6 - 14	4 - 14
15 year old adolescents (n = 17)		
Mean ± *SD*	11.6 ± 1.5	12.2 ± 1.3
(95% CI)	(10.8 to 12.4)	(11.5 to 12.9)
Observed range	8 - 14	10 - 14
16 year old adolescents (n = 25)		
Mean ± *SD*	11.7 ± 1.6	12.7 ± 1.2
(95% CI)	(11.1 to 12.4)	(12.2 to 13.2)
Observed range	7 - 14	10 - 15
17 year old adolescents (n = 24)		
Mean ± *SD*	11.9 ± 1.7	12.7 ± 2.2
(95% CI)	(11.2 to 12.6)	(11.8 to 13.6)
Observed range	8 - 15	6 - 15

Note: Higher scores indicate greater knowledge of diabetes treatment, scoring range 0-15.

Table 11.8: Pearson correlations between adolescent and parent reports on the Adherence Determinants Questionnaire, Health Value Scale, and Diabetes Knowledge Questionnaire, and adolescents' age (n = 135).

	Correlation with Adolescents' Age	
	Adolescent Reports	Parent Reports
Interpersonal Aspects of Care	0.09 (p = 0.3)	-0.04 (p = 0.6)
Perceived Utility	0.03 (p = 0.8)	-0.00 (p = 1.0)
Perceived Severity	0.02 (p = 0.9)	0.16 (p = 0.07)
Perceived Susceptibility	0.14 (p = 0.1)	-0.01 (p = 0.9)
Subjective Norms	-0.06 (p = 0.5)	-0.22 (p = 0.01)
Intentions to Adhere	-0.11 (p = 0.2)	-0.03 (p = 0.8)
Supports / Barriers	0.13 (p = 0.1)	0.13 (p = 0.1)
Health Value Scale	-0.08 (p = 0.4)	0.05 (p = 0.6)
Diabetes Knowledge	0.20 (p = 0.02)	0.003 (p = 0.97)

Table 11.9: Distributions of scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the Adherence Determinants Questionnaire by adolescents and parents, according to adolescents' gender.

	Interpersonal Aspects of Care*		Perceived Utility†		Perceived Severity‡		Perceived Susceptibility§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Male adolescents (n = 60)								
Mean ± *SD* (95% CI)	32.2 ± 4.4 (31.0 to 33.3)	32.9 ± 3.9 (31.9 to 33.9)	32.6 ± 4.2 (31.5 to 33.7)	33.3 ± 3.8 (32.3 to 34.3)	8.5 ± 2.5 (7.8 to 9.2)	10.9 ± 2.3 (10.3 to 11.5)	13.9 ± 3.1 (13.1 to 14.8)	14.5 ± 2.6 (13.8 to 15.2)
Observed range	24 - 40	25 - 40	22 - 40	22 - 40	4 - 16	6 - 18	7 - 20	8 - 20
Female adolescents (n = 75)								
Mean ± *SD* (95% CI)	30.8 ± 3.9 (29.9 to 31.7)	32.9 ± 4.3 (31.9 to 33.9)	32.4 ± 4.0 (31.5 to 33.3)	33.5 ± 4.5 (32.5 to 34.6)	8.5 ± 2.7 (7.9 to 9.1)	9.8 ± 2.4 (9.3 to 10.4)	13.7 ± 3.0 (13.0 to 14.4)	14.9 ± 2.4 (14.3 to 15.4)
Observed range	19 - 40	22 - 40	23 - 40	18 - 40	4 - 17	4 - 16	6 - 20	8 - 20

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40. † Perceived Utility: Higher scores indicate greater utility, scoring range 8-40. ‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20. § Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.

Table 11.10: Distributions of scores on the Subjective Norms, Intentions to Adhere and Supports/Barriers scales of the Adherence Determinants Questionnaire and the Health Value Scale by adolescents and parents, according to adolescents' gender.

	Subjective Norms*		Intentions to Adhere†		Supports / Barriers‡		Health Value§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Male adolescents (n = 60)								
Mean ± *SD*	-0.9 ± 1.9	-1.8 ± 2.6	16.6 ± 2.7	15.9 ± 3.1	14.9 ± 2.4	14.0 ± 2.4	14.4 ± 2.8	15.2 ± 3.0
(95% CI)	(-1.4 to -0.4)	(-2.4 to -1.1)	(15.9 to 17.3)	(15.1 to 16.6)	(14.3 to 15.6)	(13.4 to 14.6)	(13.7 to 15.2)	(14.5 to 16.0)
Observed range	-11 - 1	-12 - 1	5 - 20	6 - 20	11 - 20	8 - 19	5 - 20	8 - 20
Female adolescents (n = 75)								
Mean ± *SD*	-1.6 ± 2.3	-1.9 ± 3.3	16.6 ± 2.2	16.4 ± 2.5	14.3 ± 2.7	14.5 ± 2.3	14.8 ± 2.6	14.8 ± 2.8
(95% CI)	(-2.2 to -1.1)	(-2.6 to -1.1)	(16.1 to 17.1)	(15.8 to 17.0)	(13.7 to 14.9)	(14.0 to 15.0)	(14.2 to 15.4)	(14.2 to 15.5)
Observed range	-12 - 2	-18 - 3	11 - 20	7 - 20	8 - 20	10 - 20	7 - 20	9 - 20

* Subjective Norms: Higher scores indicate greater normative support, scoring range -18 — 18. † Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20. ‡ Supports / Barriers: Higher scores indicate greater support for adherence, scoring range 4-20. § Health Value: Higher scores indicate greater value of health, scoring range 4-20.

Table 11.11: Distribution of scores on the Diabetes Knowledge Questionnaire by adolescents and parents, according to adolescents' gender.

	Adolescent	Parent
Male adolescents (n = 60)		
Mean ± *SD* (95% CI)	11.2 ± 2.0 (10.7 to 11.8)	13.1 ± 1.4 (12.7 to 13.5)
Observed range	4 - 15	6 - 15
Female adolescents (n = 75)		
Mean ± *SD* (95% CI)	11.2 ± 2.3 (10.7 to 11.8)	12.1 ± 2.3 (11.6 to 12.7)
Observed range	3 - 15	1 - 15

Table 11.12: Distributions of scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the Adherence Determinants Questionnaire by adolescents and parents, according to parents' age.

	Interpersonal Aspects of Care*		Perceived Utility†		Perceived Severity‡		Perceived Susceptibility§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Parents under 40 years old (n = 30)								
Mean ± *SD*	31.8 ± 3.9	32.1 ± 4.2	32.1 ± 3.8	32.9 ± 4.6	7.7 ± 2.4	9.9 ± 2.2	13.4 ± 2.9	14.6 ± 2.5
(95% CI)	(30.3 to 33.2)	(30.6 to 33.7)	(30.6 to 33.6)	(31.2 to 34.7)	(6.8 to 8.6)	(9.0 to 10.7)	(12.3 to 14.4)	(13.7 to 15.6)
Observed range	24 - 40	22 - 40	25 - 39	18 - 39	4 - 13	6 - 16	7 - 20	8 - 20
Parents 40 - 45 year old (n = 66)								
Mean ± *SD*	31.0 ± 4.3	32.9 ± 4.1	32.3 ± 4.2	33.2 ± 4.1	8.5 ± 2.6	10.3 ± 2.4	14.1 ± 3.1	14.7 ± 2.6
(95% CI)	(30.0 to 32.1)	(31.9 to 33.9)	(31.2 to 33.3)	(32.2 to 34.2)	(7.9 to 9.2)	(9.7 to 10.9)	(13.4 to 14.9)	(14.0 to 15.3)
Observed range	19 - 40	25 - 40	23 - 40	24 - 40	4 - 17	5 - 16	7 - 20	8 - 20
Parents over 45 year old (n = 39)								
Mean ± *SD*	31.7 ± 4.3	33.4 ± 4.1	33.2 ± 3.9	34.2 ± 4.1	9.1 ± 2.6	10.6 ± 2.6	13.7 ± 3.1	14.8 ± 2.5
(95% CI)	(30.3 to 33.2)	(32.1 to 34.8)	(31.9 to 34.5)	(32.8 to 35.5)	(8.2 to 10.0)	(9.8 to 11.5)	(12.6 to 14.7)	(14.0 to 15.6)
Observed range	23 - 40	24 - 40	22 - 40	22 - 40	4 - 16	4 - 18	6 - 20	11 - 20

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40. † Perceived Utility: Higher scores indicate greater utility, scoring range 8-40. ‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20. § Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.

Table 11.13: Distributions of scores on the Subjective Norms, Intentions to Adhere and Supports/Barriers scales of the Adherence Determinants Questionnaire and the Health Value Scale, by adolescents and parents, according to parents' age.

	Subjective Norms*		Intentions to Adhere†		Supports / Barriers‡		Health Value§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Parents under 40 years old (n = 30)								
Mean ± *SD*	-1.2 ± 2.6	-1.0 ± 1.6	17.3 ± 2.1	15.5 ± 3.0	14.5 ± 2.4	13.9 ± 2.0	14.8 ± 2.5	14.2 ± 2.9
(95% CI)	(-2.2 to -0.3)	(-1.6 to -0.4)	(16.5 to 18.1)	(14.4 to 16.7)	(13.6 to 15.4)	(13.1 to 14.6)	(13.8 to 15.7)	(13.1 to 15.3)
Observed range	-12 - 2	-7 - 1	14 - 20	7 - 20	11 - 19	11 - 17	9 - 20	9 - 20
Parents 40 - 45 year old (n = 66)								
Mean ± *SD*	-1.4 ± 1.8	-2.1 ± 3.6	16.2 ± 2.3	16.0 ± 2.7	14.4 ± 2.7	14.2 ± 2.3	14.7 ± 2.7	15.1 ± 2.7
(95% CI)	(-1.8 to -0.9)	(-3.0 to -1.2)	(15.6 to 16.7)	(15.4 to 16.7)	(13.7 to 15.1)	(13.7 to 14.8)	(14.0 to 15.4)	(14.4 to 15.7)
Observed range	-6 - 1	-18 - 3	11 - 20	6 - 20	8 - 20	8 - 20	7 - 20	8 - 20
Parents over 45 year old (n = 39)								
Mean ± *SD*	-1.4 ± 2.5	-2.0 ± -2.6	16.8 ± 2.8	16.8 ± 2.8	14.9 ± 2.6	14.7 ± 2.5	14.5 ± 2.8	15.6 ± 3.1
(95% CI)	(-2.2 to -0.5)	(-2.8 to -1.1)	(15.8 to 17.7)	(15.9 to 17.7)	(14.0 to 15.7)	(13.8 to 15.5)	(13.6 to 15.4)	(14.5 to 16.6)
Observed range	-11 - 1	-8 - 0	5 - 20	8 - 20	8 - 20	10 - 20	5 - 20	9 - 20

* Subjective Norms: Higher scores indicate greater normative support, scoring range -18 — 18. † Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20. ‡ Supports / Barriers: Higher scores indicate greater support for adherence, scoring range 4-20. § Health Value: Higher scores indicate greater value of health, scoring range 4-20.

Table 11.14: Distribution of scores on the Diabetes Knowledge Questionnaire by adolescents and parents, according to parents' age.

	Adolescent	Parent
Parents under 40 years old (n = 30)		
Mean ± *SD*	10.7 ± 2.4	12.5 ± 2.5
(95% CI)	(9.8 to 11.6)	(11.5 to 13.4)
Observed range	5 - 14	1 - 14
Parents 40 - 45 year old (n = 66)		
Mean ± *SD*	11.2 ± 2.3	12.7 ± 1.7
(95% CI)	(10.6 to 11.8)	(12.3 to 13.1)
Observed range	3 - 15	6 - 15
Parents over 45 year old (n = 39)		
Mean ± *SD*	11.7 ± 1.6	12.4 ± 2.1
(95% CI)	(11.2 to 12.2)	(11.7 to 13.1)
Observed range	8 - 15	4 - 15

Table 11.15: Distributions of scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the Adherence Determinants Questionnaire by adolescents and parents, according to parents' gender.

	Interpersonal Aspects of Care*		Perceived Utility†		Perceived Severity‡		Perceived Susceptibility§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Mothers (n = 118)								
Mean ± *SD* (95% CI)	30.8 ± 3.8 (28.9 to 32.8)	32.4 ± 3.7 (30.6 to 34.3)	33.2 ± 4.5 (30.9 to 35.6)	35.3 ± 3.9 (33.3 to 37.2)	9.1 ± 2.8 (7.6 to 10.5)	10.2 ± 2.7 (8.8 to 11.6)	11.9 ± 2.9 (10.4 to 13.4)	14.3 ± 2.2 (13.2 to 15.4)
Observed range	24 - 39	28 - 40	26 - 40	28 - 40	4 - 14	5 - 16	6 - 16	10 - 19
Fathers (n = 17)								
Mean ± *SD* (95% CI)	31.5 ± 4.2 (30.7 to 32.3)	33.0 ± 4.2 (32.2 to 33.7)	32.4 ± 4.0 (31.6 to 33.1)	33.1 ± 4.2 (32.4 to 33.9)	8.4 ± 2.6 (7.9 to 8.9)	10.3 ± 2.4 (9.9 to 10.8)	14.1 ± 3.0 (13.6 to 14.7)	14.7 ± 2.6 (14.3 to 15.2)
Observed range	19 - 40	22 - 40	22 - 40	18 - 40	4 - 17	4 - 18	7 - 20	8 - 20

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40. † Perceived Utility: Higher scores indicate greater utility, scoring range 8-40. ‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20. § Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.

Table 11.16: Distributions of scores on the Subjective Norms, Intentions to Adhere and Supports/Barriers scales of the Adherence Determinants Questionnaire and the Health Value Scale by adolescents and parents, according to parents' gender.

	Subjective Norms*		Intentions to Adhere†		Supports / Barriers‡		Health Value§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Mothers (n = 118)								
Mean ± *SD*	-1.9 ± 3.4	-1.5 ± 4.2	16.6 ± 2.1	16.6 ± 3.1	15.2 ± 1.6	14.5 ± 2.7	14.8 ± 2.6	16.4 ± 2.5
(95% CI)	(-3.6 to -0.1)	(-3.6 to 0.6)	(15.5 to 17.7)	(15.1 to 18.1)	(14.4 to 16.0)	(13.2 to 15.8)	(13.4 to 16.1)	(15.1 to 17.7)
Observed range	-12 - 0	-18 - 0	12 - 20	8 - 20	12 - 18	8 - 20	9 - 20	11 - 20
Fathers (n = 17)								
Mean ± *SD*	-1.2 ± 1.9	-1.9 ± 2.8	16.6 ± 2.5	16.1 ± 2.8	14.5 ± 2.7	14.2 ± 2.3	14.6 ± 2.7	14.8 ± 2.9
(95% CI)	(-1.6 to -0.9)	(-2.4 to -1.4)	(16.2 to 17.1)	(15.6 to 16.6)	(14.0 to 15.0)	(13.8 to 14.7)	(14.1 to 15.1)	(14.3 to 15.3)
Observed range	-11 - 2	-14 - 3	5 - 20	6 - 20	8 - 20	10 - 20	5 - 20	8 - 20

* Subjective Norms: Higher scores indicate greater normative support, scoring range -18 — 18. † Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20. ‡ Supports / Barriers: Higher scores indicate greater support for adherence, scoring range 4-20. § Health Value: Higher scores indicate greater value of health, scoring range 4-20.

Table 11.17: Distribution of scores on the Diabetes Knowledge Questionnaire by adolescents and parents, according to parents' gender.

	Adolescent	Parent
Mothers (n = 118)		
Mean ± *SD* (95% CI)	11.0 ± 2.0 (10.0 to 12.0)	11.3 ± 2.2 (10.3 to 12.4)
Observed range	5 - 13	4 - 13
Fathers (n = 17)		
Mean ± *SD* (95% CI)	11.3 ± 2.2 (10.9 to 11.7)	12.8 ± 1.9 (12.4 to 13.1)
Observed range	3 - 15	1 - 15

Table 11.18: Distributions of scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the Adherence Determinants Questionnaire by adolescents and parents, according to parental work status.

	Interpersonal Aspects of Care*		Perceived Utility†		Perceived Severity‡		Perceived Susceptibility§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
At home (n = 64)								
Mean ± *SD* (95% CI)	31.7 ± 4.2 (30.7 to 32.8)	33.1 ± 3.9 (32.2 to 34.1)	32.1 ± 3.7 (31.1 to 33.0)	33.8 ± 3.3 (33.0 to 34.6)	8.8 ± 2.5 (8.1 to 9.4)	10.3 ± 2.4 (9.7 to 10.8)	13.6 ± 2.8 (12.9 to 14.3)	14.5 ± 2.5 (13.8 to 15.1)
Observed range	24 - 40	25 - 40	22 - 39	28 - 40	4 - 16	5 - 16	7 - 20	8 - 20
Outside the home (n = 70)								
Mean ± *SD* (95% CI)	31.1 ± 4.2 (30.1 to 32.1)	32.8 ± 4.3 (31.7 to 33.8)	32.9 ± 4.3 (31.8 to 33.9)	33.1 ± 4.9 (31.9 to 34.3)	8.2 ± 2.7 (7.5 to 8.9)	10.4 ± 2.4 (9.8 to 11.0)	14.1 ± 3.3 (13.3 to 14.9)	14.9 ± 2.5 (14.3 to 15.5)
Observed range	19 - 39	22 - 40	23 - 40	18 - 40	4 - 17	4 - 18	6 - 20	8 - 20

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40. † Perceived Utility: Higher scores indicate greater utility, scoring range 8-40. ‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20. § Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.

Table 11.19: Distributions of scores on the Subjective Norms, Intentions to Adhere and Supports/Barriers scales of the Adherence Determinants Questionnaire and the Health Value Scale by adolescents and parents, according to parental work status.

	Subjective Norms*		Intentions to Adhere†		Supports / Barriers‡		Health Value§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
At home (n = 64)								
Mean ± *SD* (95% CI)	-1.5 ± 2.2 (-2.0 to -0.9)	-1.2 ± 1.9 (-1.7 to -0.7)	16.8 ± 2.5 (16.2 to 17.5)	16.0 ± 2.6 (15.4 to 16.7)	14.5 ± 2.6 (13.9 to 15.1)	14.1 ± 2.2 (13.6 to 14.7)	14.5 ± 2.9 (13.8 to 15.2)	15.1 ± 2.7 (14.4 to 15.8)
Observed range	-11 - 0	-8 - 1	5 - 20	8 - 20	8 - 20	10 - 19	5 - 20	10 - 20
Outside the home (n = 70)								
Mean ± *SD* (95% CI)	-1.2 ± 2.2 (-1.7 to -0.7)	-2.4 ± 3.7 (-3.3 to -1.5)	16.4 ± 2.3 (15.8 to 17.0)	16.2 ± 3.0 (15.5 to 16.9)	14.6 ± 2.7 (14.0 to 15.3)	14.4 ± 2.4 (13.9 to 15.0)	14.8 ± 2.5 (14.2 to 15.4)	15.0 ± 3.0 (14.2 to 15.7)
Observed range	-12 - 2	-18 - 3	11 - 20	6 - 20	8 - 20	8 - 20	9 - 20	8 - 20

* Subjective Norms: Higher scores indicate greater normative support, scoring range -18 — 18. † Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20. ‡ Supports / Barriers: Higher scores indicate greater support for adherence, scoring range 4-20. § Health Value: Higher scores indicate greater value of health, scoring range 4-20.

Table 11.20: Distribution of scores on the Diabetes Knowledge Questionnaire by adolescents and parents, according to parental work status.

	Adolescent	Parent
At home (n = 64)		
Mean ± *SD* (95% CI)	11.1 ± 2.0 (10.6 to 11.7)	12.2 ± 2.5 (11.6 to 12.8)
Observed range	6 - 14	1 - 15
Outside the home (n = 70)		
Mean ± *SD* (95% CI)	11.4 ± 2.2 (10.8 to 11.9)	12.9 ± 1.3 (12.6 to 13.2)
Observed range	3 - 15	9 - 15

Table 11.21: Distributions of scores on the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the Adherence Determinants Questionnaire by adolescents and parents, according to household structure.

	Interpersonal Aspects of Care*		Perceived Utility†		Perceived Severity‡		Perceived Susceptibility§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Dual Parent (n = 110)								
Mean ± *SD* (95% CI)	31.4 ± 4.1 (30.6 to 32.2)	33.1 ± 4.2 (32.3 to 33.9)	32.6 ± 4.1 (31.8 to 33.4)	33.3 ± 4.4 (32.5 to 34.1)	8.5 ± 2.8 (8.0 to 9.0)	10.3 ± 2.5 (9.8 to 10.8)	13.8 ± 3.2 (13.2 to 14.4)	14.7 ± 2.6 (14.2 to 15.2)
Observed range	19 - 40	22 - 40	22 - 40	18 - 40	4 - 17	4 - 18	6 - 20	8 - 20
Single Parent (n = 25)								
Mean ± *SD* (95% CI)	31.4 ± 4.5 (29.5 to 33.3)	32.0 ± 3.7 (30.5 to 33.6)	32.1 ± 3.7 (30.5 to 33.8)	34.0 ± 3.2 (32.7 to 35.3)	8.4 ± 1.7 (7.7 to 9.2)	10.3 ± 1.9 (9.4 to 11.1)	14.0 ± 2.7 (12.8 to 15.1)	14.8 ± 2.3 (13.8 to 15.8)
Observed range	24 - 40	25 - 40	27 - 40	28 - 40	6 - 11	6 - 14	7 - 19	11 - 20

* Interpersonal Aspects of Care: Higher scores indicate greater rapport, scoring range 8-40. † Perceived Utility: Higher scores indicate greater utility, scoring range 8-40. ‡ Perceived Severity: Higher scores indicate greater severity, scoring range 4-20. § Perceived Susceptibility: Higher scores indicate greater autonomy, scoring range 4-20.

Table 11.22: Distributions of scores on the Subjective Norms, Intentions to Adhere and Supports/Barriers scales of the Adherence Determinants Questionnaire and the Health Value Scale by adolescents and parents, according to household structure.

	Subjective Norms*		Intentions to Adhere†		Supports / Barriers‡		Health Value§	
	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent	Adolescent	Parent
Dual Parent (n = 110)								
Mean ± *SD*	-1.4 ± 2.2	-1.8 ± 2.7	16.6 ± 2.3	16.3 ± 2.7	14.6 ± 2.6	14.5 ± 2.3	14.7 ± 2.6	14.9 ± 3.0
(95% CI)	(-1.8 to -1.0)	(-2.3 to-1.3)	(16.2 to 17.1)	(15.8 to 16.8)	(14.1 to 15.1)	(14.0 to 14.9)	(14.2 to 15.2)	(14.3 to 15.5)
Observed range	-12 - 2	-14 - 3	11 - 20	6 - 20	8 - 20	8 - 20	7 - 20	8 - 20
Single Parent (n = 25)								
Mean ± *SD*	-1.1 ± 1.8	-1.9 ± 4.2	16.5 ± 3.0	15.4 ± 3.2	14.6 ± 2.5	13.4 ± 2.2	14.3 ± 3.0	15.5 ± 2.6
(95% CI)	(-1.9 to -0.3)	(-3.6 to -0.1)	(15.2 to 17.8)	(14.1 to 16.8)	(13.5 to 15.7)	(12.5 to 14.4)	(13.0 to 15.7)	(14.5 to 16.6)
Observed range	-6 - 0	-18 - 1	5 - 20	8 - 20	11 - 20	10 - 19	5 - 19	10 - 20

* Subjective Norms: Higher scores indicate greater normative support, scoring range -18 — 18. † Intentions to Adhere: Higher scores indicate greater intentions, scoring range 4-20. ‡ Supports / Barriers: Higher scores indicate greater support for adherence, scoring range 4-20. § Health Value: Higher scores indicate greater value of health, scoring range 4-20.

Table 11.23: Distribution of scores on the Diabetes Knowledge Questionnaire by adolescents and parents, according to household structure.

	Adolescent	Parent
Dual Parent (n = 110)		
Mean ± *SD* (95% CI)	11.2 ± 2.2 (10.8 to 11.7)	12.7 ± 1.8 (12.3 to 13.0)
Observed range	3 - 15	4 - 15
Single Parent (n = 25)		
Mean ± *SD* (95% CI)	11.2 ± 1.7 (10.5 to 11.9)	12.1 ± 2.8 (11.0 to 13.3)
Observed range	7 - 14	1 - 15

Table 11.24: Pearson correlations between adolescent responses to scales of the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire, and adolescent and parent completed measures of adherence (n = 135).

	Adolescent Report		Parent Report	
	GAS	DSAS	GAS	DSAS
Adolescent reports				
Interpersonal Aspects of Care	0.36	0.12 (p = 0.2)	0.21 (p = 0.02)	0.08 (p = 0.4)
Perceived Utility	0.43	0.32	0.41	0.32
Perceived Severity	-0.33	-0.25 (p = 0.004)	-0.30	-0.09 (p = 0.3)
Perceived Susceptibility	-0.02 (p = 0.9)	-0.09 (p = 0.3)	-0.03 (p = 0.8)	-0.01 (p = 0.9)
Subjective Norms	0.00 (p = 1.0)	-0.10 (p = 0.3)	0.09 (p = 0.3)	-0.09 (p = 0.3)
Intentions to Adhere	0.42	0.36	0.39	0.32
Supports / Barriers	0.48	0.26 (p = 0.003)	0.37	0.14 (p = 0.1)
Health Value	0.31	0.27 (p = 0.002)	0.16 (p = 0.07)	0.18 (p = 0.04)
Diabetes Knowledge	0.14 (p = 0.1)	0.11 (p = 0.2)	0.04 (p = 0.6)	0.09 (p = 0.3)

Note: unless otherwise stated, $p < 0.001$

Table 11.25: Pearson correlations between parent responses to scales of the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire, and adolescent and parent completed measures of adherence (n = 135).

	Adolescent Report		Parent Report	
	GAS	DSAS	GAS	DSAS
Parent reports				
Interpersonal Aspects of Care	0.11 (p = 0.2)	0.01 (p = 0.9)	0.31	0.11 (p = 0.2)
Perceived Utility	0.21 (p = 0.02)	0.14 (p = 0.1)	0.38	0.24 (p = 0.01)
Perceived Severity	-0.12 (p = 0.2)	-0.02 (p = 0.9)	-0.21 (p = 0.02)	-0.04 (p = 0.6)
Perceived Susceptibility	0.07 (p = 0.4)	0.04 (p = 0.6)	0.08 (p = 0.3)	0.03 (p = 0.7)
Subjective Norms	0.09 (p = 0.3)	0.04 (p = 0.7)	0.12 (p = 0.2)	0.03 (p = 0.8)
Intentions to Adhere	0.32	0.30	0.59	0.41
Supports / Barriers	0.26 (p = 0.003)	0.16 (p = 0.06)	0.43	0.30
Health Value	0.21 (p = 0.02)	0.18 (p = 0.04)	0.20 (p = 0.02)	0.17 (p = 0.046)
Diabetes Knowledge	0.17 (p = 0.049)	0.17 (p = 0.048)	0.01 (p = 0.9)	0.03 (p = 0.7)

Note: unless otherwise stated, $p < 0.001$

Table 11.26: Pearson correlations (with *p* values) between observed blood glucose monitoring and adolescent and parent responses to the Autonomous Functioning Checklist, Health Value Scale and Diabetes Knowledge Questionnaire (*n* = 75).

	Correlation of reports with observed BGM adherence	
	Adolescent reports	Parent Reports
Interpersonal Aspects of Care	0.09 ($p = 0.5$)	0.06 ($p = 0.6$)
Perceived Utility	0.20 ($p = 0.1$)	0.15 ($p = 0.2$)
Perceived Severity	-0.15 ($p = 0.2$)	-0.01 ($p = 0.9$)
Perceived Susceptibility	-0.00 ($p = 1.0$)	0.13 ($p = 0.3$)
Subjective Norms	-0.05 ($p = 0.6$)	0.26 ($p = 0.03$)
Intentions to Adhere	0.26 ($p = 0.02$)	0.32 ($p = 0.01$)
Supports / Barriers	0.04 ($p = 0.7$)	0.16 ($p = 0.2$)
Health Value	0.10 ($p = 0.4$)	0.11 ($p = 0.4$)
Diabetes Knowledge	-0.02 ($p = 0.9$)	-0.05 ($p = 0.7$)

Table 11.27: Pearson correlations (with *p* values) between observed blood glucose monitoring over different time periods and adolescent responses to the Autonomous Functioning Checklist, Health Value Scale and Diabetes Knowledge Questionnaire (*n* = 74).

	Observed Blood Glucose Monitoring Adherence				
	Last 28 days	Last 20 days	Last 12 days	Last 8 days	Last 4 days
Adolescent reports					
Interpersonal Aspects of Care	0.08 ($p = 0.5$)	0.11 ($p = 0.4$)	0.15 ($p = 0.2$)	0.21 ($p = 0.07$)	0.20 ($p = 0.09$)
Perceived Utility	0.20 ($p = 0.1$)	0.20 ($p = 0.1$)	0.25 ($p = 0.03$)	0.33 ($p = 0.004$)	0.33 ($p = 0.004$)
Perceived Severity	-0.15 ($p = 0.2$)	-0.19 ($p = 0.1$)	-0.22 ($p = 0.05$)	-0.27 ($p = 0.02$)	-0.25 ($p = 0.03$)
Perceived Susceptibility	0.00 ($p = 1.0$)	-0.01 ($p = 0.9$)	0.01 ($p = 0.9$)	0.03 ($p = 0.8$)	0.05 ($p = 0.7$)
Subjective Norms	-0.05 ($p = 0.6$)	-0.05 ($p = 0.7$)	-0.06 ($p = 0.6$)	-0.06 ($p = 0.6$)	-0.07 ($p = 0.5$)
Intentions to Adhere	0.26 ($p = 0.02$)	0.29 ($p = 0.01$)	0.31 ($p = 0.01$)	0.35 ($p = 0.002$)	0.35 ($p = 0.002$)
Supports / Barriers	0.04 ($p = 0.7$)	0.05 ($p = 0.7$)	0.08 ($p = 0.5$)	0.15 ($p = 0.2$)	0.14 ($p = 0.2$)
Health Value	0.10 ($p = 0.4$)	0.08 ($p = 0.5$)	0.04 ($p = 0.7$)	0.08 ($p = 0.5$)	0.05 ($p = 0.7$)
Diabetes Knowledge	-0.02 ($p = 0.9$)	-0.02 ($p = 0.8$)	-0.03 ($p = 0.8$)	0.01 ($p = 0.9$)	-0.02 ($p = 0.8$)

Table 11.28: Pearson correlations (with *p* values) between observed blood glucose monitoring over different time periods and parent responses to the Autonomous Functioning Checklist, Health Value Scale and Diabetes Knowledge Questionnaire (*n* = 74).

	Observed Blood Glucose Monitoring Adherence				
	Last 28 days	Last 20 days	Last 12 days	Last 8 days	Last 4 days
Parent reports					
Interpersonal Aspects of Care	0.06 ($p = 0.6$)	0.05 ($p = 0.7$)	0.12 ($p = 0.3$)	0.11 ($p = 0.4$)	0.15 ($p = 0.2$)
Perceived Utility	0.15 ($p = 0.2$)	0.14 ($p = 0.2$)	0.18 ($p = 0.1$)	0.18 ($p = 0.1$)	0.16 ($p = 0.2$)
Perceived Severity	-0.01 ($p = 0.9$)	-0.02 ($p = 0.9$)	0.00 ($p = 1.0$)	-0.01 ($p = 0.97$)	-0.09 ($p = 0.4$)
Perceived Susceptibility	0.13 ($p = 0.3$)	0.14 ($p = 0.2$)	0.15 ($p = 0.2$)	0.14 ($p = 0.2$)	0.17 ($p = 0.2$)
Subjective Norms	0.26 ($p = 0.03$)	0.26 ($p = 0.02$)	0.29 ($p = 0.01$)	0.26 ($p = 0.03$)	0.23 ($p = 0.04$)
Intentions to Adhere	0.32 ($p = 0.01$)	0.31 ($p = 0.01$)	0.35 ($p = 0.002$)	0.35 ($p = 0.002$)	0.33 ($p = 0.003$)
Supports / Barriers	0.16 ($p = 0.2$)	0.10 ($p = 0.4$)	0.09 ($p = 0.4$)	0.11 ($p = 0.4$)	0.08 ($p = 0.5$)
Health Value	0.11 ($p = 0.4$)	0.12 ($p = 0.3$)	0.15 ($p = 0.2$)	0.14 ($p = 0.2$)	0.12 ($p = 0.3$)
Diabetes Knowledge	-0.05 ($p = 0.7$)	-0.05 ($p = 0.7$)	-0.05 ($p = 0.7$)	-0.05 ($p = 0.7$)	-0.10 ($p = 0.4$)

Table 11.29: Distribution of scores on the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire by adolescents, according to blood glucose monitoring adherence group.

	Blood Glucose Monitoring Adherence Group			
	Consistently High (n = 22)	Consistently Low (n = 33)	Rising (n = 12)	Other (n = 8)
Adolescent reports (Mean ± *SD* (95% CI))				
Interpersonal Aspects of Care	31.7 ± 3.5 (30.2 to 33.3)	30.3 ± 4.0 (28.9 to 31.7)	30.3 ± 5.1 (27.1 to 33.5)	28.8 ± 4.1 (25.4 to 32.1)
Perceived Utility	32.3 ± 3.6 (30.7 to 33.9)	30.3 ± 3.4 (29.0 to 31.5)	32.9 ± 4.6 (30.0 to 35.8)	31.8 ± 2.4 (29.8 to 33.7)
Perceived Severity	8.1 ± 2.4 (7.1 to 9.2)	9.0 ± 2.7 (8.1 to 10.0)	8.8 ± 1.6 (7.8 to 9.9)	10.8 ± 2.9 (8.3 to 13.2)
Perceived Susceptibility	13.7 ± 3.2 (12.3 to 15.1)	13.4 ± 3.0 (12.3 to 14.4)	13.8 ± 3.5 (11.6 to 16.1)	14.9 ± 3.9 (11.6 to 18.1)
Subjective Norms	-1.6 ± 3.0 (-3.0 to -0.3)	-1.3 ± 1.6 (-1.8 to -0.7)	-1.5 ± 2.7 (-3.2 to 0.2)	-1.5 ± 1.5 (-2.8 to -0.2)
Intentions to Adhere	16.9 ± 2.1 (15.9 to 17.8)	15.7 ± 2.2 (15.0 to 16.5)	17.5 ± 2.5 (15.9 to 19.1)	16.6 ± 2.6 (14.5 to 18.8)
Supports / Barriers	14.1 ± 2.5 (13.0 to 15.3)	13.6 ± 2.8 (12.6 to 14.6)	13.5 ± 2.4 (12.0 to 15.0)	13.4 ± 2.4 (11.4 to 15.4)
Health Value	15.2 ± 2.6 (14.0 to 16.3)	14.6 ± 2.6 (13.7 to 15.6)	14.3 ± 2.3 (12.9 to 15.8)	14.5 ± 3.1 (11.9 to 17.1)
Diabetes Knowledge	10.7 ± 2.6 (9.5 to 11.8)	10.9 ± 2.4 (10.1 to 11.8)	11.8 ± 1.1 (11.0 to 12.5)	12.1 ± 1.9 (10.5 to 13.7)

Table 11.30: Distribution of scores on the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire by parents, according to blood glucose monitoring adherence group.

	Blood Glucose Monitoring Adherence Group			
	Consistently High (n = 22)	Consistently Low (n = 33)	Rising (n = 12)	Other (n = 8)
Parent reports (Mean ± *SD* (95% CI))				
Interpersonal Aspects of Care	33.1 ± 4.2 (32.3 to 35.0)	32.7 ± 4.9 (30.9 to 34.4)	32.8 ± 3.1 (30.8 to 34.7)	33.5 ± 4.7 (29.6 to 37.4)
Perceived Utility	33.0 ± 4.0 (31.2 to 34.8)	31.8 ± 5.2 (29.9 to 33.6)	34.3 ± 3.8 (31.8 to 36.7)	35.0 ± 4.2 (31.5 to 38.5)
Perceived Severity	10.7 ± 1.8 (9.9 to 11.5)	10.7 ± 2.9 (9.7 to 11.7)	10.3 ± 1.8 (9.2 to 11.5)	11.0 ± 1.8 (9.5 to 12.5)
Perceived Susceptibility	14.9 ± 2.9 (13.6 to 16.2)	14.3 ± 2.6 (13.4 to 15.2)	15.1 ± 2.4 (13.6 to 16.6)	14.6 ± 2.2 (12.8 to 16.5)
Subjective Norms	-1.0 ± 1.9 (-1.8 to -0.1)	-2.3 ± 2.8 (-3.3 to -1.3)	-1.3 ± 2.5 (-2.8 to 0.3)	-1.1 ± 1.2 (-2.2 to -0.1)
Intentions to Adhere	16.6 ± 2.6 (15.5 to 17.8)	14.5 ± 3.3 (13.4 to 15.7)	16.8 ± 2.2 (15.4 to 18.2)	16.9 ± 2.9 (14.5 to 19.3)
Supports / Barriers	14.4 ± 2.2 (13.4 to 15.3)	13.5 ± 2.4 (12.6 to 14.3)	12.7 ± 2.3 (11.2 to 14.1)	14.8 ± 2.8 (12.4 to 17.1)
Health Value	15.1 ± 2.4 (14.0 to 16.2)	14.3 ± 3.1 (13.2 to 15.4)	15.3 ± 3.0 (13.4 to 17.1)	16.0 ± 3.2 (13.4 to 18.6)
Diabetes Knowledge	12.5 ± 3.5 (10.9 to 14.0)	12.6 ± 13.1 (12.1 to 13.1)	12.3 ± 1.2 (11.6 to 13.1)	12.6 ± 1.2 (11.6 to 13.6)

Table 11.31: Pearson correlations between responses to the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire, and adolescents' metabolic control (HbA_{1c}).

	Correlation of reports with HbA_{1c} levels	
	Adolescent reports (n = 135)	Parent Reports (n = 135)
Interpersonal Aspects of Care	-0.20 (p = 0.02)	-0.20 (p = 0.02)
Perceived Utility	-0.19 (p = 0.03)	-0.17 (p = 0.048)
Perceived Severity	0.09 (p = 0.3)	0.27 (p = 0.002)
Perceived Susceptibility	0.06 (p = 0.5)	-0.08 (p = 0.4)
Subjective Norms	0.07 (p = 0.4)	0.13 (p = 0.1)
Intentions to Adhere	-0.16 (p = 0.07)	-0.26 (p = 0.003)
Supports / Barriers	-0.37	-0.26 (p = 0.002)
Health Value Scale	-0.02 (p = 0.8)	-0.10 (p = 0.3)
Diabetes Knowledge	0.00 (p = 1.0)	0.10 (p = 0.2)

Note: unless otherwise stated, $p < 0.001$

Table 11.32: Hierarchical stepwise multiple regression analysis of HbA_{1c} against the adolescent completed General Adherence Scale and the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

Measures		Beta	Multiple R^2	Change in R^2	F*	p
Adolescent GAS and ADQ, HVS & DKQ						
Step 1	Adolescent GAS	-0.180	0.032	0.032	3.96	0.048
Step 2	Interpersonal Care	-0.140	0.174	0.142	2.11	0.03
	Perceived Utility	0.012				
	Perceived Severity	-0.100				
	Perc. Susceptibility	0.099				
	Subjective Norms	0.048				
	Intentions to Adhere	-0.018				
	Supports / Barriers	-0.362				
	Health Value	0.067				
	Diabetes Knowledge	0.085				
Significant predictors in the final equation:						
Supports / Barriers						

* F test on R^2 change.

Table 11.33: Hierarchical stepwise multiple regression analysis of HbA_{1c} against the adolescent completed Diabetes Specific Adherence Scale and the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

Measures		Beta	Multiple R^2	Change in R^2	F*	p
Adolescent DSAS and ADQ, HVS & DKQ						
Step 1	DSAS	-0.136	0.018	0.018	2.31	0.1
Regression halted after *Step 1*.						

* F test on R^2 change.

Table 11.34: Hierarchical stepwise multiple regression analysis of HbA_{1c} against the parent completed General Adherence Scale and the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Parent GAS and ADQ, HVS & DKQ.					
Step 1 Parent GAS	-0.303	0.092	0.092	12.62	0.001
Step 2 Interpersonal Care	-0.064	0.178	0.086	1.35	0.22
Perceived Utility	0.027				
Perceived Severity	0.183				
Perc. Susceptibility	-0.053				
Subjective Norms	0.133				
Intentions to Adhere	0.043				
Supports / Barriers	-0.135				
Health Value	-0.067				
Diabetes Knowledge	0.107				
Significant predictors in the final equation:					
Perceived Severity					

* F test on R^2 change.

Table 11.35: Hierarchical stepwise multiple regression analysis of HbA_{1c} against the parent completed Diabetes Specific Adherence Scale and the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Parent DSAS and ADQ, HVS & DKQ					
Step 1 Parent DSAS	-0.221	0.049	0.049	6.42	0.01
Step 2 Interpersonal Care	-0.101	0.155	0.106	1.61	0.12
Perceived Utility	0.029				
Perceived Severity	0.176				
Perc. Susceptibility	-0.054				
Subjective Norms	0.109				
Intentions to Adhere	0.019				
Supports / Barriers	-0.160				
Health Value	-0.059				
Diabetes Knowledge	0.120				
Significant predictors in the final equation:					
-					

* F test on R^2 change.

TABLES AND FIGURES CITED IN CHAPTER 13.

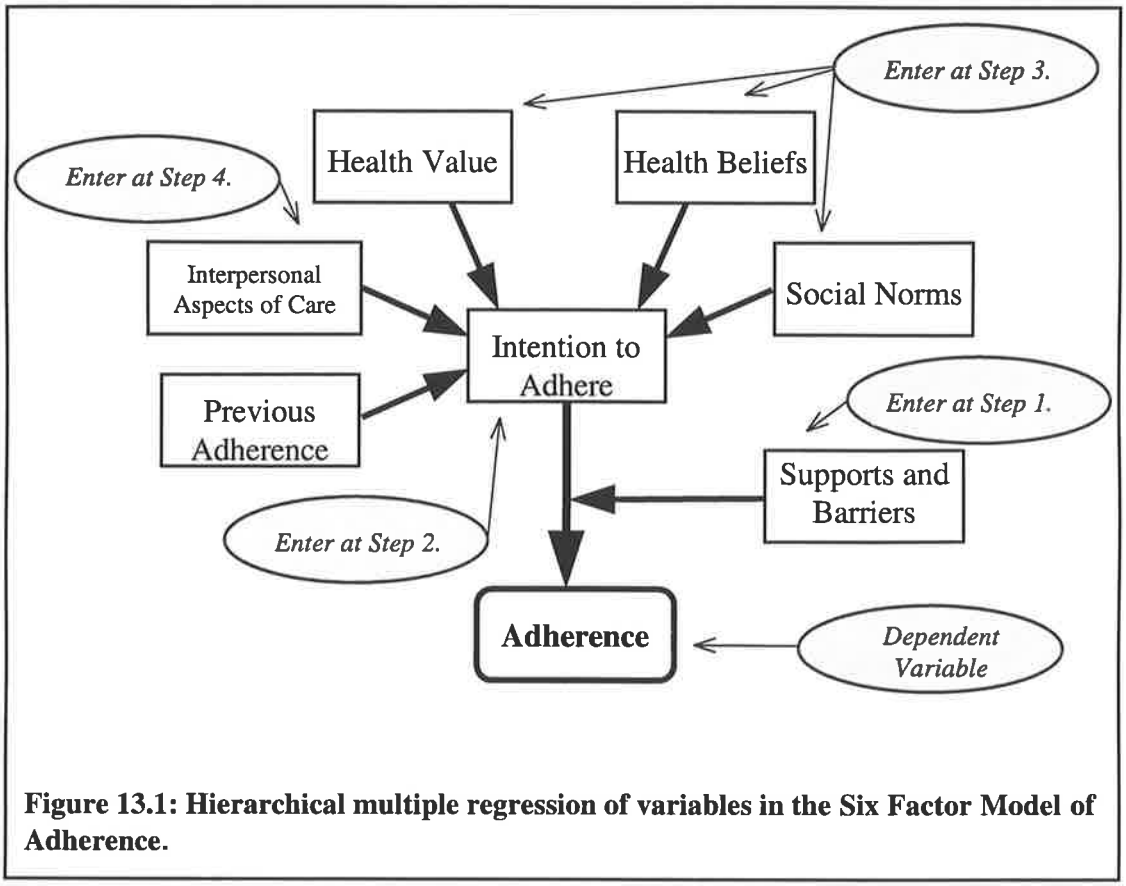


Figure 13.1: Hierarchical multiple regression of variables in the Six Factor Model of Adherence.

Table 13.1: Hierarchical multiple regression analysis of adolescent reported general adherence (GAS) against adolescent completed measures of proposed antecedents of adherence.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Adolescent GAS					
Step 1 Supports / Barriers	0.489	0.239	0.239	37.78	< 0.0001
Step 2 Intentions to Adhere	0.263	0.292	0.053	8.96	0.003
Step 3 Perceived Utility	0.204	0.366	0.073	2.63	0.03
Perceived Severity	-0.113				
Perc. Susceptibility	-0.093				
Subjective Norms	0.047				
Health Value	0.184				
Step 4 Interpersonal Care	0.075	0.373	0.007	0.64	0.5
Diabetes Knowledge	0.057				
Significant predictors in the final equation					
Supports / Barriers					
Health Value					

* F test on R^2 change.

Table 13.2: Hierarchical multiple regression analysis of adolescent reported diabetes-specific adherence (DSAS) against adolescent completed measures of proposed antecedents of adherence.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Adolescent DSAS					
Step 1 Supports / Barriers	0.283	0.080	0.080	10.79	0.001
Step 2 Intentions to Adhere	0.291	0.146	0.066	9.43	0.003
Step 3 Perceived Utility	0.158	0.221	0.076	2.30	0.049
Perceived Severity	-0.133				
Perc. Susceptibility	-0.177				
Subjective Norms	-0.076				
Health Value	0.139				
Step 4 Interpersonal Care	-0.098	0.237	0.016	1.21	0.3
Diabetes Knowledge	0.117				
Significant predictors in the final equation					
Perceived Susceptibility					

* F test on R^2 change.

Table 13.3: Hierarchical multiple regression analysis of parent reported general adherence (GAS) against parent completed measures of proposed antecedents of adherence.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Parent GAS					
Step 1 Supports / Barriers	0.443	0.196	0.196	30.73	< 0.0001
Step 2 Intentions to Adhere	0.484	0.361	0.165	32.25	< 0.0001
Step 3 Perceived Utility	0.038				
Perceived Severity	0.023				
Perc. Susceptibility	0.070	0.371	0.010	0.37	0.9
Subjective Norms	0.055				
Health Value	0.020				

Significant predictors in the regression equation, when halted at *Step 3*.

Supports / Barriers
Intentions to Adhere

* F test on R^2 change.

Table 13.4: Hierarchical multiple regression analysis of parent reported diabetes-specific adherence (DSAS) against parent completed measures of proposed antecedents of adherence.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Parent DSAS					
Step 1 Supports / Barriers	0.300	0.090	0.090	12.42	0.001
Step 2 Intentions to Adhere	0.370	0.186	0.096	14.85	0.0002
Step 3 Perceived Utility	-0.009				
Perceived Severity	0.109				
Perc. Susceptibility	0.008	0.198	0.012	0.35	0.9
Subjective Norms	-0.015				
Health Value	0.014				

Significant predictors in the regression equation, when halted at *Step 3*.

Intentions to Adhere

* F test on R^2 change.

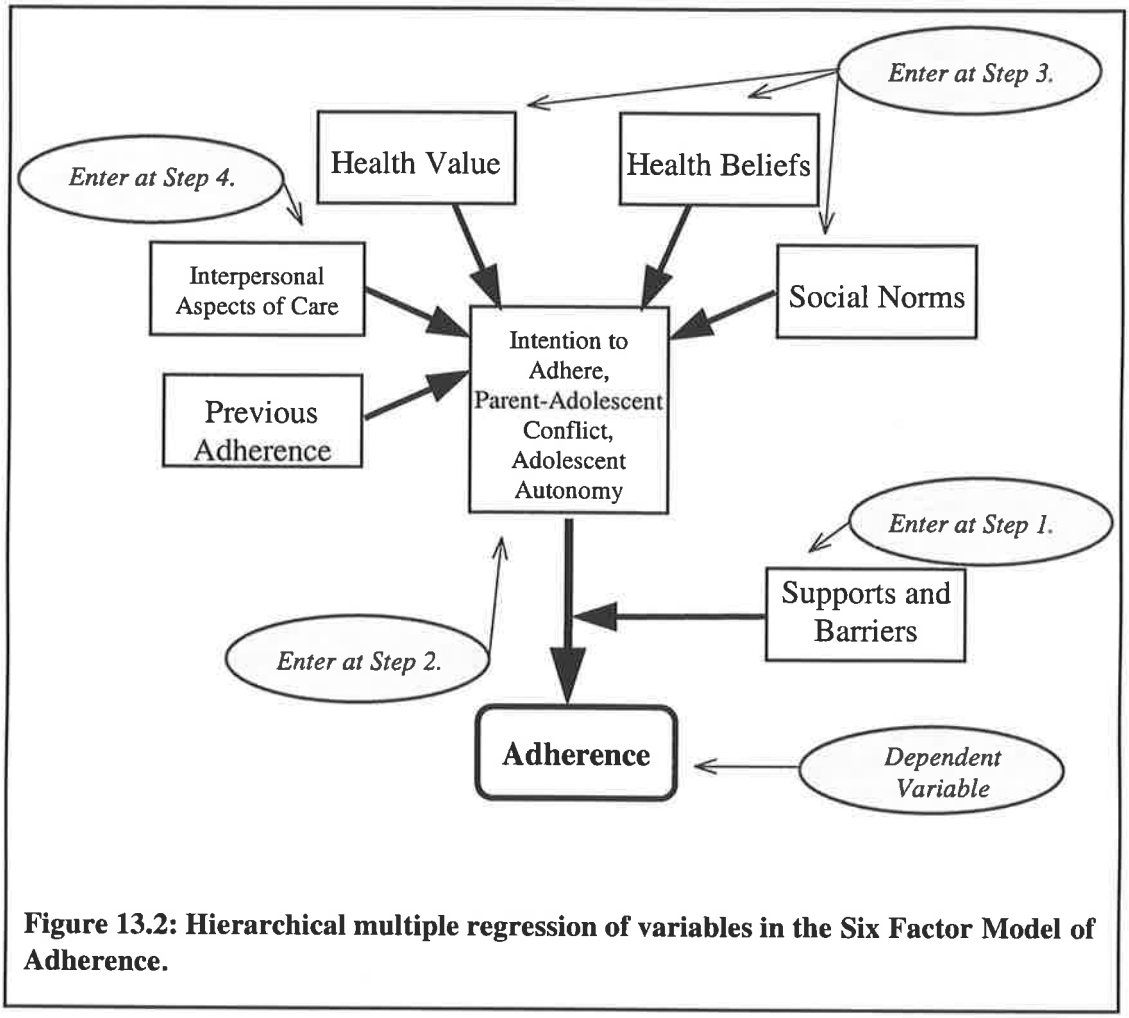


Figure 13.2: Hierarchical multiple regression of variables in the Six Factor Model of Adherence.

Table 13.5: Hierarchical multiple regression analysis of adolescent reported general adherence (GAS) against adolescent completed measures of proposed antecedents of adherence, parent-adolescent conflict, and adolescent autonomy.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Adolescent GAS					
Step 1 Supports / Barriers	0.483†	0.234	0.234	33.55	< 0.0001
Step 2 Intentions to Adhere	0.202	0.350	0.117	3.11	0.007
Conflict	-0.121				
Self- & Family-Care	-0.149				
Management	0.042				
Recreational	0.170				
Social / Vocational	0.076				
Step 3 Perceived Utility	0.214	0.421	0.070	2.40	0.04
Perceived Severity	-0.116				
Perc. Susceptibility	-0.099				
Subjective Norms	0.050				
Health Value	0.183				
Step 4 Interpersonal Care	0.049	0.422	0.001	0.13	0.9
Diabetes Knowledge	-0.004				
Significant predictors in the final equation					
Supports / Barriers					
Recreational Activity					
Health Value					

* F test on R^2 change.

† *Note:* Beta coefficients may vary from those reported in **Section 13.1** because some scores were missing for the Conflict Behavior Questionnaire and these cases were therefore excluded from this analysis.

Table 13.6: Hierarchical multiple regression analysis of adolescent reported diabetes-specific adherence (DSAS) against adolescent completed measures of proposed antecedents of adherence, parent-adolescent conflict, and adolescent autonomy.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Adolescent DSAS					
Step 1 Supports / Barriers	0.274†	0.075	0.075	9.28	0.003
Step 2 Intentions to Adhere	0.249				
Conflict	-0.119				
Self- & Family-Care	0.004	0.217	0.142	3.27	0.005
Management	-0.070				
Recreational	-0.229				
Social / Vocational	0.053				
Step 3 Perceived Utility	0.215				
Perceived Severity	-0.109				
Perc. Susceptibility	-0.169	0.297	0.080	2.34	0.047
Subjective Norms	-0.109				
Health Value	0.136				
Step 4 Interpersonal Care	-0.089	0.322	0.025	1.86	0.2
Diabetes Knowledge	0.172				
Significant predictors in the final equation					
Recreational Activity					
Perceived Susceptibility					

* F test on R^2 change.

† *Note:* Beta coefficients may vary from those reported in **Section 13.1** because some scores were missing for the Conflict Behavior Questionnaire and these cases were therefore excluded from this analysis.

Table 13.7: Hierarchical multiple regression analysis of parent reported general adherence (GAS) against parent completed measures of proposed antecedents of adherence, parent-adolescent conflict, and adolescent autonomy.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Parent GAS					
Step 1 Supports / Barriers	0.444[†]	0.197	0.197	30.01	< 0.0001
Step 2 Intentions to Adhere	0.473	0.376	0.178	5.52	< 0.0001
Conflict	-0.096				
Self- & Family-Care	0.073				
Management	-0.151				
Recreational	0.053				
Social / Vocational	0.013				
Step 3 Perceived Utility	0.036	0.390	0.014	0.52	0.8
Perceived Severity	0.031				
Perc. Susceptibility	0.098				
Subjective Norms	0.043				
Health Value	0.037				

Significant predictors in the regression equation, when halted at *Step 3*.

Supports / Barriers
Intentions to Adhere

* F test on R^2 change.

[†] *Note:* Beta coefficients may vary from those reported in **Section 13.1** because some scores were missing for the Conflict Behavior Questionnaire and these cases were therefore excluded from this analysis.

Table 13.8: Hierarchical multiple regression analysis of parent reported diabetes-specific adherence (DSAS) against parent completed measures of proposed antecedents of adherence, parent-adolescent conflict, and adolescent autonomy.

Measures	Beta	Multiple R^2	Change in R^2	F*	p
Parent DSAS					
Step 1 Supports / Barriers	0.342†	0.117	0.117	16.23	0.0001
Step 2 Intentions to Adhere	0.462	0.376	0.178	5.52	< 0.0001
Conflict	-0.007				
Self- & Family-Care	0.117				
Management	-0.268				
Recreational	-0.148				
Social / Vocational	0.291				
Step 3 Perceived Utility	-0.035	0.318	0.016	0.50	0.8
Perceived Severity	0.043				
Perc. Susceptibility	0.008				
Subjective Norms	-0.095				
Health Value	0.122				

Significant predictors in the regression equation, when halted at *Step 3*.

Supports / Barriers
Intentions to Adhere

* F test on R^2 change.

† *Note:* Beta coefficients may vary from those reported in **Section 13.1** because some scores were missing for the Conflict Behavior Questionnaire and these cases were therefore excluded from this analysis.

Table 13.9: Stepwise multiple regression analysis of adolescent reported general adherence (GAS) against adolescent completed measures.

Measures	Beta	Multiple R^2	F
Adolescent GAS			
Conflict	-0.106		
Recreational Activity	0.148		
Interpersonal Aspects of Care	0.092		
Perceived Utility	0.233*	0.324	19.04**
Perceived Severity	-0.111		
Intentions to Adhere	0.075		
Supports / Barriers	0.334*		
Health Value	0.204*		

* $p < 0.05$; ** $p < 0.0001$

Table 13.10: Stepwise multiple regression analysis of adolescent reported diabetes-specific adherence (DSAS) against adolescent completed measures.

Measures	Beta	Multiple R^2	F
Adolescent DSAS			
Conflict	-0.088		
Recreational Activity	0.185*		
Interpersonal Aspects of Care	-0.036		
Perceived Utility	0.173	0.160	11.44**
Perceived Severity	-0.115		
Intentions to Adhere	0.328*		
Supports / Barriers	0.114		
Health Value	0.138		

* $p < 0.05$; ** $p < 0.0001$

Table 13.11: Stepwise multiple regression analysis of parent reported general adherence (GAS) against parent completed measures.

Measures	Beta	Multiple R^2	F
Parent GAS			
Conflict	-0.154	0.346	64.47**
Interpersonal Aspects of Care	0.048		
Perceived Utility	0.030		
Perceived Severity	0.009		
Intentions to Adhere	0.588*		
Supports / Barriers	0.154		
Health Value	0.001		

* $p < 0.05$; ** $p < 0.0001$

Table 13.12: Stepwise multiple regression analysis of parent reported diabetes specific adherence (DSAS) against parent completed measures.

Measures	Beta	Multiple R^2	F
Parent DSAS			
Conflict	-0.102	0.169	24.76**
Recreational Activity	-0.098		
Perceived Utility	-0.012		
Perceived Severity	0.123		
Intentions to Adhere	0.411*		
Supports / Barriers	0.113		
Health Value	0.038		

* $p < 0.05$; ** $p < 0.0001$

Table 13.13: Stepwise multiple regression analysis of adolescents' metabolic control (HbA_{1c}) against adolescent and parent completed measures.

Measures	Beta	Multiple R^2	F
Adolescent Metabolic Control			
Adolescent Reported General Adherence	0.064		
Adolescent Reported Diabetes-Specific Adherence	-0.004		
Adolescent Reported Interpersonal Aspects of Care	0.054		
Adolescent Reported Perceived Utility	0.064		
Adolescent Reported Supports / Barriers	-0.330*		
Parent Reported General Adherence	-0.110		
Parent Reported Diabetes-Specific Adherence	-0.136	0.234	12.11**
Parent Reported Interpersonal Aspects of Care	-0.057		
Parent Reported Management Activity	-0.196*		
Parent Reported Perceived Utility	-0.022		
Parent Reported Perceived Severity	0.236*		
Parent Reported Intentions to Adhere	-0.011		
Parent Reported Supports / Barriers	-0.012		
Combined Reports of Conflict	0.024		

* $p < 0.05$; ** $p < 0.0001$

APPENDICES.

APPENDIX A.

Appendix A.1 The Pilot Study.

A.1.0 Introduction.

Pilot testing of the questionnaires began on 20 April, 1995, in the Diabetes Outpatients Clinic at the Women's and Children's Hospital.

The questionnaires were administered to a consecutive sample of 13 parent-adolescent dyads attending the Diabetes Outpatient Clinics. The demographic characteristics of the pilot sample are described in **Tables A.1** and **A.2**. Adolescents were selected for inclusion in the pilot study if they met the criteria for entry into the main study. That is, the adolescents were aged between 12 and 17 years, and attending the Women's and Children's Hospital Diabetes Outpatients Clinics with a parent or guardian. Additional entry criteria for the study were as follows:

- participating adolescents needed to have been diagnosed with Insulin Dependent Diabetes for a minimum of 12 months.
- participating adolescents needed to attend the Outpatient Clinics in the company of a parent or guardian.
- participating adolescents and their parents needed to have sufficient comprehension of written English to complete the questionnaires.

The pilot testing was conducted for four weeks. Participants in the pilot study were excluded from the main study, to prevent possible learning effects.

A.1.1 Pilot Study Procedures.

Subjects were approached by the investigator to participate in the study while attending outpatient clinic sessions. The collection of questionnaire data was conducted in the outpatient clinic waiting area. The investigator was present during the completion of the questionnaires, to answer any questions with which participants experienced difficulties.

A.1.2 Pilot Testing of Questionnaire Measures.

A.1.2.1Measures Employed in the Pilot Questionnaire.

Pilot testing examined the acceptability and utility of all of the questionnaire measures proposed for use in the main study. These measures are, with one exception, identical to those used in the main study. A detailed description of these measures may be found in **Chapter 3**. The exception is the Self-Efficacy for Diabetes Scale (SED; Grossman, Brink, Hauser, 1987), which was employed in the pilot study but excluded from the main study. This measure, and its exclusion from the main study, are described in detail in this chapter.

Table A.1: Demographic characteristics of pilot study adolescents.

	N = 13
Adolescent Gender (n [%])	
Male	7 (53.8 %)
Female	6 (46.2 %)
Adolescent Age (Mean years ± SD (95% CI))	14.0 ± 1.9 (12.9 to 15.1)
Adolescent Age Strata (n [%])	
12 year olds	4 (30.8 %)
13 year olds	2 (15.4 %)
14 year olds	2 (15.4 %)
15 year olds	2 (15.4 %)
16 year olds	1 (7.7 %)
17 year olds	2 (15.4 %)
IDDM Duration (Mean years ± SD (95 % CI))	4.9 ± 1.6 (3.8 to 6.0)
Parent Age (Mean ± SD (95 % CI))	41.7 ± 4.0 (39.1 to 44.4)
Family Structure (n [%])	
Two Parent	11 (84.6 %)
Single Mother	1 (7.7 %)
Single Father	1 (7.7 %)

Table A.2: Occupational prestige and educational attainment of pilot study parents.

	N = 13	
	Fathers[†]	Mothers[‡]
Occupational Prestige (n [%])*		
High (1.0 — 2.9)	1 (8.3 %)	0 (0.0 %)
Middle (3.0 — 4.9)	4 (33.3 %)	2 (16.7 %)
Low (5.0 — 7.9)	2 (16.7 %)	2 (16.7 %)
Home Duties	0 (0.0 %)	7 (58.3 %)
Student / Unemployed / Retired / Pensioner	0 (0.0 %)	0 (0.0 %)
Unclassifiable / Missing	5 (41.7 %)	1 (8.3 %)
Not present	1	1

* Daniel (1983).
[†] 1 father was not present in the household, percentages refer to sample of fathers (n=12)
[‡] 1 mother was not present in the household, percentages refer to sample of mothers (n=12)

The Self-Efficacy for Diabetes Scale (SED) is based on Bandura's conception of self-efficacy (Bandura, 1977), and was designed to evaluate adolescents' perceptions of their ability to manage their diabetes and diabetes-related situations (Grossman, Brink, & Hauser, 1987).

The SED consists of 35 items in which adolescents are asked to rate their confidence to manage described situations. Response options for each item formed a six-point Likert scale (1 = *Very sure I can't*, 6 = *Very sure I can*). The Self-Efficacy for Diabetes Scale contains three subscales: (*a*) diabetes specific SED, (*b*) medical situations SED, and (*c*) general situations SED. The total SED scale has a reported α-reliability of 0.90 (Grossman, et al, 1987). Evidence of the construct and criterion validity of the SED is provided by Grossman and colleagues (1987).

A.1.3 Results of the Pilot Study

The analysis performed on the pilot questionnaires was not extensive. Pilot analyses examined the distributions of scores on each of the questionnaire measures, with the intention of determining whether these measures were suitable for use with the target population. **Table A.3** displays the obtained mean scores, with standard deviation, as well as the minimum and maximum obtained scores on each measure.

A.1.4 Modifications Made to the Pilot Study Questionnaires.

In light of the results obtained in the pilot study, several changes were made to the questionnaire measures. First, the Self-Efficacy for Diabetes Questionnaire was removed from the questionnaire measures. As can be seen in **Table A.3**, The responses obtained for this measure were consistently high, particularly responses made by the adolescents. High responses on this measure indicate a perceived high level of Self-Efficacy in relation to diabetes management, and the small range of obtained responses for this measure limit the utility of the measure for the present research. In addition, given the total length of the questionnaire measures employed in the pilot study, the SED was removed to reduce respondent burden.

A second modification made to the questionnaire measures as a result of the Pilot Study was the rephrasing of item 9 of the Diabetes Knowledge questionnaire. The third response option was changed from "Use diabetic tablets instead of insulin" to "Take less insulin." This change was made to update the question to current paediatric diabetes management practices, and to improve the comprehensibility of the question.

Similarly, the wording of items 1, 5, 7 and 9 of the Diabetes Specific Adherence Scale were modified to make these items more comprehensible, particularly to younger adolescents. These changes were made on the basis of feedback from adolescents and parents participating in the Pilot Study, in consultation with members of the Women's and Children's Hospital Diabetes Team.

Table A.3: Summary Data obtained from the Pilot Study Questionnaires.

Measure	Number of Items	Possible Range	Observed Range		Mean ± SD	
			Adolescent	Parent	Adolescent	Parent
Diabetes Specific Adherence Scale	9	9 — 54	29 — 49	19 — 48	39.6 ± 5.4	36.4 ± 9.5
General Adherence Scale	5	5 — 30	15 — 30	11 — 27	23.0 ± 4.5	22.4 ± 4.6
Autonomous Functioning Checklist						
Self- & Family Care	22	0 — 88	13 — 64	16 — 36	36.1 ± 15.2	26.6 ± 6.6
Management Activity	20	0 — 80	23 — 76	28 — 66	54.8 ± 17.2	45.6 ± 11.9
Recreational Activity	16	0 — 64	8 — 48	10 — 37	31.0 ± 12.2	21.6 ± 8.3
Social & Vocational Activity	20	0 — 20	5 — 16	3 — 15	9.7 ± 2.9	8.6 ± 4.2
Conflict Behavior Questionnaire	20	0 — 20	2 — 6	2 — 7	3.2 ± 1.3	4.7 ± 1.8
Adherence Determinants Questionnaire						
Interpersonal Aspects of Care	8	8 — 40	24 — 37	25 — 37	31.0 ± 3.9	31.4 ± 3.6
Perceived Utility	8	8 — 40	28 — 37	30 — 40	33.3 ± 2.7	34.2 ± 3.3
Perceived Severity	4	4 — 20	4 — 10	6 — 13	7.9 ± 1.9	9.6 ± 2.3
Perceived Susceptibility	4	4 — 20	12 — 18	10 — 20	14.6 ± 2.3	14.2 ± 3.2
Subjective Norms	6	-18 — 18	-12 — 0	-4 — 0	-2.0 ± 3.5	-1.0 ± 1.4
Intentions	4	4 — 20	13 — 20	12 — 19	16.8 ± 2.0	16.3 ± 1.8
Supports / Barriers	4	4 — 20	12 — 17	11 — 16	14.6 ± 1.7	14.3 ± 1.7
Health Value Scale	4	4 — 20	10 — 20	8 — 16	14.4 ± 3.1	13.4 ± 2.7
Socially Desirable Response Set	5	0 — 5	0 — 4	0 — 3	0.6 ± 1.3	0.6 ± 0.9
Diabetes Knowledge	15	0 — 15	5 — 14	10 — 14	11.2 ± 3.0	13.0 ± 1.2
Self-Efficacy for Diabetes	35	35 — 210	153 — 202	108 — 196	178.2 ± 13.7	157.2 ± 26.6

The final change to the Pilot Study Questionnaire related to the Demographic information. At the conclusion of the Pilot Study, an item addressing the educational attainment of the non-participating parent, which was not included in the Pilot Study questionnaire, was added. This item was included to provide a more comprehensive description of the demographic characteristics of participating families, as well as to ensure that matching information was obtained from parents, whether mothers or fathers completed the questionnaire.

A.1.5 Pilot Testing of Electronic Monitoring of Self-Monitoring of Blood Glucose.

Two adolescents already using Medisense Companion 2™ Blood Glucose Monitors attended Outpatient Clinics during the pilot study period. The BGM tests recorded on these monitors were downloaded onto the SensorLink™ machines as a trial of this procedure. Formal analyses were not conducted on these results, which were used only as a trial of the procedures involved in obtaining this data.

Appendix A.2 The Information Sheet.

INFORMATION SHEET.

DIABETES AND FAMILIES STUDY.

The aim of this study is to examine adherence to medical treatment amongst adolescents with diabetes. Patient adherence to medical treatment is a critical factor in managing chronic illnesses. Previous studies have suggested that adolescents who are very dependent on their parents, and who frequently fight with their parents will not follow their medical treatment as well as other adolescents. This study is intended to examine these factors.

If you and your parent agree to take part in the study, you will be given a questionnaire that will take less than half an hour to complete. The questionnaire asks a number of questions about the way you follow your medical treatment, and about your relationship with your parent. A separate questionnaire will also be given to your parent to complete.

The information you and your parent provide will be kept in the strictest confidence, and will be used only for the purpose of this study. **It will in no way effect your medical treatment.** The answers that you provide **will not be seen by the clinicians** who are treating you.

If you have any questions about the study, please feel free to contact Mr Michael Fotheringham (Phone: 239 0133) or Dr Michael Sawyer (Phone: 239 0133) at the Women's and Children's Hospital.

Your help and cooperation are greatly appreciated.

Michael Fotheringham.
PhD Student.
Women's and Children's Hospital.

Appendix A.3 The Consent Form.

CONSENT FORM.

ADOLESCENTS' AND DIABETES.

1. The nature and purpose of the study has been explained to me, and the time required to complete the questionnaire/s has been made clear.
2. I understand that I (my child) may not be directly benefited by taking part in this study.
3. I understand that while information gained form the study will be published, I (my child) will not be identified.
4. I understand that I (my child) can withdraw from the study at any stage and that this will not effect my (child's) treatment.
5. I understand that there will be no payment to me (or my child) for taking part in this study.
6. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
7. I am aware that I should retain a copy of the Consent Form when completed and the Information Sheet.

Signed: .....

Date: .....

Parent/Guardian:

Signed: .....

Relationship to patient: .....

Full name of patient: .....

Date: .....

I certify that I have explained the study to the patient (and/or parent) and consider that he/she understands what is involved.

Signed: .....

Appendix A.4 Instructions for Completing Questionnaire Measures.

A.4.1 Instructions for Adolescents Completing Questionnaire Measures.

This questionnaire asks about your diabetes management, independence, and about your relationship with your [mother / father]. The questionnaire includes several sections.

The first section is called the Diabetes Specific Adherence Scale, please complete this scale by indicating how much each of the activities have been performed in the past four weeks, whether you do these things yourself or with help from [one of] your parent[s].

The second section is called the General Adherence Scale, again, please complete this scale by indicating how much each of the activities have been performed in the past four weeks, whether you get help with them.

The next section is the Autonomous Functioning Checklist, please complete this scale by indicating what you do.

Next is the Conflict Behaviour Questionnaire, please complete this by answering whether you think each statement is true or false

The next section is the Adherence Determinants Questionnaire. Please complete this scale by answering how much you think each statement applies.

The final scale is the Diabetes Knowledge Questionnaire, please tick the one response for each question that you think is most correct.

A.4.2 Instructions for Parents Completing Questionnaire Measures.

This questionnaire asks about your teenagers' diabetes management, independence, and about your relationship with your teenager. The questionnaire includes several sections.

The first section is called the Diabetes Specific Adherence Scale, please complete this scale by indicating how much each of the activities have been performed in the past four weeks, whether you help with them or not.

The second section is called the General Adherence Scale, again, please complete this scale by indicating how much each of the activities have been performed in the past four weeks, whether you help with them or not.

The next section is the Autonomous Functioning Checklist, please complete this scale by indicating what your teenager does.

Next is the Conflict Behaviour Questionnaire, please complete this by answering whether you think each statement is true or false

The next section is the Adherence Determinants Questionnaire. Please complete this scale by answering each question in relation to your teenager - that is, how much you think each statement applies to your teenager.

The final scale is the Diabetes Knowledge Questionnaire, please tick the one response for each question that you think is most correct.

At the end of the questionnaire there are some questions about you and you family.

Appendix A.5 The Adolescent Questionnaire.

Diabetes and Families.

Adolescent Questionnaire.

Diabetes Specific Adherence Scale.

♦ *How often have you done each of the following in the* past 4 weeks? *(Tick one box on each line)*

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Administered insulin at the times agreed with your health professional.	☐	☐	☐	☐	☐	☐
2. Self monitored blood glucose at least twice a day.	☐	☐	☐	☐	☐	☐
3. Maintained good foot hygiene.	☐	☐	☐	☐	☐	☐
4. Carried something with sugar in it as a source of glucose for emergencies.	☐	☐	☐	☐	☐	☐
5. Made food choices that follow your recommended diet.	☐	☐	☐	☐	☐	☐
6. Do you smoke?	☐	☐	☐	☐	☐	☐
7. Tested ketones when you are unwell or when your blood glucose is over 15.	☐	☐	☐	☐	☐	☐
8. Self monitored blood glucose before or after sports.	☐	☐	☐	☐	☐	☐
9. Do you change the levels of your insulin doses?	☐	☐	☐	☐	☐	☐

General Adherence Scale.

- *How often was* each *of the following statements true for you during the* past 4 weeks*? (Tick One Box on Each Line)*

1. I had a hard time doing what the doctor suggested I do	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
2. I found it easy to do the things my doctor suggested I do.	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
3. I was unable to do what was necessary to follow my doctor's treatment plans.	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
4. I followed my doctor's suggestions exactly.	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
5. Generally speaking, how often during the *past 4 weeks* were you able to do what the doctor told you?	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time

AUTONOMOUS FUNCTIONING CHECKLIST

The purpose of the Autonomous Functioning Checklist (AFC) is to learn about what you do everyday. There are no "right" or "wrong" things for you to do. Teenagers of different ages do many different things. These questions are simply for the purpose of getting an idea of your daily activity.

When you answer these questions, *first*, read the question and think about whether or not it describes what you do. You should answer the questions in relation to what you do or do not do rather than what you *believe or think* you *could* do or *could not* do.

Second, tell us how the question describes what you do by choosing one of alternatives from the scale and *ticking that box.* Here is how to use the rating scale with a sample question.

Sample Item

I pick up the trash in the yard.	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity

You will not have had a chance to participate in some of the activities the questions describe. These items should be answered as "**do not do**," even though you may feel that you could or would do this if you were given the chance. Please mark "**do not do**" for the questions that describe activities that you have *never had the chance* to do. Some of the questions describe things that you may do with help from others. Answer these questions after you think about who has the most responsibility for *completing* the activity. For example, you may cook the family meals and may be helped by other family members who set the table or chop vegetables. If you are the family member with the *most* responsibility for cooking *every* meal that the family eats together, your answer would be "**do every time there is an opportunity**." On the other hand, if you help other family members by doing jobs that they tell you to do and *never* have the *most responsibility* for fixing dinner, your answer would be "**do not do**."

Self and Family Care Activity

I:

	Do not do	Do only rarely	Do about half the time there is an opportunity	Do most of the time there is an opportunity	Do every time there is an opportunity
1. Keep my personal items and belongings in order (for example, make bed, put away own clothing and belongings).	☐	☐	☐	☐	☐
2. Prepare food that does not require cooking for myself (for example, cereal, sandwich).	☐	☐	☐	☐	☐
3. Care for my own clothing (for example, laundry, simple repair, shoe cleaning)	☐	☐	☐	☐	☐
4. Travel to and from daily activities (for example, ride bikes or walk, take bus, arrange for transportation, drive car)	☐	☐	☐	☐	☐
5. Prepare food that requires cooking for myself (for example, hamburger, soup)	☐	☐	☐	☐	☐
6. Perform simple first aid or medical care for myself (for example, bandages, take own temperature)	☐	☐	☐	☐	☐
7. Purchase my own clothing and personal items that are used on a daily basis (for example, underwear, toiletries)	☐	☐	☐	☐	☐
8. Perform minor repair and maintenance in my own environment (for example, change bulbs, hang pictures)	☐	☐	☐	☐	☐
9. Shop for and purchase my own groceries	☐	☐	☐	☐	☐

10. Respond to my own medical emergency by calling parent	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
11. Respond to my own medical emergency by calling doctor or hospital	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
12. Do designated household maintenance chores involving family living areas (for example, clean, take out trash, do simple yard work)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
13. Perform routine daily personal care for another family member (for example, dress, feed)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
14. Keep personal items and belongings of another family member in order (for example, make bed, put away clothing of another family member)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
15. Prepare meals for other family member(s)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
16. Transport (or arrange for transport of) another family member to and from daily activities	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
17. Purchase clothing and personal items (that are used on a daily basis) for other family members	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
18. Shop for and purchases family groceries	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity

	Do not do	Do only rarely	Do about half the time there is an opportunity	Do most of the time there is an opportunity	Do every time there is an opportunity
19. Perform minor repairs and maintenance in family living areas (for example, change light bulbs, hang pictures)	☐	☐	☐	☐	☐
20. Repair and maintain (or make arrangements for repair and maintenance of) major household needs (for example, plumbing, yard work, electrical wiring)	☐	☐	☐	☐	☐
21. Respond to household emergency (for example, stove fire, plumbing problem) by calling parent or neighbour	☐	☐	☐	☐	☐
22. Respond to household emergency (for example, stove fire, plumbing problem) by calling fire department, using fire extinguisher, calling repair service, or shutting off water)	☐	☐	☐	☐	☐

Management Activity

I:

	Do not do	Do only rarely	Do about half the time there is an opportunity	Do most of the time there is an opportunity	Do every time there is an opportunity
23. Use the telephone and telephone directories	☐	☐	☐	☐	☐
24. Carry out transactions with salespeople (for example, listen to information, ask questions, give payment, receive change)	☐	☐	☐	☐	☐
25. Use postal services (for example, use postage, mail letters, packages)	☐	☐	☐	☐	☐
26. Use bank (for example, fill out deposit or withdrawal slips, use passbook)	☐	☐	☐	☐	☐

27. Use travel-related services for short trips (for example, taxi, bus, subway)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
28. Use travel-related services for long trips (for example, airline, bus, train)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
29. Use library services (for example, check out books or use copying machine)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
30. Maintain and use my own saving account	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
31. Maintain and use my own checking or charge account	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
32. Maintain adequate personal care and grooming (for example, bathe, trim fingernails and toenails when needed)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
33. Maintain my routine general health and fitness (for example, have adequate eating, sleeping, exercise habits)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
34. Select clothing that is suited to the weather (for example, raincoat if raining, warm clothes in winter)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity

35. Plan and initiate activity for myself in everyday unscheduled free time (for example, choose to watch television or work on hobby if bored)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
36. Plan activity for my long-term free time (for example, make plans for summer vacation, mid-semester vacation)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
37. Initiate friendships with peers (for example, plan or attend parties, outings, games, club meetings)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
38. Meet nonacademic social obligations or commitments (for example, keep appointments for family and peer-related social events arranged by self or others)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
39. Meet academic obligations and commitments (for example, complete homework assignments on time, bring necessary supplies to class)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
40. Plan transportation to and from class (for example, arrange for rides with friends or family, plan car or bus route and schedule)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
41. Manage my own budget from allowance or income (for example, save money for large purchases, pay for routine expenses throughout week without running out of money)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity
42. Make long-term educational and/or career plans (for example, select courses, investigate colleges or technical schools)	☐ Do not do	☐ Do only rarely	☐ Do about half the time there is an opportunity	☐ Do most of the time there is an opportunity	☐ Do every time there is an opportunity

Recreational Activity

When I am *free* to *choose* how I will spend my unscheduled time, I choose to:

	Do not do	Do only rarely	Do about half the time there is an opportunity	Do most of the time there is an opportunity	Do every time there is an opportunity
43. Listen to music (for example, radio or stereo)	☐	☐	☐	☐	☐
44. Read for relaxation (for example, books, newspaper, magazines)	☐	☐	☐	☐	☐
45. Play games or puzzles (for example, cards, crossword puzzles, jigsaw puzzles, computer games)	☐	☐	☐	☐	☐
46. Write letters to friends, relatives, acquaintances	☐	☐	☐	☐	☐
47. Work on or take lessons in crafts or hobbies (for example, cooking, collections, pet care, sewing, model building, car repair)	☐	☐	☐	☐	☐
48. Practice or take lessons that involve a trained artistic or academic skill (for example, piano or other musical instrument, ballet, singing, creative writing, foreign languages)	☐	☐	☐	☐	☐
49. Go to movies, rock concerts, dances	☐	☐	☐	☐	☐
50. Go to plays, theatre, lectures	☐	☐	☐	☐	☐

	Do not do	Do only rarely	Do about half the time there is an opportunity	Do most of the time there is an opportunity	Do every time there is an opportunity
51. Pursue activities that are related to my career interest(s) (for example, run a business, work with computers, practice piano for professional preparation)	☐	☐	☐	☐	☐
52. Go for walks	☐	☐	☐	☐	☐
53. Go shopping or spend time at shopping centres or in shopping areas	☐	☐	☐	☐	☐
54. Attend club meetings or other organised social group meetings	☐	☐	☐	☐	☐
55. Work for pay (for example, babysit, play in a band, do yard work, walk dogs, work at a part-time job, deliver papers)	☐	☐	☐	☐	☐
56. Clean and/or maintain living environment or belongings (for example, clean house, wash or repair clothes, wash car, make household repairs)	☐	☐	☐	☐	☐
57. Work on schoolwork (for example, spend extra time on homework, make special preparation for class projects, spend time in the library)	☐	☐	☐	☐	☐
58. Spend time with family (for example, work on family projects, have discussions or casual conversations, attend family gatherings such as parties or picnics)	☐	☐	☐	☐	☐

Social and Vocational Activity

On these final items, please tick "YES" or "NO" in response to each description: "YES" if the description fits you; "NO" if it does not.

I:

59. Have casual friendships with teenagers of the opposite sex ☐ No ☐ Yes

60. Have close friendships with teenagers of the opposite sex ☐ No ☐ Yes

61. Have casual friendships with adults outside the family (for example, teachers, neighbours, coaches, Scout leaders) ☐ No ☐ Yes

62. Have close friendships with adults outside the family (for example, teachers, neighbours, coaches, Scout leaders) ☐ No ☐ Yes

63. Have casual friendships with younger children ☐ No ☐ Yes

64. Have close friendships with younger children ☐ No ☐ Yes

65. Am active in casual/recreational groups of teenage friends ☐ No ☐ Yes

66. Have many friendships ☐ No ☐ Yes

67. Am active in one or more organised extracurricular groups (for example, French club, student council, sports team) ☐ No ☐ Yes

68. Have a leadership position in one or more organised extracurricular groups (for example, president of the student council, captain of a sports team) ☐ No ☐ Yes

69. Have a close friendship with an adult member of the extended family (for example, uncle, aunt, or grandparent) ☐ No ☐ Yes

70. Work or have worked either for pay or as a volunteer in an area of particular career interest (for example, in science lab or legal office, as a teacher's aid or candystripe) ☐ No ☐ Yes

71. Work or have worked to earn money by providing a service on a regularly scheduled basis (for example, contracts for yard work, dog walking, babysitting) ☐ No ☐ Yes

72. Work or have worked to earn money by using a special skill (for example, musical performance, typing, tutoring) ☐ No ☐ Yes

73. Work or have worked to earn money in a self- or peer-run organisation or business ☐ No ☐ Yes

74. Work or have worked to earn money fundraising for an organisation or charity (for example, Scouts, church groups, political organisations) ☐ No ☐ Yes

75. Do or have done volunteer work without pay for a service (for example, a school or political organisation, a social agency, a club, a church, or a hospital) ☐ No ☐ Yes

76. Participate or have participated in prevocational (career) classes or training (for example, a technical training or career development class) ☐ No ☐ Yes

77. Have explored career interests by visiting work sites or interviewing people in that job or career ☐ No ☐ Yes

78. Have spent time reading, researching, or "finding out" about a career that particularly interests me ☐ No ☐ Yes

Conflict Behaviour Questionnaire: 20 Item Adolescent Version — Mother

Think back over the last 2 weeks at home. The statements below have to do with you and your mother. Read the statement, and then decide if you believe the statement is true. If it is true, then tick *true*, and if you believe the statement is not true, tick *false*. You must tick either *true* or *false*, but never both for the same item. Please answer all items. Your answers will not be shown to your parents.

1. My mum doesn't understand me. ☐ True ☐ False

2. My mum and I sometimes end our arguments calmly. ☐ True ☐ False

3. My mum understands me. ☐ True ☐ False

4. We almost never seem to agree. ☐ True ☐ False

5. I enjoy the talks we have. ☐ True ☐ False

6. When I state my own opinion, she gets upset. ☐ True ☐ False

7. At least three times a week, we get angry at each other. ☐ True ☐ False

8. My mother listens when I need someone to talk to. ☐ True ☐ False

9. My mum is a good friend to me. ☐ True ☐ False

10. She says I have no consideration for her. ☐ True ☐ False

11. At least once a day we get angry at each other. ☐ True ☐ False

12. My mother is bossy when we talk. ☐ True ☐ False

13. The talks we have are frustrating. ☐ True ☐ False

14. My mum understands my point of view, even when she doesn't agree with me. ☐ True ☐ False

15. My mum seems to be always complaining about me. ☐ True ☐ False

16. In general, I don't think we get along very well. ☐ True ☐ False

17. My mum screams a lot. ☐ True ☐ False

18. My mum puts me down. ☐ True ☐ False

19. If I run into problems, my mum helps me out. ☐ True ☐ False

20. I enjoy spending time with my mother. ☐ True ☐ False

Conflict Behaviour Questionnaire: 20 Item Adolescent Version — Father

Think back over the last 2 weeks at home. The statements below have to do with you and your father. Read the statement, and then decide if you believe the statement is true. If it is true, then tick *true*, and if you believe the statement is not true, tick *false*. You must tick either *true* or *false*, but never both for the same item. Please answer all items. Your answers will not be shown to your parents.

1. My dad doesn't understand me. ☐ True ☐ False

2. My dad and I sometimes end our arguments calmly. ☐ True ☐ False

3. My dad understands me. ☐ True ☐ False

4. We almost never seem to agree. ☐ True ☐ False

5. I enjoy the talks we have. ☐ True ☐ False

6. When I state my own opinion, he gets upset. ☐ True ☐ False

7. At least three times a week, we get angry at each other. ☐ True ☐ False

8. My father listens when I need someone to talk to. ☐ True ☐ False

9. My dad is a good friend to me. ☐ True ☐ False

10. He says I have no consideration for him. ☐ True ☐ False

11. At least once a day we get angry at each other. ☐ True ☐ False

12. My father is bossy when we talk. ☐ True ☐ False

13. The talks we have are frustrating. ☐ True ☐ False

14. My dad understands my point of view, even when he doesn't agree with me. ☐ True ☐ False

15. My dad seems to be always complaining about me. ☐ True ☐ False

16. In general, I don't think we get along very well. ☐ True ☐ False

17. My dad screams a lot. ☐ True ☐ False

18. My dad puts me down. ☐ True ☐ False

19. If I run into problems, my dad helps me out. ☐ True ☐ False

20. I enjoy spending time with my father. ☐ True ☐ False

The Adherence Determinants Questionnaire.

I. Interpersonal Aspects of Care

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
1. The doctors and other health professionals sometimes ignore what I tell them.	☐	☐	☐	☐	☐
2. The doctors and other health professionals listen carefully to what I have to say.	☐	☐	☐	☐	☐
3. The doctors and other health professionals answer all my questions.	☐	☐	☐	☐	☐
4. Sometimes the doctors and other health professionals use medical terms without explaining what they mean.	☐	☐	☐	☐	☐
5. I trust that the doctors and other health professionals have my best interests at heart.	☐	☐	☐	☐	☐
6. The doctors and other health professionals act like I'm wasting their time.	☐	☐	☐	☐	☐
7. The doctors and other health professionals treat me in a very friendly and courteous manner.	☐	☐	☐	☐	☐
8. The doctors and other health professionals show little concern for me	☐	☐	☐	☐	☐

II. Perceived Utility (Benefits/Costs and Efficacy)

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
9. The benefits of my treatment plan outweigh any difficulty I might have in following it.	☐	☐	☐	☐	☐
10. My treatment plan is too much trouble for what I get out of it.	☐	☐	☐	☐	☐
11. Because my treatment plan is too difficult, it is not worth following	☐	☐	☐	☐	☐
12. Following my treatment plan is better for me than not following my treatment plan.	☐	☐	☐	☐	☐
13. Following my treatment plan will help me to be healthy.	☐	☐	☐	☐	☐
14. I'll be just as healthy if I avoid my treatment plan.	☐	☐	☐	☐	☐
15. I believe that my treatment plan will help prevent my getting hypo or hyper again.	☐	☐	☐	☐	☐
16. It's hard to believe that my treatment plan will help me.	☐	☐	☐	☐	☐

III. Perceived Severity

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
17. There are many diseases more severe than the kind of diabetes I have.	☐	☐	☐	☐	☐
18. The kind of diabetes I have is not as bad as people say.	☐	☐	☐	☐	☐
19. The kind of diabetes I have is a terrible disease.	☐	☐	☐	☐	☐
20. There is little hope for people with the kind of diabetes that I have.	☐	☐	☐	☐	☐

IV. Perceived Susceptibility

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
21. The chances I might get hypo or hyper again are pretty high.	☐	☐	☐	☐	☐
22. I expect to be free of hypos and hypers in the future.	☐	☐	☐	☐	☐
23. No matter what I do, there's a good chance of developing hypos or hypers again.	☐	☐	☐	☐	☐
24. My body will fight off hypos and hypers in the future.	☐	☐	☐	☐	☐

V. Subjective Norms

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
25. Members of my immediate family think I should follow my treatment plan.	☐	☐	☐	☐	☐
26. I want to do what members of my immediate family think I should do about my treatment plan.	☐	☐	☐	☐	☐
27. My close friends think I should follow my treatment plan.	☐	☐	☐	☐	☐
28. I want to do what my close friends think I should do about my treatment plan.	☐	☐	☐	☐	☐
29. My relatives think I should follow my treatment plan.	☐	☐	☐	☐	☐
30. I want to do what my relatives think I should do about my treatment plan.	☐	☐	☐	☐	☐

VI. Intentions

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
31. I have made a commitment to follow my treatment plan.	☐	☐	☐	☐	☐
32. Following my treatment plan is not in my plans.	☐	☐	☐	☐	☐
33. I intend to follow my treatment plan.	☐	☐	☐	☐	☐
34. I have no intention of following my treatment plan.	☐	☐	☐	☐	☐

VII. Support / Barriers

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
35. Lots of things get in the way of following my treatment plan.	☐	☐	☐	☐	☐
36. I need more assistance in order to follow my treatment plan.	☐	☐	☐	☐	☐
37. I get the help I need to carry out my treatment plan.	☐	☐	☐	☐	☐
38. I am able to deal with any problems in following my treatment plan.	☐	☐	☐	☐	☐

Health Value Scale.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
1. If you don't have your health you don't have anything.	☐	☐	☐	☐	☐
2. There are many things I care more about than my health.	☐	☐	☐	☐	☐
3. Good health is of only minor importance in a happy life.	☐	☐	☐	☐	☐
4. There is nothing more important than good health.	☐	☐	☐	☐	☐

Socially Desirable Response Set.

Listed below are a few statements about your relationships with others.
How much is *each* statement TRUE or FALSE for you?

1. I am always courteous even to people who are disagreeable.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
2. There have been occasions when I took advantage of someone.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
3. I sometimes try to get even rather than forgive and forget.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
4. I sometimes feel resentful when I don't get my way.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
5. No matter who I'm talking to, I'm always a good listener.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False

Diabetes Knowledge Questionnaire

1. In uncontrolled diabetes the blood sugar is:
   - ☐ Normal.
   - ☐ Increased.
   - ☐ Decreased.
   - ☐ Don't Know.

2. Which one of the following is *true*?
   - ☐ It does not matter if your diabetes is not fully controlled, as long as you do not have a coma.
   - ☐ It is best to have high blood sugars in order to avoid hypos.
   - ☐ Poor control of diabetes could result in a greater chance of complications later.
   - ☐ I don't know.

3. The normal range for blood glucose is:
   - ☐ 4—8 mmol/L.
   - ☐ 7—15 mmol/L.
   - ☐ 2—10 mmol/L.
   - ☐ I don't know.

4. Butter is mainly:
   - ☐ Protein.
   - ☐ Carbohydrate.
   - ☐ Fat.
   - ☐ Mineral and vitamin.
   - ☐ I don't know.

5. Rice is mainly:
   - ☐ Protein.
   - ☐ Carbohydrate.
   - ☐ Fat.
   - ☐ Mineral and vitamin.
   - ☐ I don't know.

6. The presence of ketones in the urine is:

- [ ] A good sign.
- [ ] A bad sign.
- [ ] A usual finding in diabetes.
- [ ] I don't know.

7. Which of the following possible complications is usually *not* associated with diabetes?

- [ ] Changes in vision.
- [ ] Changes in the kidney.
- [ ] Changes in the lung.
- [ ] I don't know.

8. A person with diabetes on insulin who finds a blood glucose level is constantly above 10 should probably:

- [ ] Stop taking insulin.
- [ ] Decrease insulin.
- [ ] Increase insulin.
- [ ] I don't know.

9. When a person with diabetes becomes ill and unable to eat the prescribed diet, they should:

- [ ] Immediately stop taking their insulin.
- [ ] Continue taking their insulin.
- [ ] Take less insulin.
- [ ] I don't know.

10. If you feel the beginnings of a hypo reaction, you should:

- [ ] Immediately take some insulin.
- [ ] Immediately lie down and rest.
- [ ] Immediately eat or drink something sweet.
- [ ] I don't know.

11. Which foods contain the most calories?

- [ ] 1 teaspoon of sugar.
- [ ] 1 teaspoon fat.
- [ ] 1 teaspoon unprocessed bran.
- [ ] I don't know.

12. A hypo is caused by:
- ☐ Too much insulin.
- ☐ Too little insulin.
- ☐ Too little exercise.
- ☐ I don't know.

13. Carbohydrate foods should be spread evenly over the day because:
- ☐ They are fattening and spreading them out makes them less fattening.
- ☐ They prevent hunger pangs.
- ☐ This avoids large increases in the blood sugar level at any one time.
- ☐ I don't know.

14. Food eaten to treat hypos should be:
- ☐ Subtracted from the next meal.
- ☐ Subtracted from the evening meal.
- ☐ Taken in addition to your total food allowance.
- ☐ I don't know.

15. Which statement would most accurately describe the recommended use of fruit juice:
- ☐ Only use for hypos or before sport.
- ☐ It is a good choice for between meal snacks.
- ☐ Use plenty as long as it is a no added sugar brand.
- ☐ I don't know.

Appendix A.6 The Parent Questionnaire.

Diabetes and Families.

Parent Questionnaire.

Diabetes Specific Adherence Scale.

- *How often have you done each of the following in the* past 4 weeks? *(Tick one box on each line)*

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Administered insulin at the times agreed with your health professional.	☐	☐	☐	☐	☐	☐
2. Self monitored blood glucose at least twice a day.	☐	☐	☐	☐	☐	☐
3. Maintained good foot hygiene.	☐	☐	☐	☐	☐	☐
4. Carried something with sugar in it as a source of glucose for emergencies.	☐	☐	☐	☐	☐	☐
5. Made food choices that follow your recommended diet.	☐	☐	☐	☐	☐	☐
6. Do you smoke?	☐	☐	☐	☐	☐	☐
7. Tested ketones when you are unwell or when your blood glucose is over 15.	☐	☐	☐	☐	☐	☐
8. Self monitored blood glucose before or after sports.	☐	☐	☐	☐	☐	☐
9. Do you change the levels of your insulin doses?	☐	☐	☐	☐	☐	☐

General Adherence Scale.

- *How often was* each *of the following statements true for you during the* past 4 weeks*? (Tick One Box on Each Line)*

1. I had a hard time doing what the doctor suggested I do	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
2. I found it easy to do the things my doctor suggested I do.	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
3. I was unable to do what was necessary to follow my doctor's treatment plans.	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
4. I followed my doctor's suggestions exactly.	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time
5. Generally speaking, how often during the *past 4 weeks* were you able to do what the doctor told you?	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ A good bit of the time	☐ Most of the time	☐ All of the time

AUTONOMOUS FUNCTIONING CHECKLIST

The purpose of the Autonomous Functioning Checklist (AFC) is to learn about what your teenager does everyday. There are no "right" or "wrong" things for your teenager to do. Teenagers of different ages do many different things. These questions are simply for the purpose of getting an idea of your teenager's daily activity.

When you answer these questions, *first*, read the question and think about whether or not it describes what you see or have seen your teenager do. You should answer the questions in relation to what you *know* your teenager does or does not do rather than what you *believe or think* he or she *could* do or *could not* do.

Second, tell us how the question describes what your teenager does by choosing one of alternatives from the scale and *ticking that box*. Here is how to use the rating scale with a sample question.

Sample Item

My teenager picks up the trash in the yard.	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity

Your teenager will not have had a chance to participate in some of the activities the questions describe. These items should be answered as "**does not do**," even though you may feel that your teenager could or would do this if he or she were given the chance. Please mark "**does not do**" for the questions that describe activities that your teenager has *never had the chance* to do. Some of the questions describe things that your teenager may do with help from others. Answer these questions after you think about who has the most responsibility for *completing* the activity. For example, your teenager may cook the family meals and may be helped by other family members who set the table or chop vegetables. If your teenager is the family member with the *most* responsibility for cooking *every* meal that the family eats together, your answer would be "**does every time there is an opportunity**." On the other hand, if your teenager helps other family members by doing jobs that they tell him or her to do and *never* has the *most responsibility* for fixing dinner, your answer would be "**does not do**."

Self and Family Care Activity

My teenager:

	Does not do	Does only rarely	Does about half the time there is an opportunity	Does most of the time there is an opportunity	Does every time there is an opportunity
1. Keeps own personal items and belongings in order (for example, makes bed, puts away own clothing and belongings).	☐	☐	☐	☐	☐
2. Prepares food that does not require cooking for himself/herself (for example, cereal, sandwich).	☐	☐	☐	☐	☐
3. Cares for his/her own clothing (for example, laundry, simple repair, shoe cleaning)	☐	☐	☐	☐	☐
4. Travels to and from daily activities (for example, rides bikes or walks, takes bus, arranges for transportation, drives car)	☐	☐	☐	☐	☐
5. Prepares food that requires cooking for himself/herself (for example, hamburger, soup)	☐	☐	☐	☐	☐
6. Performs simple first aid or medical care for himself/herself (for example, bandages, takes own temperature)	☐	☐	☐	☐	☐
7. Purchases his/her own clothing and personal items that are used on a daily basis (for example, underwear, toiletries)	☐	☐	☐	☐	☐
8. Performs minor repair and maintenance in his/her own environment (for example, changes bulbs, hangs pictures)	☐	☐	☐	☐	☐
9. Shops for and purchases his/her own groceries	☐	☐	☐	☐	☐

10. Responds to his/her own medical emergency by calling parent	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
11. Responds to his/her own medical emergency by calling doctor or hospital	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
12. Does designated household maintenance chores involving family living areas (for example, cleans, takes out trash, does simple yard work)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
13. Performs routine daily personal care for another family member (for example, dresses, feeds)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
14. Keeps personal items and belongings of another family member in order (for example, makes bed, puts away clothing of another family member)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
15. Prepares meals for other family member(s)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
16. Transports (or arranges for transport of) another family member to and from daily activities	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
17. Purchases clothing and personal items (that are used on a daily basis) for other family members	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
18. Shops for and purchases family groceries	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity

	Does not do	Does only rarely	Does about half the time there is an opportunity	Does most of the time there is an opportunity	Does every time there is an opportunity
19. Performs minor repairs and maintenance in family living areas (for example, changes light bulbs, hangs pictures)	☐	☐	☐	☐	☐
20. Repairs and maintains (or makes arrangements for repair and maintenance of) major household needs (for example, plumbing, yard work, electrical wiring)	☐	☐	☐	☐	☐
21. Responds to household emergency (for example, stove fire, plumbing problem) by calling parent or neighbour	☐	☐	☐	☐	☐
22. Responds to household emergency (for example, stove fire, plumbing problem) by calling fire department, using fire extinguisher, calling repair service, or shutting off water)	☐	☐	☐	☐	☐

Management Activity

My teenager:

	Does not do	Does only rarely	Does about half the time there is an opportunity	Does most of the time there is an opportunity	Does every time there is an opportunity
23. Uses the telephone and telephone directories	☐	☐	☐	☐	☐
24. Carries out transactions with salespeople (for example, listens to information, asks questions, gives payment, receives change)	☐	☐	☐	☐	☐
25. Uses postal services (for example, uses postage, mails letters, packages)	☐	☐	☐	☐	☐
26. Uses bank (for example, fills out deposit or withdrawal slips, uses passbook)	☐	☐	☐	☐	☐

27. Uses travel-related services for short trips (for example, taxi, bus, subway)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
28. Uses travel related services for long trips (for example, airline, bus, train)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
29. Uses library services (for example, checks out books or uses copying machine)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
30. Maintains and uses his/her own saving account	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
31. Maintains and uses his/her own checking or charge account	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
32. Maintains adequate personal care and grooming (for example, bathes, trims fingernails and toenails when needed)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
33. Maintains his/her routine general health and fitness (for example, has adequate eating, sleeping, exercise habits)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
34. Selects clothing that is suited to the weather (for example, raincoat if raining, warm clothes in winter)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity

35. Plans and initiates activity for himself/herself in everyday unscheduled free time (for example, chooses to watch television or work on hobby if bored)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
36. Plans activity for his/her long-term free time (for example, makes plans for summer vacation, mid-semester vacation)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
37. Initiates friendships with peers (for example, plans or attends parties, outings, games, club meetings)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
38. Meets nonacademic social obligations or commitments (for example, keeps appointments for family and peer-related social events arranged by self or others)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
39. Meets academic obligations and commitments (for example, completes homework assignments on time, brings necessary supplies to class)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
40. Plans transportation to and from class (for example, arranges for rides with friends or family, plans car or bus route and schedule)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
41. Manages his/her own budget from allowance or income (for example, saves money for large purchases, pays for routine expenses throughout week without running out of money)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
42. Makes long-term educational and/or career plans (for example, selects courses, investigates colleges or technical schools)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity

Recreational Activity

When my teenager is *free* to *choose* how he/she will spend his/her unscheduled times, he/she chooses to:

	Does not do	Does only rarely	Does about half the time there is an opportunity	Does most of the time there is an opportunity	Does every time there is an opportunity
43. Listens to music (for example, radio or stereo)	☐	☐	☐	☐	☐
44. Read for relaxation (for example, books, newspaper, magazines)	☐	☐	☐	☐	☐
45. Play games or puzzles (for example, cards, crossword puzzles, jigsaw puzzles, computer games)	☐	☐	☐	☐	☐
46. Write letters to friends, relatives, acquaintances	☐	☐	☐	☐	☐
47. Work on or take lessons in crafts or hobbies (for example, cooking, collections, pet care, sewing, model building, car repair)	☐	☐	☐	☐	☐
48. Practice or take lessons that involve a trained artistic or academic skill (for example, piano or other musical instrument, ballet, singing, creative writing, foreign languages)	☐	☐	☐	☐	☐
49. Go to movies, rock concerts, dances	☐	☐	☐	☐	☐
50. Go to plays, theatre, lectures	☐	☐	☐	☐	☐

51. Pursue activities that are related to his/her career interest(s) (for example, run a business, work with computers, practice piano for professional preparation)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
52. Go for walks	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
53. Go shopping or spend time at shopping centres or in shopping areas	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
54. Attend club meetings or other organised social group meetings	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
55. Work for pay (for example, babysit, play in a band, do yard work, walk dogs, work at a part-time job, deliver papers)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
56. Clean and/or maintain living environment or belongings (for example, clean house, wash or repair clothes, wash car, make household repairs)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
57. Work on schoolwork (for example, spend extra time on homework, make special preparation for class projects, spend time in the library)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity
58. Spend time with family (for example, work on family projects, have discussions or casual conversations, attend family gatherings such as parties or picnics)	☐ Does not do	☐ Does only rarely	☐ Does about half the time there is an opportunity	☐ Does most of the time there is an opportunity	☐ Does every time there is an opportunity

Social and Vocational Activity

On these final items, please tick "YES" or "NO" in response to each description: "YES" if the description fits your teenager; "NO" if it does not.

My Teenager:

59. Has casual friendships with teenagers of the opposite sex	☐ No	☐ Yes
60. Has close friendships with teenagers of the opposite sex	☐ No	☐ Yes
61. Has casual friendships with adults outside the family (for example, teachers, neighbours, coaches, Scout leaders)	☐ No	☐ Yes
62. Has close friendships with adults outside the family (for example, teachers, neighbours, coaches, Scout leaders)	☐ No	☐ Yes
63. Has casual friendships with younger children	☐ No	☐ Yes
64. Has close friendships with younger children	☐ No	☐ Yes
65. Is active in casual/recreational groups of teenage friends	☐ No	☐ Yes
66. Has many friendships	☐ No	☐ Yes
67. Is active in one or more organised extracurricular groups (for example, French club, student council, sports team)	☐ No	☐ Yes
68. Has a leadership position in one or more organised extracurricular groups (for example, president of the student council, captain of a sports team)	☐ No	☐ Yes

69. Has a close friendship with an adult member of the extended family (for example, uncle, aunt, or grandparent) ☐ No ☐ Yes

70. Works or has worked either for pay or as a volunteer in an area of particular career interest (for example, in science lab or legal office, as a teacher's aid or candystripe) ☐ No ☐ Yes

71. Works or has worked to earn money by providing a service on a regularly scheduled basis (for example, contracts for yard work, dog walking, babysitting) ☐ No ☐ Yes

72. Works or has worked to earn money by using a special skill (for example, musical performance, typing, tutoring) ☐ No ☐ Yes

73. Works or has worked to earn money in a self- or peer-run organisation or business ☐ No ☐ Yes

74. Works or has worked to earn money fundraising for an organisation or charity (for example, Scouts, church groups, political organisations) ☐ No ☐ Yes

75. Does or has done volunteer work without pay for a service (for example, a school or political organisation, a social agency, a club, a church, or a hospital) ☐ No ☐ Yes

76. Participates or has participated in prevocational (career) classes or training (for example, a technical training or career development class) ☐ No ☐ Yes

77. Has explored career interests by visiting work sites or interviewing people in that job or career ☐ No ☐ Yes

78. Has spent time reading, researching, or "finding out" about a career that particularly interests him/her ☐ No ☐ Yes

Conflict Behaviour Questionnaire: 20 Item Parent Version.

You are the child's mother / father (delete as appropriate). You are filling this questionnaire out regarding you son / daughter (delete as appropriate) who is ____ years old. Think back over the last 2 weeks at home. The statements below have to do with you and your child. Read the statement, and then decide if you believe the statement is true. If it is true, then tick *true*, and if you believe the statement is not true, tick *false*. You must tick either *true* or *false*, but never both for the same item. Please answer all items. Answer for yourself, without talking it over with your spouse. Your answers will not be shown to your child.

1. My child is easy to get along with. ☐ True ☐ False

2. My child is receptive to criticism. ☐ True ☐ False

3. My child is well behaved in our discussions. ☐ True ☐ False

4. For the most part, my child likes to talk to me. ☐ True ☐ False

5. We almost never seem to agree. ☐ True ☐ False

6. My child usually listens to what I tell him/her. ☐ True ☐ False

7. At least three time a week, we get angry at each other. ☐ True ☐ False

8. My child says that I have no consideration of his/her feelings. ☐ True ☐ False

9. My child and I compromise during arguments. ☐ True ☐ False

10. My child often doesn't do what I ask. ☐ True ☐ False

11. The talks we have are frustrating. ☐ True ☐ False

12. My child often seems angry at me. ☐ True ☐ False

13. My child acts impatient when I talk. ☐ True ☐ False

14. In general, I don't think we get along very well. ☐ True ☐ False

15. My child almost never understands my side of an argument. ☐ True ☐ False

16. My child and I have big arguments over little things. ☐ True ☐ False

17. My child is defensive when I talk to him/her. ☐ True ☐ False

18. My child thinks my opinions don't count. ☐ True ☐ False

19. We argue a lot about rules. ☐ True ☐ False

20. My child tells me s/he thinks I am unfair. ☐ True ☐ False

The Adherence Determinants Questionnaire.

I. Interpersonal Aspects of Care

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
1. The doctors and other health professionals sometimes ignore what I tell them.	☐	☐	☐	☐	☐
2. The doctors and other health professionals listen carefully to what I have to say.	☐	☐	☐	☐	☐
3. The doctors and other health professionals answer all my questions.	☐	☐	☐	☐	☐
4. Sometimes the doctors and other health professionals use medical terms without explaining what they mean.	☐	☐	☐	☐	☐
5. I trust that the doctors and other health professionals have my best interests at heart.	☐	☐	☐	☐	☐
6. The doctors and other health professionals act like I'm wasting their time.	☐	☐	☐	☐	☐
7. The doctors and other health professionals treat me in a very friendly and courteous manner.	☐	☐	☐	☐	☐
8. The doctors and other health professionals show little concern for me	☐	☐	☐	☐	☐

II. Perceived Utility (Benefits/Costs and Efficacy)

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
9. The benefits of my treatment plan outweigh any difficulty I might have in following it.	☐	☐	☐	☐	☐
10. My treatment plan is too much trouble for what I get out of it.	☐	☐	☐	☐	☐
11. Because my treatment plan is too difficult, it is not worth following	☐	☐	☐	☐	☐
12. Following my treatment plan is better for me than not following my treatment plan.	☐	☐	☐	☐	☐
13. Following my treatment plan will help me to be healthy.	☐	☐	☐	☐	☐
14. I'll be just as healthy if I avoid my treatment plan.	☐	☐	☐	☐	☐
15. I believe that my treatment plan will help prevent my getting hypo or hyper again.	☐	☐	☐	☐	☐
16. It's hard to believe that my treatment plan will help me.	☐	☐	☐	☐	☐

III. Perceived Severity

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
17. There are many diseases more severe than the kind of diabetes I have.	☐	☐	☐	☐	☐
18. The kind of diabetes I have is not as bad as people say.	☐	☐	☐	☐	☐
19. The kind of diabetes I have is a terrible disease.	☐	☐	☐	☐	☐
20. There is little hope for people with the kind of diabetes that I have.	☐	☐	☐	☐	☐

IV. Perceived Susceptibility

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
21. The chances I might get hypo or hyper again are pretty high.	☐	☐	☐	☐	☐
22. I expect to be free of hypos and hypers in the future.	☐	☐	☐	☐	☐
23. No matter what I do, there's a good chance of developing hypos or hypers again.	☐	☐	☐	☐	☐
24. My body will fight off hypos and hypers in the future.	☐	☐	☐	☐	☐

V. Subjective Norms

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
25. Members of my immediate family think I should follow my treatment plan.	☐	☐	☐	☐	☐
26. I want to do what members of my immediate family think I should do about my treatment plan.	☐	☐	☐	☐	☐
27. My close friends think I should follow my treatment plan.	☐	☐	☐	☐	☐
28. I want to do what my close friends think I should do about my treatment plan.	☐	☐	☐	☐	☐
29. My relatives think I should follow my treatment plan.	☐	☐	☐	☐	☐
30. I want to do what my relatives think I should do about my treatment plan.	☐	☐	☐	☐	☐

VI. Intentions

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
31. I have made a commitment to follow my treatment plan.	☐	☐	☐	☐	☐
32. Following my treatment plan is not in my plans.	☐	☐	☐	☐	☐
33. I intend to follow my treatment plan.	☐	☐	☐	☐	☐
34. I have no intention of following my treatment plan.	☐	☐	☐	☐	☐

VII. Support / Barriers

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
35. Lots of things get in the way of following my treatment plan.	☐	☐	☐	☐	☐
36. I need more assistance in order to follow my treatment plan.	☐	☐	☐	☐	☐
37. I get the help I need to carry out my treatment plan.	☐	☐	☐	☐	☐
38. I am able to deal with any problems in following my treatment plan.	☐	☐	☐	☐	☐

Health Value Scale.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
1. If you don't have your health you don't have anything.	☐	☐	☐	☐	☐
2. There are many things I care more about than my health.	☐	☐	☐	☐	☐
3. Good health is of only minor importance in a happy life.	☐	☐	☐	☐	☐
4. There is nothing more important than good health.	☐	☐	☐	☐	☐

Socially Desirable Response Set.

Listed below are a few statements about your relationships with others.
How much is *each* statement TRUE or FALSE for you?

1. I am always courteous even to people who are disagreeable.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
2. There have been occasions when I took advantage of someone.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
3. I sometimes try to get even rather than forgive and forget.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
4. I sometimes feel resentful when I don't get my way.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False
5. No matter who I'm talking to, I'm always a good listener.	☐ Definitely True	☐ Mostly True	☐ Don't Know	☐ Mostly False	☐ Definitely False

Diabetes Knowledge Questionnaire

1. In uncontrolled diabetes the blood sugar is:
   - ☐ Normal.
   - ☐ Increased.
   - ☐ Decreased.
   - ☐ Don't Know.

2. Which one of the following is *true*?
   - ☐ It does not matter if your diabetes is not fully controlled, as long as you do not have a coma.
   - ☐ It is best to have high blood sugars in order to avoid hypos.
   - ☐ Poor control of diabetes could result in a greater chance of complications later.
   - ☐ I don't know.

3. The normal range for blood glucose is:
   - ☐ 4—8 mmol/L.
   - ☐ 7—15 mmol/L.
   - ☐ 2—10 mmol/L.
   - ☐ I don't know.

4. Butter is mainly:
   - ☐ Protein.
   - ☐ Carbohydrate.
   - ☐ Fat.
   - ☐ Mineral and vitamin.
   - ☐ I don't know.

5. Rice is mainly:
   - ☐ Protein.
   - ☐ Carbohydrate.
   - ☐ Fat.
   - ☐ Mineral and vitamin.
   - ☐ I don't know.

6. The presence of ketones in the urine is:

- ☐ A good sign.
- ☐ A bad sign.
- ☐ A usual finding in diabetes.
- ☐ I don't know.

7. Which of the following possible complications is usually *not* associated with diabetes?

- ☐ Changes in vision.
- ☐ Changes in the kidney.
- ☐ Changes in the lung.
- ☐ I don't know.

8. A person with diabetes on insulin who finds a blood glucose level is constantly above 10 should probably:

- ☐ Stop taking insulin.
- ☐ Decrease insulin.
- ☐ Increase insulin.
- ☐ I don't know.

9. When a person with diabetes becomes ill and unable to eat the prescribed diet, they should:

- ☐ Immediately stop taking their insulin.
- ☐ Continue taking their insulin.
- ☐ Take less insulin.
- ☐ I don't know.

10. If you feel the beginnings of a hypo reaction, you should:

- ☐ Immediately take some insulin.
- ☐ Immediately lie down and rest.
- ☐ Immediately eat or drink something sweet.
- ☐ I don't know.

11. Which foods contain the most calories?

- ☐ 1 teaspoon of sugar.
- ☐ 1 teaspoon fat.
- ☐ 1 teaspoon unprocessed bran.
- ☐ I don't know.

12. A hypo is caused by:

- ☐ Too much insulin.
- ☐ Too little insulin.
- ☐ Too little exercise.
- ☐ I don't know.

13. Carbohydrate foods should be spread evenly over the day because:

- ☐ They are fattening and spreading them out makes them less fattening.
- ☐ They prevent hunger pangs.
- ☐ This avoids large increases in the blood sugar level at any one time.
- ☐ I don't know.

14. Food eaten to treat hypos should be:

- ☐ Subtracted from the next meal.
- ☐ Subtracted from the evening meal.
- ☐ Taken in addition to your total food allowance.
- ☐ I don't know.

15. Which statement would most accurately describe the recommended use of fruit juice:

- ☐ Only use for hypos or before sport.
- ☐ It is a good choice for between meal snacks.
- ☐ Use plenty as long as it is a no added sugar brand.
- ☐ I don't know.

Background Information.

- To be completed by the parent guardian.

1. Your sex:
   - ☐ **Male**
   - ☐ **Female**

2. Your age: _____ years.

3. What is the sex of the child in this study:
   - ☐ **Male**
   - ☐ **Female**

4. What is the age of the child in this study: _____ years, _____ months.

5. How old was this child when diagnosed with diabetes? _____ years, _____ months.

6. Which one of the following best describes your relationship to the child in this study?
   - ☐ **Natural mother**
   - ☐ **Natural father**
   - ☐ **Stepmother**
   - ☐ **Stepfather**
   - ☐ **Other** _____ (please describe)

7. What are the ages of ALL other children under the age of 20 in your home? ____ ____ ____ ____ ____ ____

8. What is the main language spoken at home? _____

9. Which one of the following best applies to you? (TICK ONLY ONE)
   - ☐ **Employed**
   - ☐ **Unemployed**
   - ☐ **Home duties**
   - ☐ **Student**
   - ☐ **Pensioner**
   - ☐ **Retired**
   - ☐ **Other.** _____ (please describe)

10. What is your present occupation? _____
(please be specific)

11. Which is your highest COMPLETED level of schooling? (TICK ONLY ONE)

- ☐ **Some years of primary school**
- ☐ **Primary school**
- ☐ **Some years of high school**
- ☐ **Matric, SAS, or equivalent**
- ☐ **Technical, trade, or TAFE certificate**
- ☐ **Tertiary qualifications**

12. Which one of the following best applies to you? (TICK ONLY ONE)

I am:
- ☐ **Married**
- ☐ **Widowed**
- ☐ **Separated / divorced**
- ☐ **Never married**

13. Which one of the following best applies to you? (TICK ONLY ONE)

I live:
- ☐ **With spouse / partner and dependent children**
- ☐ **Alone with dependent children**
- ☐ **With spouse / partner only**
- ☐ **By myself**
- ☐ **Other.** _____ (please describe)

14. If you live with a spouse / partner, what is their usual occupation? _____
(please be specific)

15. Which is your spouse's highest COMPLETED level of schooling? (TICK ONLY ONE)

- ☐ **Some years of primary school**
- ☐ **Primary school**
- ☐ **Some years of high school**
- ☐ **Matric, SAS, or equivalent**
- ☐ **Technical, trade, or TAFE certificate**
- ☐ **Tertiary qualifications**

16. Do you / your family receive a pension or benefit of any kind?
- ☐ **Yes** _____ (Please be specific)
- ☐ **No**

APPENDIX B.

Appendix B.1: Mean responses (± standard deviations) to items of the Diabetes Specific Adherence Scale by adolescents and parents.

	Scoring Range	Adolescent scores (mean ± SD)	Parent scores (mean ± SD)
1. Administered insulin at the times agreed with your health professional	1 - 6	5.26 ± 1.17	5.00 ± 1.53
2. Self monitored blood glucose at least twice a day	1 - 6	4.70 ± 1.65	4.56 ± 1.76
3. Maintained good foot hygiene	1 - 6	4.81 ± 1.19	4.64 ± 1.46
4. Carried something with sugar in it as a source of glucose for emergencies	1 - 6	4.29 ± 1.58	4.53 ± 1.53
5. Made food choices that follow you recommended diet	1 - 6	4.49 ± 1.11	4.53 ± 1.12
6. Do you smoke*	1 - 6	1.26 ± 0.91	1.29 ± 1.05
7. Tested ketones when you are unwell or when your blood glucose is over 15	1 - 6	3.02 ± 1.78	3.18 ± 1.76
8. Self monitored blood glucose before or after sports	1 - 6	2.53 ± 1.58	2.51 ± 1.54
9. Do you change the levels of your insulin doses	1 - 6	3.38 ± 1.52	3.16 ± 1.48

* Scoring was reversed in this item - lower scores indicating greater adherence.

Appendix B.2: Mean responses (± standard deviations) to items of the General Adherence Scale by adolescents and parents.

	Scoring Range	Adolescent scores (mean ± SD)	Parent scores (mean ± SD)
1. I had a hard time doing what the doctor suggested I do*	1 - 6	1.98 ± 1.17	2.17 ± 1.09
2. I found it easy to do the things my doctor suggested I do.	1 - 6	4.58 ± 1.31	4.39 ± 1.37
3. I was unable to do what was necessary to follow my doctor's treatment plans.*	1 - 6	1.91 ± 1.33	1.93 ± 1.39
4. I followed my doctor's suggestions exactly.	1 - 6	4.42 ± 1.32	4.45 ± 1.42
5. Generally speaking, how often during the *past 4 weeks* were you able to do what the doctor told you?	1 - 6	4.74 ± 1.18	4.69 ± 1.16

* Scoring was reversed in these items - lower scores indicating greater adherence.

Appendix B.3: Correlations (with *p* values*) between adolescent responses to Diabetes Specific Adherence Scale items

	Adolescent DSAS 1	Adolescent DSAS 2	Adolescent DSAS 3	Adolescent DSAS 4	Adolescent DSAS 5	Adolescent DSAS 6	Adolescent DSAS 7	Adolescent DSAS 8	Adolescent DSAS 9
Adolescent DSAS 1	--	0.32	0.28 ($p = 0.001$)	0.23 ($p = 0.007$)	0.35	-0.29 ($p = 0.001$)	0.10 ($p = 0.2$)	0.16 ($p = 0.06$)	-0.07 ($p = 0.4$)
Adolescent DSAS 2		--	0.36	0.33	0.36	-0.20 ($p = 0.02$)	0.29 ($p = 0.001$)	0.14 ($p = 0.1$)	-0.01 ($p = 0.9$)
Adolescent DSAS 3			--	0.27 ($p = 0.002$)	0.26 ($p = 0.003$)	-0.28 ($p = 0.001$)	0.17 ($p = 0.05$)	0.13 ($p = 0.1$)	-0.02 ($p = 0.8$)
Adolescent DSAS 4				--	0.51	-0.14 ($p = 0.1$)	0.21 ($p = 0.02$)	0.34	-0.07 ($p = 0.4$)
Adolescent DSAS 5					--	-0.21 ($p = 0.02$)	0.20 ($p = 0.02$)	0.25 ($p = 0.004$)	-0.06 ($p = 0.5$)
Adolescent DSAS 6						--	-0.05 ($p = 0.5$)	-0.04 ($p = 0.6$)	-0.13 ($p = 0.2$)
Adolescent DSAS 7							--	0.36	-0.19 ($p = 0.03$)
Adolescent DSAS 8								--	-0.10 ($p = 0.3$)
Adolescent DSAS 9									--

* unless otherwise stated, $p < 0.001$

Appendix B.4: Correlations (with *p* values*) between adolescent responses to General Adherence Scale items.

	Adolescent GAS 1	Adolescent GAS 2	Adolescent GAS 3	Adolescent GAS 4	Adolescent GAS 5
Adolescent GAS 1	--	-0.44	0.30	-0.30 ($p = 0.001$)	-0.30 ($p = 0.001$)
Adolescent GAS 2		--	-0.32	0.58	0.63
Adolescent GAS 3			--	-0.36	-0.34
Adolescent GAS 4				--	0.70
Adolescent GAS 5					--

* unless otherwise stated, $p < 0.001$

Appendix B.5: Correlations (with *p* values*) between parent responses to Diabetes Specific Adherence Scale items.

	Parent DSAS 1	Parent DSAS 2	Parent DSAS 3	Parent DSAS 4	Parent DSAS 5	Parent DSAS 6	Parent DSAS 7	Parent DSAS 8	Parent DSAS 9
Parent DSAS 1	--	0.50	0.42	0.16 ($p = 0.07$)	0.23 ($p = 0.009$)	-0.18 ($p = 0.04$)	0.19 ($p = 0.03$)	0.17 ($p = 0.05$)	0.27 ($p = 0.002$)
Parent DSAS 2		--	0.48	0.19 ($p = 0.03$)	0.21 ($p = 0.02$)	-0.05 ($p = 0.6$)	0.22 ($p = 0.01$)	0.19 ($p = 0.03$)	0.34
Parent DSAS 3			--	0.30	0.33	-0.12 ($p = 0.2$)	0.08 ($p = 0.3$)	0.26 ($p = 0.002$)	0.14 ($p = 0.1$)
Parent DSAS 4				--	0.46	-0.17 ($p = 0.046$)	0.23 ($p = 0.007$)	0.29 ($p = 0.001$)	0.00 ($p = 1.0$)
Parent DSAS 5					--	-0.20 ($p = 0.02$)	0.17 ($p = 0.04$)	0.23 ($p = 0.009$)	0.12 ($p = 0.2$)
Parent DSAS 6						--	0.00 ($p = 1.0$)	-0.10 ($p = 0.2$)	0.09 ($p = 0.3$)
Parent DSAS 7							--	0.37	0.07 ($p = 0.4$)
Parent DSAS 8								--	0.18 ($p = 0.04$)
Parent DSAS 9									--

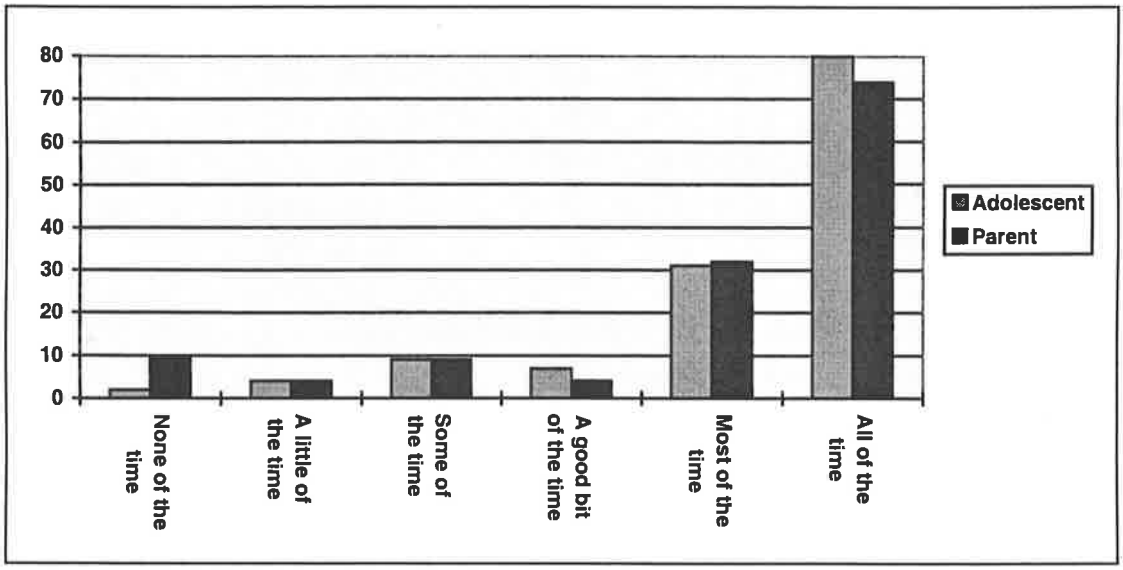
* unless otherwise stated, $p < 0.001$

Appendix B.6: Correlations (with *p* values*) between parent responses to General Adherence Scale items.

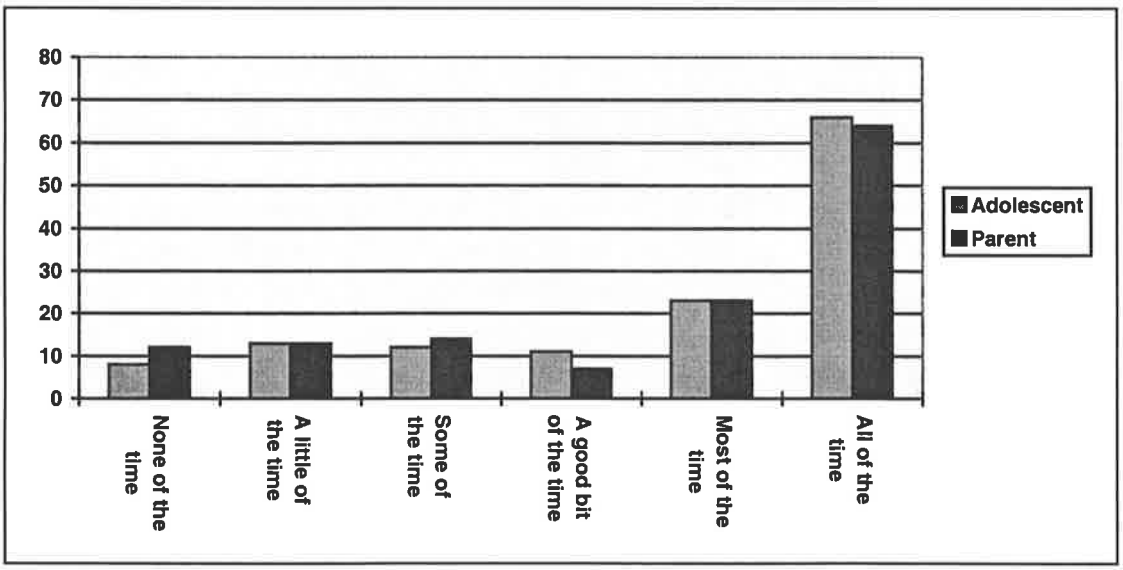
	Parent GAS 1	Parent GAS 2	Parent GAS 3	Parent GAS 4	Parent GAS 5
Parent GAS 1	--	-0.47	0.36	-0.53	-0.35
Parent GAS 2		--	-0.30 ($p = 0.001$)	0.69	0.58
Parent GAS 3			--	-0.29 ($p = 0.001$)	-0.35
Parent GAS 4				--	0.75
Parent GAS 5					--

* unless otherwise stated, $p < 0.001$

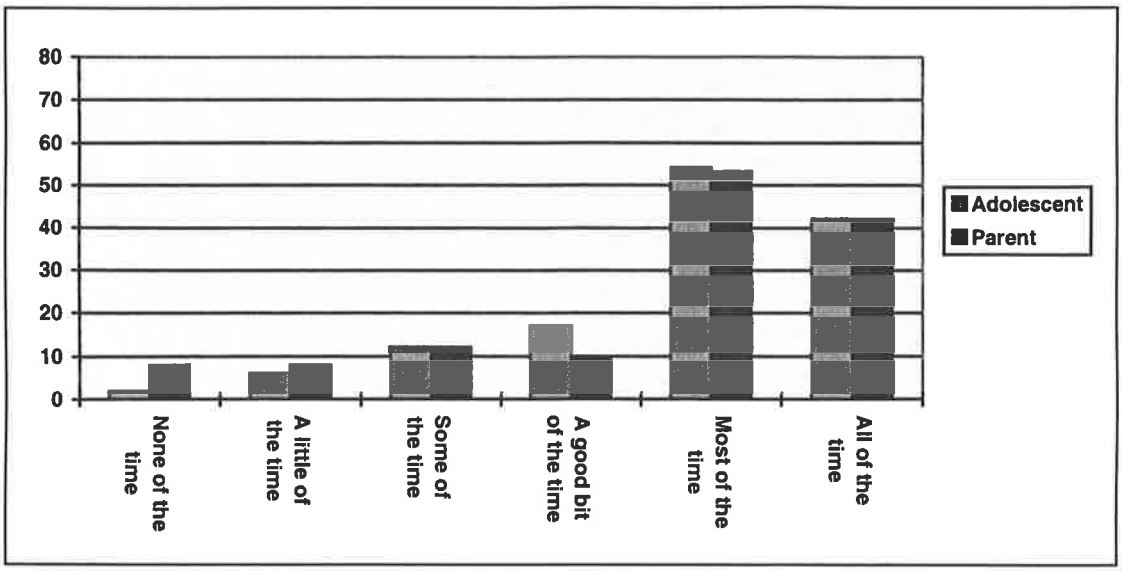
Appendix B.7: Frequency of adolescent and parent responses to each item of the Diabetes Specific Adherence Scale.



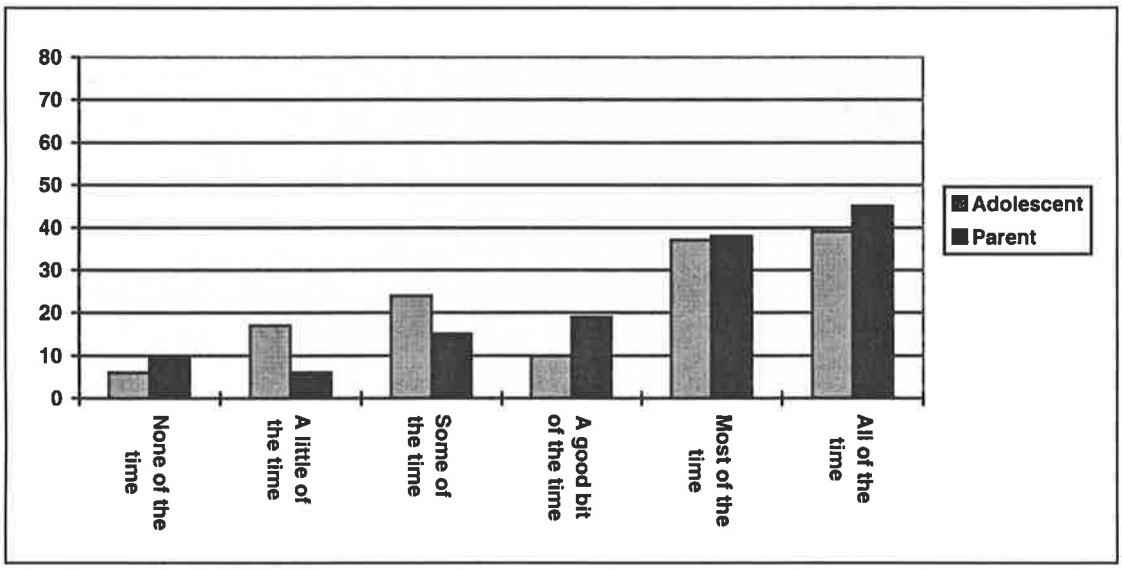
DSAS Item 1: Administered insulin at agreed times.



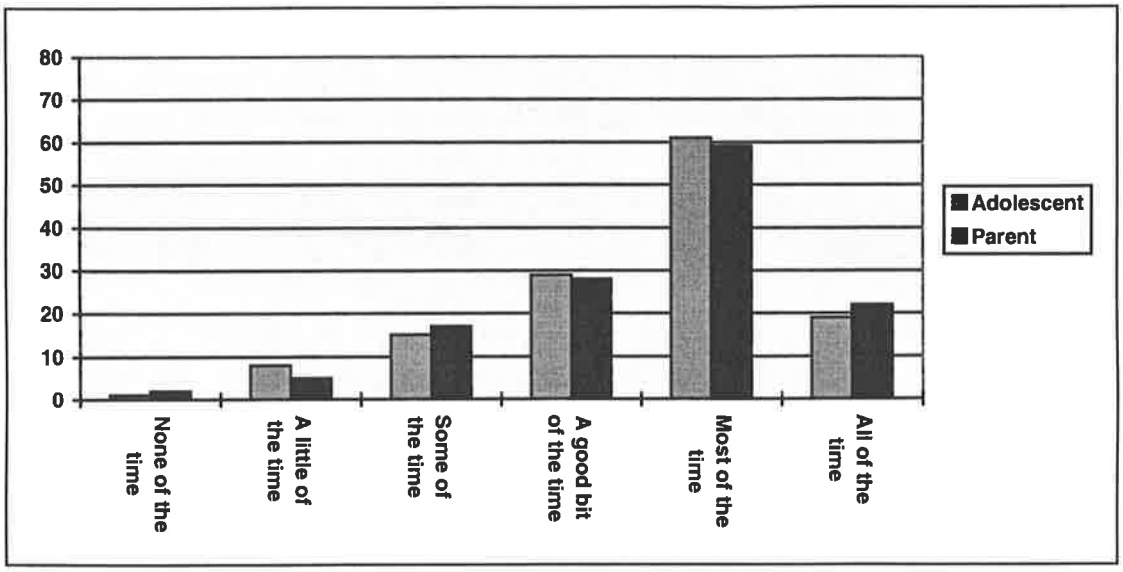
DSAS Item 2: Self-monitored blood glucose at least twice a day.



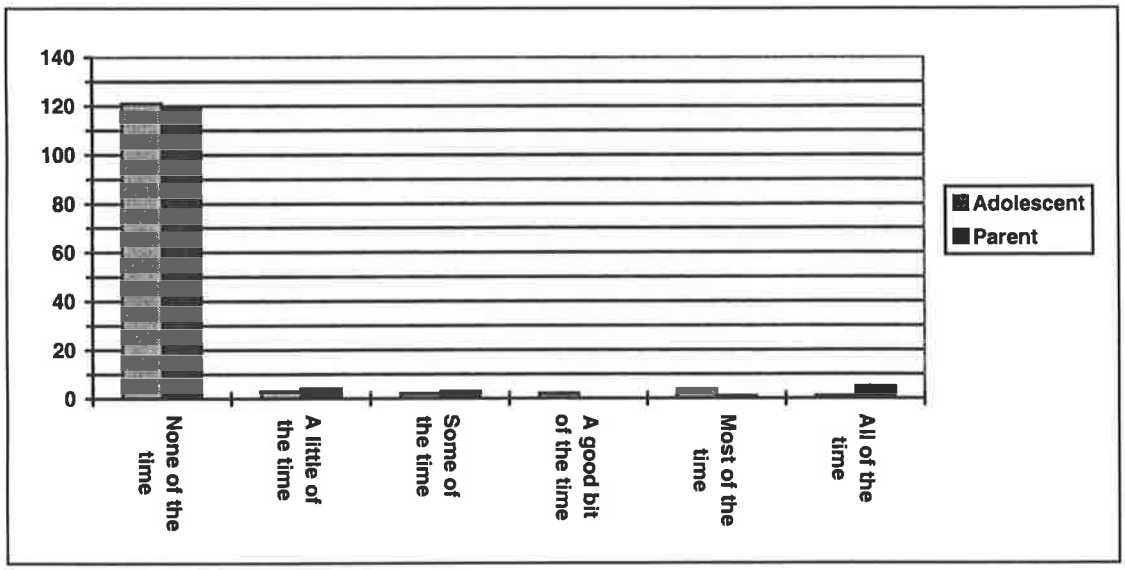
DSAS Item 3: Maintained good foot hygiene



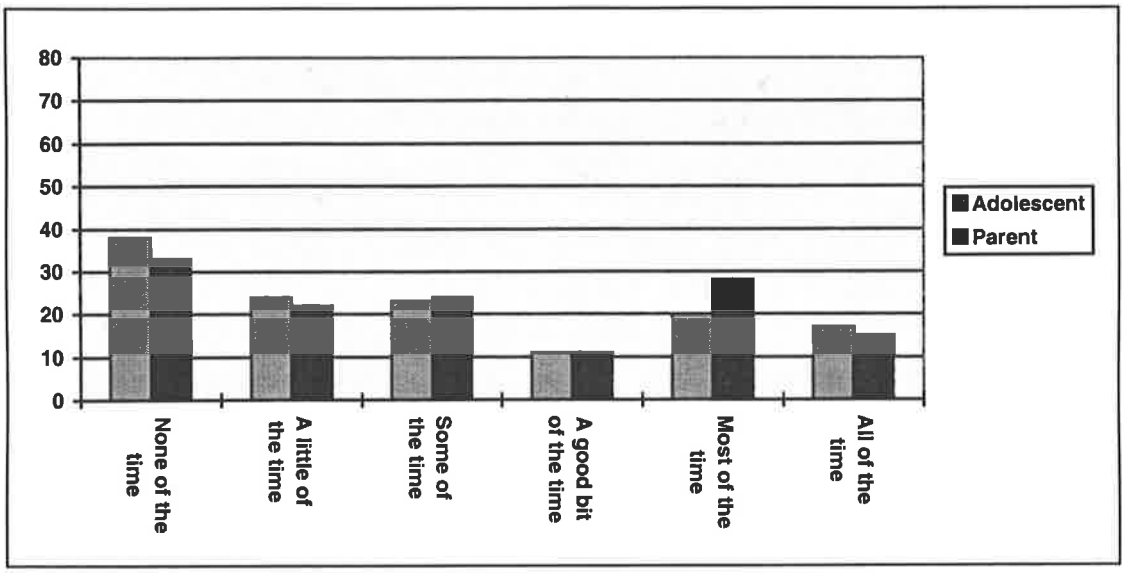
DSAS Item 4: Carried something with sugar in it as a source of glucose for emergencies.



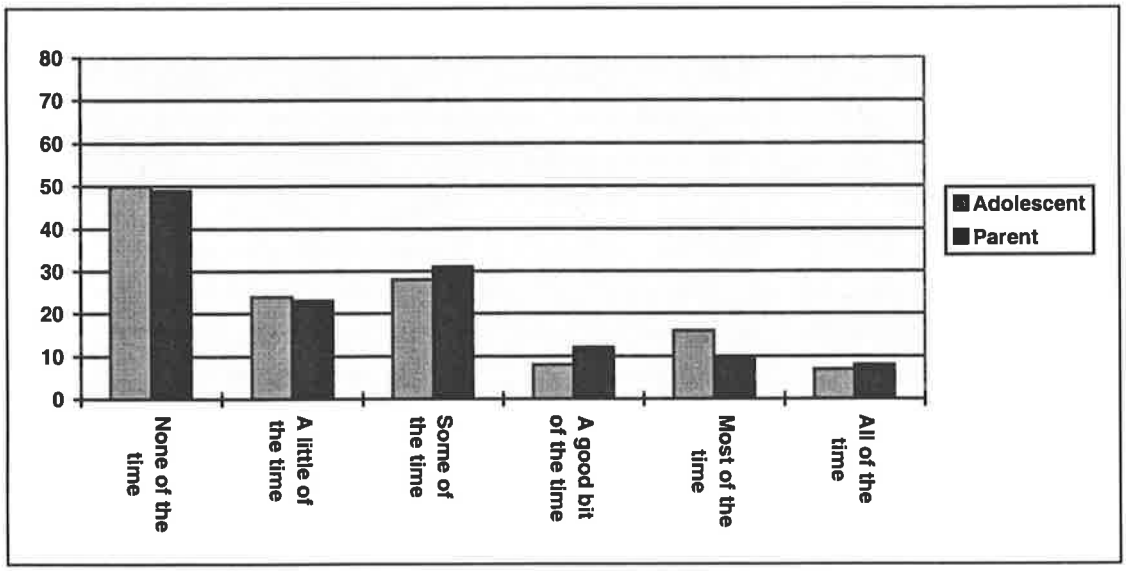
DSAS Item 5: Made Healthy food choices.



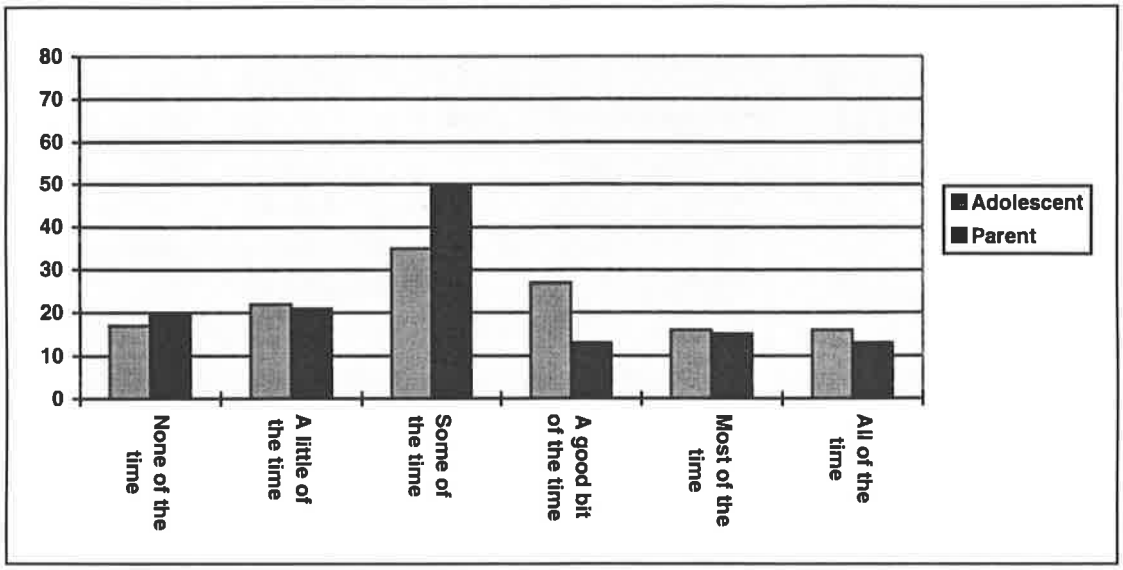
DSAS Item 6: Do you smoke?



DSAS Item 7: Tested ketones when your blood glucose is over 15 or you are unwell.



DSAS Item 8: Self-monitored blood glucose before or after sports.



DSAS Item 9: Do you adjust your insulin doses?

Appendix B.8: Correlations (with *p* values*) between adolescent and parent responses to Diabetes Specific Adherence Scale items

	Parent DSAS 1	Parent DSAS 2	Parent DSAS 3	Parent DSAS 4	Parent DSAS 5	Parent DSAS 6	Parent DSAS 7	Parent DSAS 8	Parent DSAS 9
Adolescent DSAS 1	**0.25 (*p* = 0.004)**	0.13 (*p* = 0.1)	0.17 (*p* = 0.04)	0.18 (*p* = 0.04)	0.19 (*p* = 0.03)	-0.09 (*p* = 0.3)	0.09 (*p* = 0.3)	0.15 (*p* = 0.09)	0.03 (*p* = 0.7)
Adolescent DSAS 2	0.10 (*p* = 0.3)	**0.59**	0.20 (*p* = 0.02)	0.17 (*p* = 0.06)	0.22 (*p* = 0.01)	-0.06 (*p* =0.5)	0.18 (*p* = 0.04)	0.16 (*p* = 0.06)	0.26 (*p* = 0.003)
Adolescent DSAS 3	0.09 (*p* = 0.3)	0.20 (*p* = 0.02)	**0.29 (*p* = 0.001)**	0.13 (*p* = 0.1)	0.21 (*p* = 0.02)	-0.10 (*p* = 0.3)	0.14 (*p* = 0.1)	0.15 (*p* = 0.09)	0.14 (*p* = 0.1)
Adolescent DSAS 4	0.20 (*p* = 0.02)	0.22 (*p* = 0.01)	0.13 (*p* = 0.1)	**0.54**	0.35	-0.22 (*p* = 0.01)	0.04 (*p* = 0.7)	0.23 (*p* = 0.007)	0.14 (*p* = 0.1)
Adolescent DSAS 5	0.13 (*p* = 0.1)	0.22 (*p* = 0.01)	0.10 (*p* = 0.3)	0.31	**0.42**	0.05 (*p* = 0.6)	0.24 (*p* = 0.006)	0.22 (*p* = 0.01)	0.18 (*p* = 0.04)
Adolescent DSAS 6	-0.02 (*p* = 0.9)	0.08 (*p* = 0.3)	-0.06 (*p* = 0.5)	-0.07 (*p* = 0.5)	-0.24 (*p* = 0.006)	**0.34**	-0.06 (*p* = 0.5)	-0.16 (*p* = 0.06)	-0.05 (*p* = 0.6)
Adolescent DSAS 7	-0.006 (*p* = 0.95)	0.15 (*p* = 0.09)	-0.02 (*p* = 0.8)	0.15 (*p* = 0.09)	0.08 (*p* = 0.4)	-0.02 (*p* = 0.8)	**0.56**	0.25 (*p* = 0.004)	0.01 (*p* = 0.9)
Adolescent DSAS 8	0.05 (*p* = 0.5)	0.08 (*p* = 0.4)	0.12 (*p* = 0.2)	0.34	0.30	-0.11 (*p* = 0.2)	0.24 (*p* = 0.006)	**0.52**	-0.01 (*p* = 0.9)
Adolescent DSAS 9	0.07 (*p* = 0.4)	0.09 (*p* = 0.3)	-0.06 (*p* = 0.5)	-0.06 (*p* = 0.5)	-0.04 (*p* = 0.7)	-0.07 (*p* = 0.5)	-0.11 (*p* = 0.2)	0.00 (*p* = 1.0)	**0.42**

* unless otherwise stated, $p < 0.001$

Appendix B.9: Correlations (with *p* values*) between adolescent and parent responses to General Adherence Scale items.

	Parent GAS 1	Parent GAS 2	Parent GAS 3	Parent GAS 4	Parent GAS 5
Adolescent GAS 1	**0.39**	-0.31	0.27 ($p = 0.002$)	-0.30 ($p = 0.001$)	-0.26 ($p = 0.003$)
Adolescent GAS 2	-0.37	**0.42**	-0.32	0.36	0.24 ($p = 0.007$)
Adolescent GAS 3	0.29 ($p = 0.001$)	-0.12 ($p = 0.2$)	**0.20 ($p = 0.03$)**	-0.14 ($p = 0.1$)	-0.03 ($p = 0.7$)
Adolescent GAS 4	-0.23 ($p = 0.009$)	0.31	-0.13 ($p = 0.1$)	**0.36**	0.32
Adolescent GAS 5	-0.18 ($p = 0.04$)	0.30	-0.23 ($p = 0.008$)	0.33	**0.25 ($p = 0.004$)**

* unless otherwise stated, $p < 0.001$

Appendix B.10: Tests of Location of Differences in Correlations of Parent and Adolescent Scores According to Adolescent Age on the Diabetes Specific Adherence Scale.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 12 year old adolescents and 13 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{13}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{13}-3)}}}$$

$$z = \frac{0.172 - 0.377}{\sqrt{\frac{1}{17} + \frac{1}{21}}}$$

$$= \frac{-0.205}{\sqrt{0.107}}$$

$$= -0.63$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 12 year old adolescents and 14 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{14}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{14}-3)}}}$$

$$z = \frac{0.172 - 0.563}{\sqrt{\frac{1}{17} + \frac{1}{22}}}$$

$$= \frac{-0.391}{\sqrt{0.104}}$$

$$= -1.21$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 12 year old adolescents and 15 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{15}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{15}-3)}}}$$

$$z = \frac{0.172 - 0.867}{\sqrt{\frac{1}{17} + \frac{1}{14}}}$$

$$= \frac{-0.695}{\sqrt{0.130}}$$

$$= -1.93$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 12 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{0.172 - 0.829}{\sqrt{\frac{1}{17} + \frac{1}{22}}}$$

$$= \frac{-0.657}{\sqrt{0.104}}$$

$$= -2.04$$

This test result was significant at the $p < 0.05$ level. However, the criterion p level was set at $p < 0.01$ because of the use of multiple tests (see **Section 3.4.3**). The results of this test were not significant at this more stringent level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 12 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.172 - 1.376}{\sqrt{\frac{1}{17} + \frac{1}{21}}}$$

$$= \frac{-1.204}{\sqrt{0.107}}$$

$$= -3.68$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 13 year old adolescents and 14 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{14}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{14}-3)}}}$$

$$z = \frac{0.377 - 0.563}{\sqrt{\frac{1}{22} + \frac{1}{21}}}$$

$$= \frac{-0.186}{\sqrt{0.093}}$$

$$= -0.61$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 13 year old adolescents and 15 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{15}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{15}-3)}}}$$

$$z = \frac{0.377 - 0.867}{\sqrt{\frac{1}{21} + \frac{1}{14}}}$$

$$= \frac{-0.490}{\sqrt{0.119}}$$

$$= -1.42$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 13 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{0.377 - 0.829}{\sqrt{\frac{1}{21} + \frac{1}{22}}}$$

$$= \frac{-0.452}{\sqrt{0.093}}$$

$$= -1.48$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 13 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.377 - 1.376}{\sqrt{\frac{1}{21} + \frac{1}{21}}}$$

$$= \frac{-0.999}{\sqrt{0.096}}$$

$$= -3.22$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 14 year old adolescents and 15 year old adolescents:

$$z = \frac{z_{r_{14}} - z_{r_{15}}}{\sqrt{\frac{1}{(n_{14}-3)} + \frac{1}{(n_{15}-3)}}}$$

$$z = \frac{0.563 - 0.867}{\sqrt{\frac{1}{22} + \frac{1}{14}}}$$

$$= \frac{-0.304}{\sqrt{0.116}}$$

$$= -0.89$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 14 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{14}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{14}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{0.563 - 0.829}{\sqrt{\frac{1}{22} + \frac{1}{22}}}$$

$$= \frac{-0.266}{\sqrt{0.090}}$$

$$= -0.89$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 14 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{14}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{14}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.563 - 1.376}{\sqrt{\frac{1}{22} + \frac{1}{21}}}$$

$$= \frac{-0.813}{\sqrt{0.093}}$$

$$= -2.67$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 15 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{15}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{15}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{0.867 - 0.829}{\sqrt{\frac{1}{14} + \frac{1}{22}}}$$

$$= \frac{0.038}{\sqrt{0.116}}$$

$$= 0.11$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 15 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{15}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{15}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.867 - 1.376}{\sqrt{\frac{1}{14} + \frac{1}{21}}}$$

$$= \frac{-0.509}{\sqrt{0.119}}$$

$$= -1.48$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the DSAS for samples of 16 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{16}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{16}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.829 - 1.376}{\sqrt{\frac{1}{22} + \frac{1}{21}}}$$

$$= \frac{-0.547}{\sqrt{0.093}}$$

$$= -1.79$$

This test result is not significant at the $p < 0.01$ level.

A summary of the results of these tests is provided in **Table 5.11.**

Appendix B.11: Pearson correlations (with *p* values*) between adolescent age level and questionnaire measures of adherence.

	Adolescent Age level	Adolescent GAS	Adolescent DSAS	Parent GAS	Parent DSAS
Adolescent Age level	--	- 0.13 ($p = 0.3$)	- 0.26 ($p = 0.02$)	- 0.20 ($p = 0.09$)	- 0.15 ($p = 0.2$)
Adolescent GAS		--	0.54	0.38 ($p = 0.001$)	0.22 ($p = 0.06$)
Adolescent DSAS			--	0.39 ($p = 0.001$)	0.54
Parent GAS				--	0.49
Parent DSAS					--

* unless otherwise stated, $p < 0.001$

Appendix B.12: One-way Analyses of Variance of adherence reports in relation to adolescent age.

Source	SS	df	MS	F*
Adolescent GAS				
Between Groups	34.941	5	6.988	0.284
Within Groups	1627..059	66	24.652	
TOTAL	1662.000	71		
Adolescent DSAS				
Between Groups	260.959	5	52.192	1.432
Within Groups	2514.161	69	36.437	
TOTAL	2775.120	74		
Parent GAS				
Between Groups	86.966	5	17.393	0.724
Within Groups	1658.821	69	24.042	
TOTAL	1745.787	74		
Parent DSAS				
Between Groups	168.091	5	33.618	0.787
Within Groups	2948.790	69	42.736	
TOTAL	3116.880	74		

* *p* not significant unless otherwise stated.

Appendix B.13: Trend analysis of blood glucose monitoring data, using four-day blocks.

The mean square corresponding to the quadratic comparison is

$$MS_{quad} = \frac{C_{quad}^2}{n\sum c^2}$$

$$MS_{quad} = \frac{(383)^2}{(74)(84)}$$
$$= 23.60$$

A test on whether or not the quadratic trend adds significant predictability beyond that given by the linear trend employs the statistic

$$F = \frac{MS_{quad}}{MS_{res}}$$

$$F = \frac{23.60}{6.44}$$
$$= 3.66$$

The sampling distribution of this statistic (assuming no quadratic trend) may be approximated by an F distribution having (1,432) degrees of freedom. The critical value when $\alpha = 0.05$ is 3.86. Hence, the data indicate that, within the range of blocks included in this study, the quadratic comparison does not add significant predictability to that given by the linear trend.

The total variation between blocks, calculated in the repeated measures ANOVA, is 217.09 (**Table 5.27**). Of this total, 209.72 is accounted for by the linear and quadratic

trends. The remaining between-block variation appears negligible relative to experimental error. The between block variation due to higher-order trend components is

$$SS_{higher\ order} = SS_{blocks} - SS_{lin} - SS_{quad}$$
$$= 7.37$$

The corresponding mean square is

$$MS_{higher\ order} = \frac{7.37}{2}$$
$$= 3.69$$

The F ratio in the test for trend components higher than the quadratic trend is

$$F = \frac{MS_{higher\ order}}{MS_{res}}$$

$$F = \frac{3.69}{6.44}$$
$$= 0.57$$

Again, since this ratio is less than 1, the data indicate that no component higher than the quadratic is relevant (Winer, 1971).

Appendix B.14: Trend analysis of blood glucose monitoring data, using seven-day blocks.

The mean square corresponding to the linear comparison is calculated as

$$MS_{lin} = \frac{C_{lin}^2}{n\sum c^2}$$

$$MS_{lin} = \frac{(679)^2}{(74)(20)}$$
$$= 311.51$$

The test of significance for the linear trend is calculated by the F ratio

$$F = \frac{MS_{lin}}{MS_{res}}$$

$$F = \frac{311.51}{12.91}$$
$$= 24.13$$

The sampling distribution of this statistic (assuming no linear trend) may be approximated by an F distribution having (1,216) degrees of freedom. The linear trend is significant beyond the 0.01 level.

The mean square corresponding to the quadratic comparison is

$$MS_{quad} = \frac{C_{quad}^2}{n\sum c^2}$$

$$MS_{quad} = \frac{(79)^2}{(74)(4)}$$
$$= 21.08$$

A test on whether or not the quadratic trend adds significant predictability beyond that given by the linear trend employs the statistic

$$F = \frac{MS_{quad}}{MS_{res}}$$

$$F = \frac{21.08}{12.91}$$
$$= 1.63$$

The sampling distribution of this statistic (assuming no quadratic trend) may be approximated by an F distribution having (1,216) degrees of freedom. The quadratic comparison does not add significant predictability to that given by the linear trend.

The total variation between blocks, calculated in the repeated measures ANOVA, is 348.42 (**Table 5.29**). Of this total, 332.59 is accounted for by the linear and quadratic trends. The remaining between-block variation appears negligible relative to experimental error. The between block variation due to higher-order trend components is

$$SS_{higher\ order} = SS_{blocks} - SS_{lin} - SS_{quad}$$
$$= 15.83$$

The corresponding mean square is

$$MS_{higher\ order} = \frac{15.83}{2}$$
$$= 7.92$$

The F ratio in the test for trend components higher than the quadratic trend is

$$F = \frac{MS_{higher\ order}}{MS_{res}}$$

$$F = \frac{7.92}{12.91}$$
$$= 0.61$$

Since this ratio is less than 1, the data indicate that no component higher than the quadratic is relevant (Winer, 1971).

APPENDIX C.

Appendix C.1: Frequency of adolescent response options to items of the Diabetes Specific Adherence Scale.

1. Administered insulin at the agreed times.	2 None of the time	4 A little of the time	9 Some of the time	7 A good bit of the time	31 Most of the time	80 All of the time
2. Self monitored blood glucose at least twice a day.	8 None of the time	13 A little of the time	12 Some of the time	11 A good bit of the time	23 Most of the time	66 All of the time
3. Maintained good foot hygiene.	2 None of the time	6 A little of the time	12 Some of the time	17 A good bit of the time	54 Most of the time	42 All of the time
4. Carried something with sugar in it as a source of glucose for emergencies.	6 None of the time	17 A little of the time	24 Some of the time	10 A good bit of the time	37 Most of the time	39 All of the time
5. Made healthy food choices.	1 None of the time	8 A little of the time	15 Some of the time	29 A good bit of the time	61 Most of the time	19 All of the time
6. Do you smoke?	121 None of the time	3 A little of the time	2 Some of the time	2 A good bit of the time	4 Most of the time	1 All of the time
7. Tested ketones when your blood glucose is over 15 or when you are unwell.	38 None of the time	24 A little of the time	23 Some of the time	11 A good bit of the time	20 Most of the time	17 All of the time
8. Self monitored blood glucose before or after sports.	50 None of the time	24 A little of the time	28 Some of the time	8 A good bit of the time	16 Most of the time	7 All of the time
9. Do you adjust your insulin doses?	17 None of the time	22 A little of the time	35 Some of the time	27 A good bit of the time	16 Most of the time	16 All of the time

Appendix C.2: Frequency of parent response options to items of the Diabetes Specific Adherence Scale.

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Administered insulin at the agreed times.	10	4	9	4	32	74
2. Self monitored blood glucose at least twice a day.	12	13	14	7	23	64
3. Maintained good foot hygiene.	8	8	12	10	53	42
4. Carried something with sugar in it as a source of glucose for emergencies.	10	6	15	19	38	45
5. Made healthy food choices.	2	5	17	28	59	22
6. Do you smoke?	120	4	3	0	1	5
7. Tested ketones when your blood glucose is over 15 or when you are unwell.	33	22	24	11	28	15
8. Self monitored blood glucose before or after sports.	49	23	31	12	10	8
9. Do you adjust your insulin doses?	20	21	50	13	15	13

APPENDIX D.

Appendix D.1: The Level of Agreement Between Adolescent and Parent Reports of Parent-Adolescent Conflict.

The first analyses presented in this appendix examined the level of association between adolescent responses and parent responses on the Conflict Behaviour Questionnaire. A combined score, summing the responses of adolescents and their parents, is also related to these measures. Pearson correlations between these reports are presented in **Table D.1**. The very high correlations between the adolescent completed CBQ and parent completed CBQ with the combined measure are not surprising given that the combined measure is the sum of the two individual measures. The strong correlation between the adolescent and parent completed versions of the CBQ ($r = 0.39$) provides support for the interrater reliability of this measure.

Table D.1 Pearson correlations between adolescent reports, parent reports, and combined adolescent and parent reports of parent-adolescent conflict.

	Combined CBQ	Adolescent CBQ	Parent CBQ
Combined CBQ	--	0.77	0.89
Adolescent CBQ		--	0.39
Parent CBQ			--

Note: unless otherwise stated, $p < 0.001$

Appendix D.2: Variation in Parent-Adolescent Agreement on the Conflict Behaviour Questionnaire According to Adolescent Age.

Parent-adolescent agreement on the CBQ appeared to differ depending on the age of the adolescent. A statistical test for differences between correlations across the six age strata (12 year olds, 13 year olds, 14 year olds, 15 year olds, 16 year olds and 17 year olds) was conducted (Snedecor and Cochran, 1980). **Table D.2** displays the tests of significance of differences between correlations amongst different adolescent age groups.

Table D.2: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Conflict Behaviour Questionnaire according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	18	15	0.464	0.497	7.455	3.705
13 year old	23	20	0.900	1.472	29.440	43.336
14 year old	24	21	0.357	0.377	7.917	2.985
15 year old	16	13	-0.019	-0.020	-0.260	0.005
16 year old	23	20	0.111	0.110	2.200	0.242
17 year old	23	20	0.296	0.310	6.200	1.922
Total		109			52.952	52.195

Following the methodology described in **Section 5.2.1**, and outlined in Snedecor and Cochran (1980), the correlation coefficients were converted to z scores, and (n - 3) values calculated. The test of significance is performed as a Chi-square analysis:

$$\chi^2 = \sum (n-3)z^2 - \frac{\left[\sum (n-3)z\right]^2}{\sum (n-3)}$$

$$\chi^2 = 52.195 - \frac{[52.952]^2}{109}$$
$$= 26.471$$

With 5 degree of freedom, $p < 0.005$. Therefore a significant variation in parent-adolescent agreement on the CBQ was observed.

In order to determine the location of the difference, further tests were performed to examine the difference between correlations. Ferguson and Takane (1989) give the formula for testing the significance of the difference between two correlation coefficients for independent samples as:

$$z = \frac{z_{r_1} - z_{r_2}}{\sqrt{\frac{1}{(n_1 - 3)} + \frac{1}{(n_2 - 3)}}}$$

To determine the location of the differences in parent-adolescent score correlations on the CBQ according to adolescent age, this test was applied between the correlations produced by each of the six age strata. Because of the use of multiple tests, the criterion value was set at $p < 0.01$ (see **Section 3.4.3**).

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 12 year old adolescents and 13 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{13}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{13}-3)}}}$$

$$z = \frac{0.497 - 1.472}{\sqrt{\frac{1}{15} + \frac{1}{20}}}$$

$$= \frac{-0.975}{\sqrt{0.117}}$$

$$= -2.85$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 12 year old adolescents and 14 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{14}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{14}-3)}}}$$

$$z = \frac{0.497 - 0.377}{\sqrt{\frac{1}{15} + \frac{1}{21}}}$$

$$= \frac{0.120}{\sqrt{0.115}}$$

$$= 0.35$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 12 year old adolescents and 15 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{15}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{15}-3)}}}$$

$$z = \frac{0.497 - (-0.020)}{\sqrt{\frac{1}{15} + \frac{1}{13}}}$$

$$= \frac{0.517}{\sqrt{0.144}}$$

$$= 1.36$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 12 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{0.497 - 0.110}{\sqrt{\frac{1}{15} + \frac{1}{20}}}$$

$$= \frac{0.387}{\sqrt{0.117}}$$

$$= 1.13$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 12 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{12}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{12}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.497 - 0.310}{\sqrt{\frac{1}{15} + \frac{1}{20}}}$$

$$= \frac{0.187}{\sqrt{0.117}}$$

$$= 0.55$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 13 year old adolescents and 14 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{14}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{14}-3)}}}$$

$$z = \frac{1.472 - 0.377}{\sqrt{\frac{1}{20} + \frac{1}{21}}}$$

$$= \frac{1.095}{\sqrt{0.098}}$$

$$= 3.50$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 13 year old adolescents and 15 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{15}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{15}-3)}}}$$

$$z = \frac{1.472 - (-0.020)}{\sqrt{\frac{1}{20} + \frac{1}{13}}}$$

$$= \frac{1.492}{\sqrt{0.127}}$$

$$= 4.19$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 13 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{1.472 - 0.110}{\sqrt{\frac{1}{20} + \frac{1}{20}}}$$

$$= \frac{1.362}{\sqrt{0.100}}$$

$$= 4.31$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 13 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{13}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{13}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{1.472 - 0.310}{\sqrt{\frac{1}{20} + \frac{1}{20}}}$$

$$= \frac{1.162}{\sqrt{0.100}}$$

$$= 3.68$$

This test result is significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 14 year old adolescents and 15 year old adolescents:

$$z = \frac{z_{r_{14}} - z_{r_{15}}}{\sqrt{\frac{1}{(n_{14}-3)} + \frac{1}{(n_{15}-3)}}}$$

$$z = \frac{0.377 - (-0.020)}{\sqrt{\frac{1}{21} + \frac{1}{13}}}$$

$$= \frac{0.397}{\sqrt{0.125}}$$

$$= 1.12$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 14 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{14}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{14}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{0.377 - 0.110}{\sqrt{\frac{1}{21} + \frac{1}{20}}}$$

$$= \frac{0.267}{\sqrt{0.098}}$$

$$= 0.85$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 14 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{14}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{14}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.377 - 0.310}{\sqrt{\frac{1}{21} + \frac{1}{20}}}$$

$$= \frac{0.067}{\sqrt{0.098}}$$

$$= 0.21$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 15 year old adolescents and 16 year old adolescents:

$$z = \frac{z_{r_{15}} - z_{r_{16}}}{\sqrt{\frac{1}{(n_{15}-3)} + \frac{1}{(n_{16}-3)}}}$$

$$z = \frac{(-0.020) - 0.110}{\sqrt{\frac{1}{13} + \frac{1}{20}}}$$

$$= \frac{-0.130}{\sqrt{0.127}}$$

$$= -0.37$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 15 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{15}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{15}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{(-0.020) - 0.310}{\sqrt{\frac{1}{13} + \frac{1}{20}}}$$

$$= \frac{-0.330}{\sqrt{0.127}}$$

$$= -0.93$$

This test result is not significant at the $p < 0.01$ level.

Test of the difference between correlation coefficients between parent and adolescent scores on the CBQ for samples of 16 year old adolescents and 17 year old adolescents:

$$z = \frac{z_{r_{16}} - z_{r_{17}}}{\sqrt{\frac{1}{(n_{16}-3)} + \frac{1}{(n_{17}-3)}}}$$

$$z = \frac{0.110 - 0.310}{\sqrt{\frac{1}{20} + \frac{1}{20}}}$$

$$= \frac{-0.200}{\sqrt{0.100}}$$

$$= -0.63$$

This test result is not significant at the $p < 0.01$ level.

A summary of the results of these tests is provided in **Table D.3**.

Table D.3: Summary of results of tests of differences between correlations of parent-adolescent agreement on the Conflict Behaviour Questionnaire according to adolescents' age strata.

	12 year olds	13 year olds	14 year olds	15 year olds	16 year olds	17 year olds
12 year old adolescents	--	$p < 0.01$	n.s.	n.s.	n.s.	n.s.
13 year old adolescents		--	$p < 0.01$	$p < 0.01$	$p < 0.01$	$p < 0.01$
14 year old adolescents			--	n.s.	n.s.	n.s.
15 year old adolescents				--	n.s.	n.s.
16 year old adolescents					--	n.s.
17 year old adolescents						--

Appendix D.3: Variation in Parent-Adolescent Agreement on the Conflict Behaviour Questionnaire According to Adolescent Gender.

Parent-adolescent agreement on the CBQ appeared to differ depending on the gender of the adolescent. A statistical test for differences between the correlations of parent-adolescent agreement obtained from dyads with male and female adolescents was conducted (Snedecor and Cochran, 1980). **Table D.4** displays the test of significance of differences between correlations.

Table D.4: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Conflict Behaviour Questionnaire according to adolescent gender.

Adolescent gender	n	$(n - 3)$	r	z	$1/(n-3)$
Male	58	55	0.552	0.618	0.018
Female	69	66	0.272	0.277	0.015
			D =	0.341	Sum = 0.033

As outlined in Snedecor and Cochran (1980) and in **Section 8.2.2.3** of this thesis, the test of significance between two correlation coefficients is calculated from the formula

$$t = D/\sigma_D$$

$$t = 0.341/\sqrt{0.033}$$
$$= 1.874$$

This results is not significant, suggesting that parent-adolescent agreement on the CBQ is not varied according to the gender of the adolescent.

Appendix D.4: Frequency of response options to items of the Conflict Behaviour Questionnaire: Adolescent responses to mother version.

	True	False
1. My mum doesn't understand me.	32	84
2. My mum and I sometimes end our arguments calmly.	102	13
3. My mum understands me.	91	25
4. We almost never seem to agree.	33	83
5. I enjoy the talks we have.	97	18
6. When I state my own opinion, she gets upset.	40	76
7. At least three times a week, we get angry at each other.	50	66
8. My mother listens when I need someone to talk to.	99	16
9. My mum is a good friend to me.	101	15
10. She says I have no consideration for her.	28	88

11. At least once a day we get angry at each other.	18 **True**	98 **False**
12. My mother is bossy when we talk.	30 **True**	86 **False**
13. The talks we have are frustrating.	39 **True**	77 **False**
14. My mum understands my point of view, even when she doesn't agree with me.	80 **True**	35 **False**
15. My mum seems to be always complaining about me.	29 **True**	86 **False**
16. In general, I don't think we get along very well.	13 **True**	103 **False**
17. My mum screams a lot.	22 **True**	94 **False**
18. My mum puts me down.	10 **True**	105 **False**
19. If I run into problems, my mum helps me out.	104 **True**	12 **False**
20. I enjoy spending time with my mother.	99 **True**	17 **False**

Appendix D.5: Frequency of response options to items of the Conflict Behaviour Questionnaire: Adolescent responses to father version.

1. My dad doesn't understand me.	4 True	12 False
2. My dad and I sometimes end our arguments calmly.	14 True	2 False
3. My dad understands me.	13 True	3 False
4. We almost never seem to agree.	4 True	12 False
5. I enjoy the talks we have.	14 True	2 False
6. When I state my own opinion, he gets upset.	5 True	11 False
7. At least three times a week, we get angry at each other.	7 True	9 False
8. My father listens when I need someone to talk to.	13 True	3 False
9. My dad is a good friend to me.	14 True	2 False
10. He says I have no consideration for him.	5 True	11 False

11. At least once a day we get angry at each other.	3 True	13 False
12. My father is bossy when we talk.	5 True	11 False
13. The talks we have are frustrating.	2 True	14 False
14. My dad understands my point of view, even when he doesn't agree with me.	8 True	8 False
15. My dad seems to be always complaining about me.	3 True	13 False
16. In general, I don't think we get along very well.	2 True	14 False
17. My dad screams a lot.	2 True	14 False
18. My dad puts me down.	2 True	14 False
19. If I run into problems, my dad helps me out.	15 True	1 False
20. I enjoy spending time with my father.	14 True	2 False

Appendix D.6: Frequency of response options to items of the Conflict Behaviour Questionnaire: Parent responses

	True	False
1. My child is easy to get along with.	111	20
2. My child is receptive to criticism.	79	53
3. My child is well behaved in our discussions.	114	18
4. For the most part, my child likes to talk to me.	119	13
5. We almost never seem to agree.	37	95
6. My child usually listens to what I tell him/her.	108	24
7. At least three time a week, we get angry at each other.	60	72
8. My child says that I have no consideration of his/her feelings.	39	93
9. My child and I compromise during arguments.	104	28
10. My child often doesn't do what I ask.	43	87

11. The talks we have are frustrating.	45 **True**	86 **False**
12. My child often seems angry at me.	40 **True**	92 **False**
13. My child acts impatient when I talk.	58 **True**	74 **False**
14. In general, I don't think we get along very well.	15 **True**	116 **False**
15. My child almost never understands my side of an argument.	28 **True**	104 **False**
16. My child and I have big arguments over little things.	25 **True**	107 **False**
17. My child is defensive when I talk to him/her.	47 **True**	85 **False**
18. My child thinks my opinions don't count.	24 **True**	108 **False**
19. We argue a lot about rules.	27 **True**	105 **False**
20. My child tells me s/he thinks I am unfair.	47 **True**	85 **False**

Appendix D.7: Variation in Parent-Adolescent Agreement on the Conflict Behaviour Questionnaire According to Parental Work-Status.

To determine whether the level of parent-adolescent agreement on the Conflict Behaviour Questionnaire varied depending upon whether the participating parent was working primarily in the home or outside the home, a statistical test for differences between correlations was conducted. **Table D.5** displays the results of this test.

Table D.5: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Conflict Behaviour Questionnaire according to parental work-status.

Parental work	n	$(n-3)$	r	z	$1/(n-3)$
At home	60	57	0.339	0.354	0.017
Out of home	66	63	0.429	0.460	0.016
			D =	0.814	Sum = 0.033

As outlined in Snedecor and Cochran (1980), the test of significance between two correlation coefficients is calculated according to the formula

$$t = D/\sigma_D$$

$$t = 0.814/\sqrt{0.033}$$
$$= 4.473$$

This result is significant at the $p < 0.05$ level. This result indicates that the level of agreement between adolescent and parent reports of parent-adolescent conflict was significantly greater amongst the parent-adolescent dyads where the parent worked

primarily outside the home, than in those dyads where the parent was primarily in the home.

APPENDIX E.

Appendix E.1: Associations Between the Measures of Adherence and the Measures of Conflict According to Whether or not Blood Glucose Monitoring Data was Obtained.

Table E.1: Pearson correlations between adolescent, parent, and combined reports of parent-adolescent conflict, and adolescent and parent completed measures of adherence, for sample providing BGM data (n = 75).

	Adolescent Report		Parent Report	
	GAS	DSAS	GAS	DSAS
Adolescent CBQ	-0.35 (p = 0.004)	-0.28 (p = 0.02)	-0.32 (p = 0.006)	-0.14 (p = 0.2)
Parent CBQ	-0.16 (p = 0.2)	-0.08 (p = 0.5)	-0.34 (p = 0.003)	-0.15 (p = 0.2)
Combined CBQ	-0.28 (p = 0.02)	-0.22 (p = 0.07)	-0.38 (p = 0.001)	-0.20 (p = 0.1)

Note: unless otherwise stated, $p < 0.001$

Table E.2: Pearson correlations between adolescent, parent, and combined reports of parent-adolescent conflict, and adolescent and parent completed measures of adherence, for sample not providing BGM data (n = 60).

	Adolescent Report		Parent Report	
	GAS	DSAS	GAS	DSAS
Adolescent CBQ	-0.20 (p = 0.1)	-0.22 (p = 0.09)	-0.34 (p = 0.01)	-0.35 (p = 0.007)
Parent CBQ	-0.39 (p = 0.003)	-0.09 (p = 0.5)	-0.38 (p = 0.003)	-0.25 (p = 0.06)
Combined CBQ	-0.37 (p = 0.005)	-0.16 (p = 0.23)	-0.41 (p = 0.002)	-0.33 (p = 0.01)

Note: unless otherwise stated, $p < 0.001$

APPENDIX F.

Appendix F.1: The Level of Agreement Between Adolescent and Parent Reports of Autonomy.

The first analyses presented in this chapter examine the level of association between adolescent responses and parent responses on the AFC. Pearson correlations were employed for this analysis. **Table F.1** displays the correlation coefficients for these analyses. The correlation between adolescent and parent scores on the total AFC scale was high, as were the correlations between adolescent and parent responses on each of the subscales.

Table F.1: Pearson correlations between adolescent completed and parent completed subscales of the Autonomous Functioning Checklist.

Autonomous Functioning Checklist	Adolescent Report (Mean ± *SD*)	Parent Report (Mean ± *SD*)	*r*	*p*
Total score	122.1 ± 29.6	114.8 ± 30.1	0.50	< 0.001
Subscales				
Self- & Family Care	33.2 ± 12.7	30.3 ± 12.2	0.53	< 0.001
Management Activity	50.3 ± 13.0	48.9 ± 13.9	0.54	< 0.001
Recreational Activity	27.8 ± 9.7	26.8 ± 8.6	0.28	0.001
Social / Vocational Activity	10.0 ± 3.2	8.7 ± 3.6	0.60	< 0.001

This result provides support for the interrater reliability of the AFC between adolescent and parent respondents. Previous studies employing the AFC have not examined this psychometric property of the scale. Sigafoos et al (1988) examined the interrater reliability of the AFC among fifty-two two-parent dyads, and found Pearson correlations of a similar magnitude to those reported in **Table F.1**. These results were

interpreted as supportive of the interrater reliability of the measure. The authors suggested that the coefficients underestimated the interrater reliability of the measure because of the naturally occurring variations in perceptions of autonomy held by the parents. The same interpretation may be made of the data reported here - the correlations between adolescent and parent responses were high, but the differences between the scores are likely to reflect the naturally different views of the respondents, rather than a weakness of the measure.

Appendix F.2: Variation in Parent-Adolescent Agreement on the Autonomous Functioning Checklist According to Adolescent Age.

Parent-adolescent agreement on the AFC appeared to differ depending on the age of the adolescent. A statistical test for differences between correlations across the six age strata (12 year olds, 13 year olds, 14 year olds, 15 year olds, 16 year olds and 17 year olds) was conducted (Snedecor and Cochran, 1980). Due to the use of multiple tests, the criterion value was set at $p < 0.01$ (see **Section 3.4.3**). **Tables F.2** through **F.6** display the tests of significance of differences between correlations amongst different adolescent demographic criteria.

The first of these analyses examined the variation in parent-adolescent agreement in AFC total scores according to adolescent age. **Table F.2** displays the details of this test.

Table F.2: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Autonomous Functioning Checklist according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	18	15	0.323	0.332	4.980	1.653
13 year old	23	20	0.468	0.510	10.200	5.202
14 year old	23	20	0.414	0.436	8.720	3.802
15 year old	16	13	0.411	0.436	5.668	2.471
16 year old	23	20	0.575	0.662	13.240	8.765
17 year old	23	20	0.361	0.377	7.540	2.843
Total		108			50.348	24.736

Following the methodology described in **Section 5.2.1**, and outlined in Snedecor and Cochran (1980), the correlation coefficients were converted to z scores, and (n - 3) values calculated. The test of significance is performed as a Chi-square analysis:

$$\chi^2 = \sum (n-3)z^2 - \frac{\left[\sum (n-3)z\right]^2}{\sum (n-3)}$$

$$\chi^2 = 24.736 - \frac{[50.348]^2}{108}$$

$$= 1.265$$

This result was not statistically significant.

The next analysis examined parent-adolescent agreement on the first AFC subscale, 'Self- and Family-Care,' according to adolescent age (**Table F.3**).

Table F.3: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Self- and Family-Care,' according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	20	17	0.536	0.604	10.268	6.202
13 year old	23	20	0.304	0.310	6.200	1.922
14 year old	25	22	0.378	0.400	8.800	3.520
15 year old	16	13	0.586	0.678	8.814	5.976
16 year old	24	21	0.577	0.662	13.902	9.203
17 year old	23	20	0.567	0.648	12.960	8.398
Total		113			60.944	35.221

$$\chi^2 = \sum (n-3)z^2 - \frac{\left[\sum (n-3)z\right]^2}{\sum (n-3)}$$

$$\chi^2 = 35.221 - \frac{[60.944]^2}{113}$$
$$= 2.352$$

This result was not statistically significant.

Next the analysis was performed to examine parent-adolescent agreement on the second AFC subscale, 'Management Activity' according to adolescent age (**Table F.4**).

Table F.4: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Management Activity,' according to adolescent age.

Adolescent Age	*n*	*(n - 3)*	*r*	*z*	Weighted *z* = *(n - 3)z*	Weighted Square = $(n - 3)z^2$
12 year old	18	15	0.079	0.080	1.200	0.096
13 year old	24	21	0.534	0.590	12.390	7.310
14 year old	24	21	0.359	0.377	7.917	2.985
15 year old	17	14	0.237	0.245	3.430	0.840
16 year old	24	21	0.599	0.693	14.553	10.085
17 year old	24	21	0.416	0.448	9.408	4.215
Total		113			48.898	25.531

$$\chi^2 = 25.531 - \frac{[48.898]^2}{113}$$
$$= 4.372$$

This result was not statistically significant at the $p < 0.01$ level.

The analysis was next performed on the third subscale of the AFC, 'Recreational Activity' (**Table F.5**).

Table F.5: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Recreational Activity,' according to adolescent age.

Adolescent Age	*n*	*(n - 3)*	*r*	*z*	Weighted *z* = *(n - 3)z*	Weighted Square = $(n - 3)z^2$
12 year old	20	17	0.313	0.321	5.457	1.752
13 year old	24	21	0.351	0.365	7.665	2.798
14 year old	23	20	0.257	0.266	5.320	1.415
15 year old	17	14	0.150	0.151	2.114	0.319
16 year old	25	22	0.435	0.472	10.384	4.901
17 year old	24	21	0.103	0.100	2.100	0.210
Total		115			33.040	11.395

$$\chi^2 = 11.395 - \frac{[33.040]^2}{113}$$
$$= 1.734$$

Again, the result was not statistically significant.

Finally, this analysis was performed on the fourth subscale of the AFC, 'Social and Vocational Activity' (**Table F.6**).

Table F.6: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Social/Vocational Activity,' according to adolescent age.

Adolescent Age	*n*	*(n - 3)*	*r*	*z*	Weighted *z* = *(n - 3)z*	Weighted Square = $(n - 3)z^2$
12 year old	20	17	-0.038	-0.040	-0.680	0.027
13 year old	24	21	0.488	0.536	11.256	6.033
14 year old	24	21	0.741	0.950	19.950	18.953
15 year old	17	14	0.547	0.618	8.652	5.347
16 year old	24	21	0.716	0.908	19.068	17.314
17 year old	24	21	0.689	0.848	17.808	15.101
Total		115			76.054	62.775

$$\chi^2 = 62.775 - \frac{[76.054]^2}{115}$$
$$= 12.478$$

This result was also not significant at the $p < 0.01$ criterion level.

Appendix F.3: Variation in Parent-Adolescent Agreement on the Autonomous Functioning Checklist According to Adolescent Gender.

Parent-adolescent agreement on the AFC appeared to differ depending on the gender of the adolescent. A statistical test for differences between correlations between genders was conducted (Snedecor and Cochran, 1980). Due to the use of multiple tests, the criterion value was set at $p < 0.01$ (see **Section 3.4.3**). **Tables F.7** through **F.11** display the tests of significance of differences between correlations amongst different adolescent demographic criteria.

The analyses examined the difference in parent-adolescent agreement on the AFC according to adolescent gender. The details of the test examining parent-adolescent agreement on the total AFC are shown in **Table F.7**.

Table F.7: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the total Autonomous Functioning Checklist according to adolescent gender.

Adolescent gender	n	$(n - 3)$	r	z		$1/(n-3)$
Male	59	56	0.509	0.563		0.018
Female	67	64	0.480	0.523		0.016
				D = 0.040	Sum =	0.034

$$t = D/\sigma_D$$

$$t = 0.040/\sqrt{0.034}$$
$$= 0.217$$

This results is not significant, suggesting that parent-adolescent agreement on the total AFC is not varied according to the gender of the adolescent. Subsequent analyses examined this relationship on each of the AFC subscales.

Table F.8 shows the details of the analysis of the first subscale, 'Self- and Family-Care.'

Table F.8: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Self- and Family-Care,' according to adolescent gender.

Adolescent gender	n	$(n-3)$	r	z		$1/(n-3)$
Male	60	57	0.576	0.662		0.018
Female	71	68	0.498	0.549		0.015
				D = 0.113	Sum =	0.033

$$t = D/\sigma_D$$

$$t = 0.113/\sqrt{0.033}$$
$$= 0.621$$

Table F.9 shows the details of the analysis of the second subscale of the AFC, 'Management Activity.'

Table F.9: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Management Activity,' according to adolescent gender.

Adolescent gender	*n*	*(n - 3)*	*r*	*z*		$1/(n-3)$
Male	59	56	0.530	0.590		0.018
Female	72	69	0.538	0.604		0.014
				D = 0.014	Sum =	0.032

$$t = D/\sigma_D$$

$$t = 0.014/\sqrt{0.032}$$
$$= 0.078$$

Table F.10 shows the details of the analysis of the third AFC subscale, 'Recreational Activity.'

Table F.10: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Recreational Activity,' according to adolescent gender.

Adolescent gender	*n*	*(n - 3)*	*r*	*z*		$1/(n-3)$
Male	59	56	0.344	0.354		0.018
Female	74	71	0.219	0.224		0.014
				D = 0.130	Sum =	0.032

$$t = D/\sigma_D$$

$$t = 0.130/\sqrt{0.032}$$
$$= 0.726$$

Table F.11 shows the details of the analysis of the final AFC subscale, 'Social and Vocational Activity.'

Table F.11: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the AFC subscale 'Social/Vocational Activity,' according to adolescent gender.

Adolescent gender	n	$(n - 3)$	r	z		$1/(n-3)$
Male	59	56	0.581	0.662		0.018
Female	74	71	0.616	0.725		0.014
			D =	0.063	Sum =	0.032

$$t = D/\sigma_D$$

$$t = 0.063/\sqrt{0.032}$$
$$= 0.352$$

The results of the analyses examining the variation of parent-adolescent agreement on the AFC subscales according to adolescent gender were all non-significant at the criterion level of $p < 0.01$.

APPENDIX G.

Appendix G.1: Level of Agreement Between Adolescent and Parent Reports of The Proposed Antecedents of Adherence.

The first analyses presented in this appendix were designed to examine the level of association between adolescent responses and parent responses on the ADQ, HVS, and DKQ. Pearson correlations between these responses are presented in **Table G.1**.

Table G.1: Pearson correlations between adolescent completed and parent completed Adherence Determinants Questionnaire, Health Value Scale, and Diabetes Knowledge Questionnaire.

	Scoring Range	Adolescent Report (Mean±*SD*)	Parent Report (Mean±*SD*)	*r*	*p**
Interpersonal Aspects of Care	8 - 40	31.4 ± 4.2	32.9 ± 4.1	0.21	0.01
Perceived Utility	8 - 40	32.5 ± 4.1	33.4 ± 4.2	0.27	0.002
Perceived Severity	4 - 20	8.5 ± 2.6	10.3 ± 2.4	0.28	0.002
Perceived Susceptibility	4 - 20	13.8 ± 3.1	14.7 ± 2.5	0.21	0.01
Subjective Norms	-18 - 18	-1.3 ± 2.2	-1.8 ± 3.0	0.00	1.0
Intentions to Adhere	4 - 20	16.6 ± 2.4	16.1 ± 2.8	0.47	
Supports / Barriers	4 - 20	14.6 ± 2.6	14.3 ± 2.3	0.35	
Health Value Scale	6 - 30	14.7 ± 2.7	16.0 ± 2.9	0.23	0.01
Diabetes Knowledge	0 - 15	11.2 ± 2.2	12.6 ± 2.0	0.19	0.03

* unless otherwise stated, $p < 0.001$

Adolescent and parent responses to the Interpersonal Aspects of Care, Perceived Utility, Perceived Severity and Perceived Susceptibility scales of the ADQ were similarly correlated ($r = 0.21$, $r = 0.27$, $r = 0.28$, and $r = 0.21$ respectively). Further, the Intentions to Adhere and Supports / Barriers scales showed good correlations

between adolescent and parent responses (r = 0.47 and r = 0.35 respectively). The only ADQ scale to show poor correlations between adolescent and parent responses was Subjective Norms (r = 0.004). This poor association is likely to reflect the differing views held by adolescent and parents about the social norms or the adolescents' peers and families, and the importance of these norms.

The adolescent and parent responses to the HVS were moderately correlated (r = 0.23), indicating reasonable agreement between informants about the importance of good health. Finally, the correlation between adolescent and parent scores on the DKQ was not high, but did reach statistical significance (r = 0.19, $p < 0.05$). This result indicates that adolescents' knowledge about diabetes treatment was associated with their parents' knowledge about the regimen. However, this result does not provide evidence for a causal relationship.

Appendix G.2: Variation in Parent-Adolescent Agreement on the Adherence Determinants Questionnaire and Health Value Scale According to Adolescent Age.

The next set of analyses were performed to determine whether the level of parent-adolescent agreement on the ADQ and HVS differed depending on the age of the adolescent. A statistical test for differences between correlations across the six age levels (12 year olds, 13 year olds, 14 year olds, 15 year olds, 16 year olds and 17 year olds) was conducted (Snedecor and Cochran, 1980). Because of the use of multiple tests, the criterion value was set at $p < 0.01$ (see **Section 3.4.3**). **Tables G.2** through **G.9** display the tests of significance of differences between correlations.

The first of these analyses examined the variation in parent-adolescent agreement on the first scale of the ADQ, Interpersonal Aspects of Care, according to adolescent age. **Table G.2** displays the details of this test.

Table G.2: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Interpersonal Aspects of Care scale according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	19	16	0.049	0.050	0.800	0.040
13 year old	24	21	0.329	0.343	7.203	2.471
14 year old	22	19	-0.035	-0.040	-0.760	0.030
15 year old	17	14	-0.020	-0.020	-0.280	0.006
16 year old	25	22	0.495	0.549	12.078	6.631
17 year old	24	21	0.316	0.332	6.972	2.315
Total		113			26.013	11.493

Following the methodology described in **Section 5.2.1**, and outlined in Snedecor and Cochran (1980), the correlation coefficients were converted to z score, and (n - 3) values calculated. The test of significance is performed as a Chi-square analysis:

$$\chi^2 = \sum (n-3)z^2 - \frac{\left[\sum (n-3)z\right]^2}{\sum (n-3)}$$

$$\chi^2 = 11.493 - \frac{[26.013]^2}{113}$$

$$= 5.505$$

With 5 degrees of freedom, this result is not significant, indicating that parent-adolescent agreement on the Interpersonal Aspects of Care scale was not dependent on adolescent age.

The next test examined parent-adolescent agreement on the ADQ scale Perceived Utility in relation to adolescent age. The details of this test are shown in **Table G.3**.

Table G.3: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Perceived Utility scale according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	20	17	0.377	0.400	6.800	2.720
13 year old	23	20	0.577	0.662	13.240	8.765
14 year old	22	19	0.222	0.224	4.256	0.953
15 year old	17	14	0.376	0.400	5.600	2.240
16 year old	23	20	-0.030	-0.030	-0.600	0.018
17 year old	23	20	0.233	0.234	4.680	1.095
Total		110			33.976	15.791

Snedecor and Cochran's test of significance produced a chi-square of 5.297. With 5 degrees of freedom, this result is also not significant at the criterion p level. This result indicates that parent-adolescent agreement on the Perceived Utility scale was not dependent on adolescent age.

The third test examined parent-adolescent agreement on the Perceived Severity scale of the ADQ in relation to adolescent age. The details of this test are shown in **Table G.4**.

Table G.4: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Perceived Severity scale according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	20	17	0.272	0.277	4.709	1.304
13 year old	23	20	0.351	0.365	7.300	2.665
14 year old	23	20	0.481	0.523	10.460	5.471
15 year old	16	13	0.519	0.576	7.488	4.313
16 year old	25	22	-0.112	-0.110	-2.420	0.266
17 year old	22	19	0.147	0.151	2.869	0.433
Total		111			30.406	14.452

The resulting chi-square analysis produced the result $\chi^2 = 6.123$. Again this result was not significant, indicating that parent-adolescent agreement on the Perceived Severity scale was not dependent on adolescent age.

The next test examined differences in parent-adolescent agreement on the Perceived Susceptibility scale according to adolescent age. The details of this test are shown in **Table G.5**.

Table G.5: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Perceived Susceptibility scale according to adolescent age.

Adolescent Age	*n*	*(n - 3)*	*r*	*z*	Weighted *z* = *(n - 3)z*	Weighted Square = $(n - 3)z^2$
12 year old	20	17	-0.006	-0.010	-0.170	0.002
13 year old	23	20	0.606	0.709	14.180	10.054
14 year old	23	20	-0.088	-0.090	-1.800	0.162
15 year old	16	13	0.328	0.343	4.459	1.529
16 year old	25	22	0.112	0.110	2.420	0.266
17 year old	22	19	0.149	0.151	2.869	0.433
Total		111			21.958	12.446

This test produced the chi-square result of $\chi^2 = 8.102$. This result was also not significant at criterion *p*. This indicates that parent-adolescent agreement on the Perceived Susceptibility scale of the ADQ was not differentiated on the basis of adolescent age.

The next test examined differences in parent-adolescent agreement on the Subjective Norms ADQ scale according to adolescent age. The details of this test are shown in **Table G.6**.

Snedecor and Cochran's test of significance produced a chi-square result of $\chi^2 = 6.371$. Again this result was not significant, indicating that parent-adolescent agreement on the Subjective Norms scale was not differentiated by the adolescents' age.

Table G.6: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Subjective Norms scale according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	20	17	-0.117	-0.121	-2.057	0.249
13 year old	23	20	-0.229	-0.234	-4.680	1.095
14 year old	23	20	0.115	0.121	2.420	0.293
15 year old	16	13	0.537	0.604	7.852	4.743
16 year old	25	22	0.134	0.131	2.882	0.378
17 year old	24	21	0.009	0.010	0.210	0.002
Total		113			6.627	6.760

The next test focused on the parent-adolescent agreement according to adolescent age on the Intentions to Adhere scale of the ADQ. The details of this test are shown in **Table G.7**.

Table G.7: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Intentions to Adhere scale according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	20	17	0.371	0.388	6.596	2.559
13 year old	23	20	0.635	0.758	15.160	11.491
14 year old	23	20	0.362	0.377	7.540	2.843
15 year old	16	13	0.504	0.549	7.137	3.918
16 year old	25	22	0.516	0.576	12.672	7.299
17 year old	24	21	0.317	0.332	6.972	2.315
Total		113			56.077	30.425

Snedecor and Cochran's test of significance was performed, $\chi^2 = 2.596$. Again, the results of this test were not statistically significant, indicating that parent-adolescent agreement on this scale was not differentiated by adolescent age.

The next test examined the parent-adolescent agreement on the final scale of the ADQ, Supports / Barriers, across the six adolescent age levels. **Table G.8** provides the details of this test.

Table G.8: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Supports / Barriers scale according to adolescent age.

Adolescent Age	*n*	*(n - 3)*	*r*	*z*	Weighted *z* = *(n - 3)z*	Weighted Square = $(n - 3)z^2$
12 year old	20	17	0.307	0.321	5.457	1.752
13 year old	23	20	0.355	0.377	7.540	2.843
14 year old	21	18	0.412	0.436	7.848	3.422
15 year old	16	13	0.355	0.377	4.901	1.848
16 year old	25	22	0.371	0.388	8.536	3.312
17 year old	24	21	0.320	0.332	6.972	2.315
Total		111			41.254	15.492

Snedecor and Cochran's test of significance was calculated as: $\chi^2 = 0.160$. This result was not statistically significant. This result indicates that parent-adolescent agreement on this scale was not differed depending on the age of the adolescent.

The final test of parent-adolescent agreement according to adolescent age examined the scores obtained on the Health Value Scale. The details of this test are shown in **Table G.9**.

Table G.9: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Health Value Scale according to adolescent age.

Adolescent Age	n	$(n - 3)$	r	z	Weighted z $= (n - 3)z$	Weighted Square $= (n - 3)z^2$
12 year old	19	16	0.264	0.266	4.256	1.132
13 year old	24	21	0.419	0.448	9.408	4.215
14 year old	22	19	0.112	0.110	2.090	0.230
15 year old	16	13	0.133	0.131	1.703	0.223
16 year old	25	22	0.230	0.234	5.148	1.205
17 year old	24	21	0.244	0.245	5.145	1.261
Total		112			27.750	8.266

The Chi-square test of significance produced the result $\chi^2 = 1.390$. Once again, this result was not significant at the $p < 0.01$ level, suggesting that parent-adolescent agreement on the HVS was not dependent upon the age of the adolescent.

Table G.12: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Perceived Severity scale according to adolescent gender.

Adolescent gender	*n*	*(n - 3)*	*r*	*z*		$1/(n-3)$
Male	58	55	0.258	0.266		0.018
Female	71	68	0.299	0.310		0.015
				D = 0.044	Sum =	0.033

$$D/\sigma_D = 0.044/\sqrt{0.033}$$
$$= 0.242$$

This result was not significant, indicating that parent-adolescent agreement on this measure did not differ depending on the gender of the adolescent.

The next test examined the differences in parent-adolescent agreement on the fourth scale of the ADQ, Perceived Susceptibility, according to adolescent gender. The details of this test are shown in **Table G.13**.

Table G.13: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Perceived Susceptibility scale according to adolescent gender.

Adolescent gender	*n*	*(n - 3)*	*r*	*z*		$1/(n-3)$
Male	58	55	0.201	0.203		0.018
Female	71	68	0.234	0.234		0.015
				D = 0.031	Sum =	0.033

$$D/\sigma_D = 0.031/\sqrt{0.033}$$
$$= 0.170$$

This result was not significant, indicating that parent-adolescent agreement on this measure did not differ depending on the gender of the adolescent.

The next test examined the differences in parent-adolescent agreement on the fifth scale of the ADQ, Subjective Norms, according to adolescent gender. The details of this test are shown in **Table G.14**.

Table G.14: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Subjective Norms scale according to adolescent gender.

Adolescent gender	n	$(n-3)$	r	z		$1/(n-3)$
Male	58	55	-0.121	-0.121		0.018
Female	73	70	0.067	0.070		0.014
				D = 0.191	Sum =	0.032

$$D/\sigma_D = 0.191/\sqrt{0.032}$$
$$= 1.067$$

This result was not significant, indicating that parent-adolescent agreement on this measure did not differ depending on the gender of the adolescent.

The next test examined the differences in parent-adolescent agreement on the sixth scale of the ADQ, Intentions to Adhere, according to adolescent gender. The details of this test are shown in **Table G.15**.

Table G.15: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Intentions to Adhere scale according to adolescent gender.

Adolescent gender	n	$(n - 3)$	r	z		$1/(n-3)$
Male	58	55	0.559	0.633		0.018
Female	73	70	0.354	0.365		0.014
				D = 0.268	Sum =	0.032

$$D/\sigma_D = 0.268/\sqrt{0.032}$$
$$= 1.497$$

This result was not significant, indicating that parent-adolescent agreement on this measure did not differ depending on the gender of the adolescent.

The next test examined the differences in parent-adolescent agreement on the final scale of the ADQ, Supports / Barriers, according to adolescent gender. The details of this test are shown in **Table G.16**.

Table G.16: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Supports / Barriers scale according to adolescent gender.

Adolescent gender	n	$(n - 3)$	r	z		$1/(n-3)$
Male	57	54	0.402	0.424		0.019
Female	72	69	0.339	0.354		0.014
				D = 0.070	Sum =	0.033

$$D/\sigma_D = 0.070/\sqrt{0.033}$$
$$= 0.385$$

This result was not significant, indicating that parent-adolescent agreement on this measure did not differ depending on the gender of the adolescent.

The final test examined the differences in parent-adolescent agreement on the Health Value Scale according to adolescent gender. The details of this test are shown in **Table G.17**.

Table G.17: Test of significance of difference between correlation coefficients of adolescent-parent agreement on the Health Value Scale according to adolescent gender.

Adolescent gender	n	$(n - 3)$	r	z		$1/(n-3)$
Male	56	53	0.403	0.424		0.019
Female	74	71	0.090	0.090		0.014
				D = 0.334	Sum =	0.033

$$D/\sigma_D = 0.334/\sqrt{0.033}$$
$$= 1.835$$

Again, this result was not significant, indicating that parent-adolescent agreement on the HVS did not differ depending on the gender of the adolescent.

APPENDIX H.

Appendix H.1: Correlations (with p values*) between adolescent responses to scales of the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

	Interpersonal Asp. Care	Perceived Utility	Perceived Severity	Perceived Susceptibility	Subjective Norms	Intentions to Adhere	Supports / Barriers	Health Value	Diabetes Knowledge
Interpersonal Asp. Care	--	0.49	-0.39	0.19 ($p = 0.03$)	-0.01 ($p = 0.9$)	0.39	0.45	0.18 ($p = 0.46$)	0.25 ($p = 0.004$)
Perceived Utility		--	-0.33	0.17 ($p = 0.06$)	-0.05 ($p = 0.6$)	0.55	0.47	0.22 ($p = 0.01$)	0.26 ($p = 0.003$)
Perceived Severity			--	-0.14 ($p = 0.1$)	-0.08 ($p = 0.4$)	-0.36	-0.40	-0.15 ($p = 0.09$)	-0.07 ($p = 0.5$)
Perceived Susceptibility				--	0.02 ($p = 0.9$)	0.12 ($p = 0.2$)	0.03 ($p = 0.7$)	0.00 ($p = 1.0$)	0.29 ($p = 0.001$)
Subjective Norms					--	-0.06 ($p = 0.5$)	-0.07 ($p = 0.4$)	-0.08 ($p = 0.4$)	0.09 ($p = 0.3$)
Intentions to Adhere						--	0.48	0.48	0.21 ($p = 0.01$)
Supports / Barriers							--	0.16 ($p = 0.7$)	0.17 ($p = 0.05$)
Health Value								--	0.05 ($p = 0.6$)
Diabetes Knowledge									--

* unless otherwise stated, $p < 0.001$

Appendix H.2: Correlations (with p values*) between parent responses to scales of the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

	Interpersonal Asp. Care	Perceived Utility	Perceived Severity	Perceived Susceptibility	Subjective Norms	Intentions to Adhere	Supports / Barriers	Health Value	Diabetes Knowledge
Interpersonal Asp. Care	--	0.51	-0.22 ($p = 0.01$)	0.19 ($p = 0.03$)	-0.01 ($p = 0.9$)	0.46	0.26 ($p = 0.002$)	0.31	0.10 ($p = 0.2$)
Perceived Utility		--	-0.21 ($p = 0.02$)	0.09 ($p = 0.3$)	0.03 ($p = 0.8$)	0.61	0.36	0.40	0.11 ($p = 0.2$)
Perceived Severity			--	0.06 ($p = 0.5$)	-0.01 ($p = 0.9$)	-0.36	-0.28 ($p = 0.001$)	0.00 ($p = 1.0$)	0.07 ($p = 0.5$)
Perceived Susceptibility				--	-0.07 ($p = 0.4$)	0.09 ($p = 0.3$)	-0.10 ($p = 0.3$)	0.07 ($p = 0.4$)	0.06 ($p = 0.5$)
Subjective Norms					--	0.13 ($p = 0.2$)	-0.04 ($p = 0.7$)	0.15 ($p = 0.09$)	-0.01 ($p = 0.9$)
Intentions to Adhere						--	0.55	0.34	0.07 ($p = 0.4$)
Supports / Barriers							--	0.17 ($p = 0.05$)	0.08 ($p = 0.4$)
Health Value								--	0.08 ($p = 0.3$)
Diabetes Knowledge									--

* unless otherwise stated, $p < 0.001$

Appendix H.3: Correlations (with p values*) between adolescent responses of Conflict Behaviour Questionnaire and subscales of the Autonomous Functioning Checklist with scales of the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

	Interpersonal Asp. Care	Perceived Utility	Perceived Severity	Perceived Susceptibility	Subjective Norms	Intentions to Adhere	Supports / Barriers	Health Value	Diabetes Knowledge
Conflict Behaviour	-0.18 ($p = 0.45$)	-0.32	0.22 ($p = 0.02$)	0.09 ($p = 0.3$)	0.04 ($p = 0.7$)	-0.36	-0.29 ($p = 0.001$)	-0.17 ($p = 0.06$)	-0.03 ($p = 0.7$)
Autonomous Functioning:									
Self- and Family-Care	0.08 ($p = 0.4$)	0.11 ($p = 0.2$)	-0.20 ($p = 0.02$)	-0.01 ($p = 0.9$)	-0.04 ($p = 0.6$)	0.12 ($p = 0.2$)	0.09 ($p = 0.3$)	0.09 ($p = 0.3$)	0.02 ($p = 0.9$)
Management Activity	0.20 ($p = 0.02$)	0.29 ($p = 0.001$)	-0.29 ($p = 0.001$)	0.11 ($p = 0.2$)	-0.14 ($p = 0.1$)	0.18 ($p = 0.04$)	0.09 ($p = 0.3$)	0.12 ($p = 0.2$)	0.22 ($p = 0.01$)
Recreational Activity	0.12 ($p = 0.2$)	0.11 ($p = 0.2$)	-0.16 ($p = 0.07$)	0.01 ($p = 0.9$)	-0.03 ($p = 0.8$)	0.15 ($p = 0.09$)	0.07 ($p = 0.4$)	0.06 ($p = 0.5$)	0.16 ($p = 0.07$)
Social/Vocational Act.	0.14 ($p = 0.1$)	0.06 ($p = 0.5$)	-0.18 ($p = 0.04$)	0.17 ($p = 0.05$)	0.08 ($p = 0.4$)	0.09 ($p = 0.3$)	0.00 ($p = 1.0$)	0.09 ($p = 0.3$)	0.29 ($p = 0.001$)

* unless otherwise stated, $p < 0.001$

Appendix H.4: Correlations (with p values*) between parent responses of Conflict Behaviour Questionnaire and subscales of the Autonomous Functioning Checklist with scales of the Adherence Determinants Questionnaire, Health Value Scale and Diabetes Knowledge Questionnaire.

	Interpersonal Asp. Care	Perceived Utility	Perceived Severity	Perceived Susceptibility	Subjective Norms	Intentions to Adhere	Supports / Barriers	Health Value	Diabetes Knowledge
Conflict Behaviour	-0.28 ($p = 0.001$)	-0.14 ($p = 0.1$)	0.30 ($p = 0.001$)	0.15 ($p = 0.08$)	-0.07 ($p = 0.4$)	-0.44	-0.42	-0.06 ($p = 0.5$)	-0.07 ($p = 0.4$)
Autonomous Functioning:									
Self- and Family-Care	0.04 ($p = 0.7$)	-0.09 ($p = 0.3$)	0.11 ($p = 0.2$)	-0.06 ($p = 0.5$)	-0.13 ($p = 0.2$)	0.08 ($p = 0.4$)	0.02 ($p = 0.9$)	0.11 ($p = 0.2$)	-0.08 ($p = 0.4$)
Management Activity	0.23 ($p = 0.01$)	0.10 ($p = 0.2$)	-0.07 ($p = 0.4$)	-0.03 ($p = 0.8$)	-0.17 ($p = 0.06$)	0.36	0.37	0.17 ($p = 0.05$)	0.16 ($p = 0.07$)
Recreational Activity	0.15 ($p = 0.09$)	0.04 ($p = 0.7$)	0.005 ($p = 0.96$)	-0.07 ($p = 0.5$)	-0.01 ($p = 0.9$)	0.16 ($p = 0.06$)	0.05 ($p = 0.5$)	0.22 ($p = 0.01$)	-0.02 ($p = 0.8$)
Social/Vocational Act.	-0.04 ($p = 0.7$)	-0.04 ($p = 0.6$)	0.08 ($p = 0.3$)	-0.08 ($p = 0.4$)	-0.02 ($p = 0.8$)	0.01 ($p = 0.9$)	0.01 ($p = 0.9$)	0.12 ($p = 0.2$)	-0.02 ($p = 0.8$)

* unless otherwise stated, $p < 0.001$

APPENDIX I.

PUBLICATIONS ARISING FROM THE THESIS.

Fotheringham, M.J. & Sawyer, M.G. (1995) Review Article: Adherence to recommended medical regimens in childhood and adolescence.
Journal of Paediatrics and Child Health, v. 31(2), pp. 72-78

NOTE:
This publication is included on pages 323-329 in the print copy of the thesis held in the University of Adelaide Library.

Fotheringham, M.J., Couper, J.J. & Sawyer, M.G. (1996) Adherence to IDDM treatment: relation to parent-adolescent conflict and adolescent autonomy.
Presented at: Proceedings of the Australian Diabetes Society, A 89

NOTE:
This publication is included on page 330 in the print copy
of the thesis held in the University of Adelaide Library.

Taylor, J.D., Fotheringham, M.J., Sawyer, M.G. & Couper, J.J. (1996) Ambulatory intervention in adolescents with insulin dependent diabetes: impact of metabolic control and psychosocial functioning. *Presented at: Proceedings of the Australian Diabetes Society, A 62*

NOTE:
This publication is included on page 331 in the print copy
of the thesis held in the University of Adelaide Library.

Fotheringham, M.J., Couper, J.J. & Sawyer, M.G. (1997) Associations between adolescents' metabolic control, IDDM adherence and objective data of blood glucose monitoring.
Presented at: Proceedings of the Australian Diabetes Society, A 93

NOTE:
This publication is included on page 332 in the print copy
of the thesis held in the University of Adelaide Library.

Taylor, J.D., Fotheringham, M.J., Sawyer, M.G. & Couper, J.J. (1997) Followup of ambulatory intervention in adolescents with poorly controlled insulin dependent diabetes.
Presented at: Proceedings of the Australian Diabetes Society, A 69

NOTE:
This publication is included on page 333 in the print copy
of the thesis held in the University of Adelaide Library.

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