



**THE BURDEN OF ILLNESS IN FAMILIES
OF THE MENTALLY ILL: A VIEW FROM
GENERAL PRACTICE**

IAN GEOFFREY WILSON

**DEPARTMENT OF GENERAL PRACTICE
THE UNIVERSITY OF ADELAIDE**

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Abstract

Aims:

It is well documented that the families of patients with severe mental illness suffer from an increased burden of illness. This thesis examines the health of families, as seen in general practice, where a member of the family had counselling as the only treatment for a mental health problem, or a family member had been referred to a psychiatrist for treatment of a mental illness. Two additional groups that consisted of families of patients who had developed a breast cancer or suffered a myocardial infarction were examined to provide comparisons.

Methods:

Random selection of identified families was undertaken from one general practice in suburban Adelaide, South Australia. Twenty families were selected for each group.

The Duke University Severity of Illness scale (DUSOI) was modified to provide measures of burden of illness of the family for the years prior to and after the index events. This modification of the DUSOI was validated.

Scores in each year for each family, with the patient excluded from the calculation, were then compared. Secondary analyses were then carried out to explore reasons for any change of score.

Results:

For families where a family member had received counselling for a mental health problem, the change in the burden of illness (0.25, 95% CI -2.20 to 3.41) was not significant. For families where a member had been referred to psychiatrist for the treatment of a mental illness, the decrease in the burden of illness after referral (-3.88, 95% CI -1.04 to -6.72) was significant.

For the families in the comparator groups the difference in burden was not significant for the breast cancer group (-0.28, 95% CI -3.10 to 2.54), while there was a significant increase in burden for the myocardial infarction group (5.08, 95% CI 0.62 to 9.55).

Discussion:

The results indicate that when patients are referred to a psychiatrist the burden of illness in the family decreases, but conditions of lesser severity do not produce such an effect. The gender of the spouse seems to lessen the measured effect in the breast cancer group, while leading to a significant increase in the infarction group.

This work 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, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis, when deposited in the University Library, being available for loan and photocopying.

Ian Wilson

25 June 2002

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Introduction

General practice is a diverse profession with a broad spectrum of doctors, patients and activities. It operates in an environment where any patient with any problem may seek attention. A large number of the patients have psychiatric illnesses or psychological or psychosocial problems (mental health problems) and the management of these illnesses or problems is a large part of general practice. The problems range markedly in severity from major psychotic illness to brief adjustment disorders or to what has been called “the worried well”.

Individual general practitioners possess different interests and skills in the recognition and management of mental health problems. Some find managing such problems rewarding and develop significant skills in their recognition and management.

In managing mental health problems general practice has a distinct advantage over other branches of the medical profession because the practitioner often treats the whole family. It is in this setting that the author became interested in the effects on the family of mental ill health in a family member. The effects the author noted in some long-term families heightened this interest.

- Mr A was a radio technician who had been promoted to a senior management position in his organisation. He did not have the management skills for this position and felt unsupported. He felt that the company would not help him gain the skills to do the work effectively. During this time he attended for consultations frequently with recurrent upper respiratory tract infections (URTI) and recurrent undiagnosed abdominal pain. At the same time his wife

became very troubled with her osteoarthritis and required frequent alterations to medication and referrals to physiotherapists, podiatrists and a rheumatologist. The couple's visits suddenly ceased. They were next seen nine months later when the author discovered that Mr A had resigned from work and retired. Mrs A's symptoms and use of services had minimised at the same time.

- Jamie was four weeks post-partum and still below birth weight. He was continually crying and refusing to feed. Mother appeared tense and could not relax around the child. The situation deteriorated to the point that Jamie was admitted to the local hospital for feeding. In hospital he was relaxed and could be easily fed by the nurses. Feeds given by mother continued to be problematic. Suddenly at seven weeks mother appeared relaxed and the feeding difficulties resolved. Father, who had been released from prison one week before the birth of the child, had been arrested and held on remand after a bank robbery.
- Michael, a shy, reserved 15-year-old, was brought to the author for investigation of dizziness. His dizziness was unusual because it only occurred when he walked down a corridor. He felt that the walls were falling in on top of him. He seemed to "bounce from wall to wall." Examination was normal. His performance at school was poor and he was the butt of numerous schoolyard pranks. He had had numerous consultations for minor skin complaints. It eventually transpired that his parents had separated but still lived in the same house so as to "provide a good environment for the children." Mother was dictatorial in the way she ran the house and father was terribly unsure if he was doing the right thing. There were constant "private" battles between the parents that were supposedly hidden from the children. Michael's

symptoms settled when father left the house. Michael, although living with his mother, developed a very close relationship with his father.

The author wanted then to see if the increase in illness in the family, applied to all patients with mental health problems and if so, did the burden improve with treatment of the mental health problem.

The Duke University Severity of Illness (DUSOI) scale (1) is a well documented and validated scale used to measure the severity of illness in an individual. Studies within the Department of General Practice at Adelaide University have used the score, averaged over a family, to provide a measure of a family's burden of illness at a given time. (2, 3) This makes the DUSOI appealing as a measure of family illness.

The Department of General Practice has demonstrated that the burden of illness in a family, at the time of diagnosis of depression, is higher than matched control families without a depressed member. (2) The family member with depression had been excluded from the calculations. The burden of illness reverted after treatment of the depression to that seen in control families.

The DUSOI measures the severity of illness at a point in time. It scores any condition present at that time or in the previous 2 weeks. (1) In order to take into account the frequent consultations for minor complaints it will be necessary to modify the scoring of the DUSOI so that it measures the burden of illness over periods of three months to one year. Such a method will allow measurement of a family's burden of illness in the years before and after treatment commences.

To provide a comparison the measurements will be repeated in the years before and after the occurrence of a myocardial infarction or the diagnosis of a breast cancer.

The thesis reports on

1. the development of the DUSOI as a measure of a family's burden of illness

and

2. its use to examine the following hypotheses:

Hypothesis 1

A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a family member is treated for mental health problems with either of two levels of severity, those requiring counselling in general practice and those requiring referral to a psychiatrist.

Hypothesis 2

A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a family member suffers from either of two severe physical illnesses, breast cancer or myocardial infarction.

Chapter 1

Literature review

This chapter examines the literature relevant to this study. In particular it examines the literature relating to the effects of mental illness on patients and their families, the outcomes of counselling in general practice, family therapy as a treatment of mental illness, the effects of acute myocardial infarction and breast cancer on family members, and the Duke University Severity of Illness scale (DUSOI). Each of these topics has a significant impact on the structure of the study and the aim of the literature review is to provide a context for this project and for the research structure.

This chapter will demonstrate that severe mental illness in a family member places significant stress on the patient and other family members. This results in deterioration in the health of family members. Very few studies however have examined the effects of patients with less severe mental illness managed in general practice. It will also demonstrate that counselling does the least harm to patients with emotional distress and that counselling is generally free of side effects, patients are highly satisfied with the result, and monitoring of mental state and compliance are easy for the treating doctor.

The chapter also demonstrates that, despite some limitations, the Duke University Severity of Illness scale will, with appropriate modification, provide an instrument that will be effective. Such a modification will require validation. The chapter will demonstrate that patients with breast cancer and myocardial infarction provide appropriate comparators in this study.

The effect of mental illness on patients and family members

The effects of mental illness on the patient as an individual have been widely studied with consistent results reported in published studies. When applied to families and carers the results have been variable. The research on both individuals and families has particularly applied to severe mental illness, but early steps are being taken to investigate the impact of mental illness seen in general practice. There is also another level in which patients are cared for by psychiatrists, but do not have a severe mental illness. There has not been any published research at this level.

The effect of mental illness on the health of the sufferer

The effect of mental illness on the sufferer has been studied in both general and specific terms.

Davidson et al (4) examined the health of a convenience sample of patients from a regional mental health service in an urban setting. There was a high proportion (79%) of psychotic illness. They found high rates of smoking, obesity and illicit drug use. Hendrick (5) examined 101 patients with long-term mental illness treated in general practices in the United Kingdom. He also found high rates of smoking and obesity, as well as hypertension. There were high rates of respiratory symptoms (daily cough with sputum, shortness of breath and wheezing) which were possibly related to smoking. These studies confirm that risk factors for physical illness are more prevalent in the mentally ill and contain the suggestion that risk factors are not managed well in patients with severe mental illness.

The morbidity among the mentally ill is also increased. Forsen et al (6) examined the development of hip fractures in approximately 18,600 women over the age of 50 in a three-year follow-up. They found a twofold increase in risk of hip fracture between the top and bottom deciles for mental distress measured at entry to the study. Although this study used a measure of mental distress, the questions in the instrument emphasised mental illness. This study supports a previous study by Michelson et al (7) that showed a decrease in bone mineral density in patients who suffer from depression. Specific studies have looked at the effects of depression on cardiovascular disease. The studies, (for example references (8-11)) consistently show an increased incidence of cardiovascular disease in people with a history of major depressive disorder. The one exception has been a study carried out in general practice in the Netherlands. This high quality study (12) showed that there was no increase in mortality for patients from general practice with depression, when followed for ten years.

Another general practice study (13) showed high levels of disability in patients from general practice with depression. A community study of elderly patients (14) reported that following the onset of depression there is an increased risk for incident disability. The most significant causes of this increase were new cases of arthritis and angina.

Mortality is increased among the mentally ill. Baxter (15) and Ruschena et al (16) examined mortality of patients with long-term mental illness and found large increases in the mortality. Baxter pulled together a large group of studies which indicate significant increases in mortality. The relative risk from the nine research papers he studied ranged from approximately 1.6 to 3 or more. Baxter then examined all cause mortality for 6952 individuals enrolled on the psychiatric case register in a region of England. Patients were followed for at least 15 years. The overall relative risk of death was 1.65 that of the general

population in the same region. Of the excess deaths just over one third were due to circulatory disorders, 30.5% were due to injury and poisonings (this group included suicides), and 16.5% were due to respiratory and nervous system diseases.

A study by Ruschena et al (16) was conducted in Victoria, Australia and examined sudden deaths reported to the coroner. The relative risk for sudden death among the mentally ill was 5.4 compared to the general population and this rose to 6.3 if the patient had had a psychiatric hospital admission in the previous year. The relative risk of suicide was 12.4 and this increased to 17.9 if hospitalised in the previous year. The relative risk of death from natural causes (suicide, accidents and homicide excluded) was 3.0. A large part of this excess was due to cardiovascular disease, particularly in patients suffering from schizophrenia.

Two recent publications (17, 18) from the Departments of Public Health, and Psychiatry and Behavioural Health at the University of Western Australia have examined the morbidity and mortality of the mentally ill in their state. While supporting the above findings they also indicate that some of the excess morbidity and mortality is due to patients with mental illness not receiving treatment to the same level as people without mental illness. For instance patients with mental illness have lower rates of cardiac revascularisation procedures than the non-mentally ill. Rates of hospitalisation for medical conditions and procedures are lower than the general population. Despite higher rates of smoking the rate of malignancies in the mentally ill was about the same as for the general population. "However, once a cancer was diagnosed, there was a 30% higher death rate in users of mental health services." (18, page 5)

At a more general level increases in stress in patients have been shown to have detrimental effects. Cohen et al (19) were able to show that the development of upper respiratory infections after inoculating the patients noses with cold viruses was associated in a dose-response manner with psychological distress, as measured at entry to the study.

Overall mental illness has been shown to be associated with significant physical consequences for the patient. The consequences seem to be more severe for serious mental illness and have been particularly well documented for depression.

The effect of mental illness on the health of family members

Since the mid-1960s the effect of mental illness on non-mentally ill family members has been the subject of ongoing research. (20) Initially the studies looked at the 'costs' or burden to families of having a mentally ill member. In the 1980s the studies started to examine the consequences in terms of effects on the health of family members.

A number of studies (for example see (20, 21)) have examined the effect of mental illness in general. Most studies deal with patients with serious mental illness. Serious mental illness in these studies refers to patients who have a psychotic illness and/or have had a long-term relationship with psychiatric services. The effects of a seriously mentally ill family member on other family members is perhaps best summarised by Gallagher et al (20) when they state;

“(w)hen other predictors of health are controlled, sharing a household with a mentally ill person is associated with poorer self-reported physical health, increased risk of reporting some activity limitation, and increased service utilisation – both greater risk of

hospitalization, or visiting a physician, and a greater number of days hospitalized and number of physician visits among those utilizing these services.”

Some studies have examined patients from specialist services where the patient may be more typical of those seen in general practice. Svenson et al (22) studied the families with a drug dependent member. The drug dependent patient was in remission at the time of the study. They found that there was an increased level of morbidity in family members when compared to the general population. They noted that the pattern of morbidity was similar to that seen for actively drug-dependent patients.

Krantz and Moos (23) reported on patients attending inpatient and outpatient facilities with depression. Patients were either in remission or had ongoing depression. Their spouses were compared with each other and a group of community controls. Spouses in the remitted group had similar scores to the control group, except in the area of social and family problems, where the scores indicated more problems. Spouses in the unremitted group had significantly higher scores (ie more problems) in all areas.

In a study based in a centre treating resistant depression, Coyne et al (24) were able to show that 40% of respondents, who were living with a depressed person, met the criteria for referral for therapy due to their distress. That is 40% of the respondents were suffering from clinical depression.

Other studies have examined the effects of mental illness in a parent on children of the family. The outcomes include poor social and intellectual functioning, (25) increased rates of depression, (26) an increased risk of medical problems and hospitalisation (27), and an increased rate of psychiatric disorders in adult life. (28)

Studies from general practice

Very few studies have been carried out in general practice. In 1993 Leach et al (29) reported on the consultation rates for children of 174 families. A total of 134 families (77% response rate) completed all parts of the study. The General Health Questionnaire (GHQ) (30) was used to determine the mothers' mental state. "Analyses of the data showed that the factors most significantly associated with a child's consultation frequency were the psychological state of the mother, the mother's own consultation frequency and the number of children in the family; the last being an inverse relationship."

This study was carried out in a medical practice on an army base in the United Kingdom. Many patients were social class IV or V, although being service personnel they were well catered for as far as housing and community services.

In 1998 Sobieraj et al (2) reported on a study of the consequences of depression to the health of the family. The study, based in a suburban general practice in Australia, examined the burden of illness in families with a member suffering from depression and compared them to matched controls. They examined 88 families in each group. Scoring took place at the time of diagnosis and used the Duke University Severity of Illness (DUSOI) scale as their measure. Each family member was scored and the mean was taken to provide a family score. They calculated three scores, the family mean, the family mean with all patients with depression excluded and the family mean with the index patient excluded. In all cases the score for the families with a depressed member was significantly greater than the scores in the control families.

Possible explanations

A number of explanations have been proposed for the effect on the family. MacGregor (31) and, Solomon and Draine (32) have written about grief as a possible mechanism. MacGregor explored the literature around the grieving of parents for a mentally ill child and concluded that the bereavement process is significantly suppressed in parents and this adds to the distress within family members.

Solomon and Draine examined the family carers of severely mentally ill patients and found significant associations between the level of grief and the severity of the illness. They also noted that perceived burden correlated strongly with their measure of grief. It would appear that grief is one of the mechanisms that leads to distress within families.

Others have examined effects of stress on the immune system. In a naturalistic study Clover et al (33) examined the antibody levels in patients before and after a seasonal outbreak of influenza. They correlated the change in antibody titre with measures of family function. They showed that dysfunctional families, that is those families that were “chaotic” or “rigid” had higher rates of infection than “balanced” families. They examined for a number of confounders and did not find any that changed the outcomes. Thus it would seem likely that family dysfunction affects immune function and thus the susceptibility to influenza. This is similar to the responses seen in individuals.

Vedhara et al (34) examined the response to influenza vaccination of 50 carers of people with dementia. They were able to show that carers had a more limited response to influenza vaccination than the 67 controls. Only 16% of carers showed a response to at least one of the four vaccine components, compared to 39% of controls. This was a

statistically significant difference ($p = 0.0007$). They also noted higher cortisol levels in the carers and suggested that this may be the cause of the lower immune response.

Cohen et al (35) conducted a critical review of the literature relating to antibody response to immunisation. While not a meta-analysis the results provide convincing evidence for the effect of stress on the humoral immune response. They do note this evidence is most convincing for secondary responses rather than primary antibody production.

Parkerson et al in 1989 (36) examined the effects of the perception of family stress on individual family members. They used the Duke University Social Support and Stress Scale (DUSOCS) and the Duke University Severity of Illness Scale (DUSOI) to study 249 ambulatory patients aged from 18 to 49. "Stress from family members was strongly associated negatively with symptom status and emotional function and to a somewhat less, but still statistically significant, degree with physical function."

In a further study Parkerson et al in 1995 (37) examined health-related outcomes in relation to perceived family stress. "At baseline, patients with high self-reported family stress ... had lower quality of life, functional health, and social support scores and higher dysfunctional health and social stress scores than other patients. High baseline family stress scores ... predicted follow-up ..., frequent follow-up ..., referral and/or hospitalization ..., and high follow-up charges ... after controlling for the effects of social support, age, gender, and race." The study examined 413 adult patients and used the DUSOCS as a predictor of costs over the ensuing 18 months. The study was based in a rural primary care clinic in the USA and about 50% of the patients were African-American. Being African-American predicted a decrease in frequent follow-up, referral and hospitalisation, severity of condition at follow-up and follow-up charges.

Other studies have particularly looked at cardiovascular disease and demonstrate a significant association between cardiovascular disease and stress or mental illness. There are now a number of studies linking depression and myocardial infarction. (11, 38-42) In summary depression is a risk factor for myocardial infarction and for poorer recovery after myocardial infarction.

At a simpler and perhaps explanatory level there are now studies of psychosocial predictors and hypertension. For instance Levenstein et al (43) found, in a study of 2,357 adults that were followed over 20 years and were free of hypertension on entry, that low occupational status and performance and the threat or reality of unemployment increased the likelihood of developing hypertension, particularly in men. Sutton et al (44) have also demonstrated the deleterious effects of unemployment on the health of men.

The results of investigations into the biological reasons for this interaction were brought together in a single review. (45) The authors examine in some detail the interaction between physical and mental illness. In particular they highlight

1. The role of neuroendocrine mediators, particularly the hypothalamic-pituitary-adrenal cortex axis;
2. The role of neuroimmunological mediators (psychoneuroimmunology);
3. The action of neuropeptides such as endorphins; and
4. The interaction between stress/mental illness and cardiovascular disease.

The authors concluded "The scientific evidence ... provides some support for biobehavioural processes in mediating the effect of psychological states on disease onset and progression."

The stresses of living with a family member who is mentally ill

As indicated above the perception of stress may be the mechanism by which mental illness produces physical problems in family members. What causes the stress has been elucidated for the severely mentally ill patient, but unfortunately no research has been carried out in general practice.

Ostman et al (46) described the development of an instrument to measure burden on family members. The instrument was validated on in-patients, aged 18 to 70 years, in a psychiatric institution. Patients with alcohol abuse, mental retardation, severe dementia and forensic patients were excluded. A total of 71 committed and 95 voluntary patients were included in the study. Seventy-four relatives were also interviewed. The authors provided a list of fifteen burdens but indicate the first seven are the most significant for the relatives. They can be summarised as follows

- Restriction of leisure time;
- Interference with employment;
- Interference with a personal social life;
- Fear of physical violence by the patient;
- Fear of suicide or self-harm by the patient;
- Concern that the carer may develop a mental illness; and
- Concern that the relationship with the patient may be affected by the mental illness.

Stern et al (47) used a qualitative processes to analyse the narratives of family members caring for a relative with serious mental illness. They conducted in depth interviews with 7 relatives of 6 patients. All relatives had a significant carer role. The average length of contact with the mental health service was 15.6 years. The main themes applicable to patients seen in general practice can be summarised as follows;

- A patient with mental illness is sensitive;
- A family members' worst fear is that patient will suicide;
- Coping with behaviour that is not understood: how to combine acceptance with limit setting;
- Distinguishing “illness” from “personality” and “circumstances”;
- Unpredictability limits future planning;
- Fear that the illness will become a lifelong condition (if patient is young);
- Concerns over medication; and
- Stigmatisation.

In a study where 27 families with a depressed mother were observed for 10 days and their interactions compared to 25 normal families, Hops et al (48) found differences in the family interaction. They found that dysphoric (depressed) affect in the mother decreased aggressive affect in her husband and children.

Others have examined the effect of mental illness on the perceptions of family member of the ill patient. As an example Levkovitz et al (49) studied the spouses perception of a partner with depression during remission. “Well spouses of affective patients in remission

reported less consensus, unity and expressions of affection in their marital relationship, and ranked their ill spouses lower on positive qualities and higher on negative qualities than did controls. In addition, the well spouses reported receiving less emotional and practical support from their ill partners as compared to controls.”

These studies reveal the stresses caused by caring for a patient with a serious mental illness. Unfortunately there are no studies that examine the stresses of living with a patient with a mental illness that is being treated in general practice. It would however be expected that some of the factors mentioned above would apply in this situation. The author’s experience from interviewing families would suggest that family members express the following concerns:

- Patient with mental illness is sensitive:
- Distinguishing “illness” from “personality” and “circumstances”;
- Concerns over medication:
- Restriction of leisure time:
- Interference with a personal social life; and
- Concern that the relationship with the patient may be affected by the mental illness.

Summary

Severe mental illness in a family member places significant stress on the patient and other family members. This results in deterioration in the health of family members. Very few studies have examined the effects of mentally ill patients managed in general practice. Those that have been carried out have looked at depression, (2) which revealed an increase

in severity of illness in family members, and the children of emotionally stressed parents, (29) which revealed an increased rate of consultation for children with distressed parents. These results are generally consistent with the studies relating to severe mental illness.

Counselling in general practice

Distress is a frequent event in our lives. The death of a loved one, getting stuck in peak hour traffic, an argument, and failure to achieve our goals are just some of the multitude of causes of distress. In the majority of cases the distress is short-lived and resolves spontaneously. However when distress does not resolve people often seek help.

Seeking help may take many forms and varies with the cultural setting. The author's experience of general practice in Malaysia and Hong Kong indicates that psychological and emotional distress are handled within the extended family and the help of a doctor is not sought. In cultures with a strong religious belief, advisers and counsellors may come from within the religion. In Australia, where the extended family is not the norm (50, 51) and there is not a strong religious emphasis, (52) the general practitioner is often asked to take on this role. The author's experience confirms the high number of people who seek assistance from general practitioners for persistent distress.

The author believes the general practitioner is chosen for the following reasons.

1. Doctors are compassionate, sympathetic, understanding and held in high esteem.
2. General practitioners are readily available in the community.
3. Attending a general practitioner is not associated with the stigma of attending a psychiatrist or psychologist.
4. The costs of attending a general practitioner are subsidised by the universal health insurance in Australia.

An extensive search of Medline, Embase-Psychiatry and PsychLit failed to find any support for these suggestions. There is an extensive literature on the barriers to patient

disclosure of psychosocial distress (53, 54) but none on the reasons for such patients attending a medical practitioner in the first place.

When a distressed patient attends a general practitioner they often do so with physical symptoms. (55-57) Recognition of the distress can therefore be problematic for the general practitioner. (58-60) The majority of studies however do not show a worse outcome for unrecognised psychological problems. (61) There is now evidence that recognition of psychological distress is related to, among other things, the severity of the distress. (59) The natural history of these less severe levels of psychological distress seems to be for the majority to improve during the ensuing twelve months. (62, 63) There has not been any investigation of the effects of a general practitioner failing to recognise emotional distress on the doctor-patient relationship, the satisfaction with medical care or short-term outcome.

Much the same could apply to situations where the doctor recognises the distress and decides not to take any action or colludes with the patient to ignore the distress. The recognition and acknowledgment of the distress by the treating doctor is thought to be therapeutic. This is accepted by most brief psychotherapies, but the author was unable to find any reference supporting this after an extensive search of the Medline, Embase-Psychiatry and PsychLit databases.

Beyond recognition the doctor faces a number of options. The doctor can prescribe medication, refer to a mental health professional, undertake counselling or any combination of these options.

Prescription of medication

The prescription of medication is a common method of treating emotional distress in general practice. (64) The use of antidepressants for mild to moderate depression is accepted, but psychotherapy has been shown to be as effective as antidepressants (65, 66) and to reduce the recurrence rate. (67) Despite the documented effectiveness of antidepressant medication, research by Jorm et al in Australia (68) and Angermeyer and Matschinger in Germany (69) has revealed the very negative view the public has of the use of medication for psychiatric illness.

A recent paper (70) discussed the reasons for the failure of a trial that used general practitioners to recruit patients to a study comparing a method of psychotherapy to the prescription of selective serotonin re-uptake inhibitors (SSRIs) for mild depression. The authors concluded that the general practitioners preferred to prescribe SSRIs, despite most of the general practitioners having undertaken a higher degree in general practice psychiatry.

For distress, anxiety and similar conditions there has been a tendency for general practitioners to prescribe benzodiazepines. (64) It is widely accepted that benzodiazepines are addictive and show tachyphylaxis, (71) and there are significant side effects including increased falls in the elderly (72) and an increase in motor vehicle accidents. (73)

The main difficulties with medication for emotional distress are the side effects and the inability, in the case of benzodiazepines, to “cure” the problem. As mentioned above the natural history of these conditions is to spontaneously resolve and to use medication with an addictive potential seems inappropriate.

Referral to a mental health professional

For a severe mental illness this is quite an appropriate course of action. Much of the distress seen in general practice does not warrant referral and is often resisted by patients because of the stigma associated with receiving mental health care. (74)

In the United Kingdom the use of professional counsellors in general practices is common. (75-77) Counsellors are trained in Rogerian non-directive counselling (78) and evaluations reveal they are well received by patients, (77, 79-82) but the outcome over twelve months does not differ from usual general practitioner care. In all these studies there has been no attempt to define the usual care provided by general practitioners, and thus we are not sure that the general practitioners have not been counselling.

In one interesting study, (63) four hundred and sixty four patients with depression were randomised to, or chose usual general practitioner care, non-directive counselling or cognitive behavioural therapy (CBT). At four months those patients receiving non-directive counselling or CBT did better, as measured by change in Beck Depression Inventory scores than those receiving usual general practitioner care. At twelve months there were no significant differences between the three groups.

The Cochrane collaboration has undertaken a systematic review (83) of the use of counselling in primary care for the treatment of depression. They found four randomised controlled trials of variable quality with suggestions in two of the studies that randomisation had been compromised. This review confirmed the satisfaction of patients referred for counselling and the limited effect size (0.3).

Counselling

Counselling of distressed patients by general practitioners is thought to be common.

Swansson (84) surveyed 301 Ontario family physicians and received useable replies from 201 (65.9%). At least one half-hour psychotherapy or counselling session was carried out per week by 89% of respondents. Supportive psychotherapy made up 71.7% of the psychotherapy. This study relies on what family physicians report without any attempt to corroborate the figures.

Robinson et al (85) examined the use of cognitive behavioural therapy (CBT) techniques by surveying 155 patients with depression being treated by a primary care physician. A majority of patients (61%) reported physician advice that could be construed as CBT. Patient selection was based on the prescription of an antidepressant, thus this study did not examine counselling without the prescription of an antidepressants. This study relies on the memories of patients which are not always reliable. (86, 87)

Olfson et al (88) asked seven physicians to report the use of psychological measures after seeing 937 adult patients. At least one psychological intervention was used for 24.1% of patients. Mental health interventions included

Listening to the problem	22.4%
Giving advice	19.0%
Discussing the diagnosis	11.4%
Counselling the patient	8.4%
Counselling the family	0.6%

Additional interventions included referral to a mental health professional or organisation (3.5%) and prescription of psychotropic medication (5.1%). Prior to the consultation patients completed a questionnaire to assess mental health status. These results were not revealed to the physicians. Of those who reported poor emotional health 66.7% received at least one of the mental health interventions. Once again this relies on reports of what happened without any attempt at corroboration.

One study that attempted to deal with a reporting bias was carried out by Robinson et al. (89) This study was part of a larger study examining the effects of a communication skills intervention. Audiotapes were made of 652 consultations, but this paper reported on the tapes of 308 patients who had General Health Questionnaire (GHQ-28) scores that indicated psychological distress. Of the 308 patients with positive GHQ-28 scores, only 157 (51.0%) disclosed distress to the physician. Where distress was disclosed 64% of visits included psychosocial counselling. This figure excludes the effects of the training course. The mean duration of counselling was 5.2 minutes and the total consultation time increased by 28%. The physicians under-reported their counselling by 47%, but 31% reported counselling that was not apparent on the audiotapes.

Very few studies have examined the outcomes of counselling by general practitioners. An Australian study carried out in 1983 (90) compared outcomes for a mix of psychiatric problems. Three treatment methods were compared:

- Brief psychotherapy performed by a psychiatrist working within the general practices;
- A weekly therapeutic conversation between the patient and his or her general practitioner; and
- No active intervention.

Over six months there was no difference in outcome. The mix of conditions and poor recruitment with consequent reduction in power limited the study's ability to demonstrate positive outcomes.

Mynors-Wallis et al (91) compared 4 treatment outcomes for major depression. Treatments consisted of

- antidepressant medication alone (GP),
- antidepressant medication plus problem solving therapy (GP),
- problem solving therapy alone (GP), and
- problem solving therapy alone (practice nurse).

A research general practitioner or a research practice nurse delivered the problem solving therapy. The therapy lasted for 12 weeks and after that general practitioners were free to treat the patients in whatever way they felt appropriate. The 151 patients were followed for a total of 52 weeks and re-assessed at 6, 12 and 52 weeks.

All groups showed clear improvement over twelve weeks. There was no significant difference between any of the treatment groups at any stage and there was no difference between therapy provided by a general practitioner or practice nurse. For ethical reasons there was not a placebo control group so the authors are unable to say whether the response is due to the intervention or not.

A recent review of the literature (92) confirmed the over-reporting of counselling activities by general practitioners (when compared to observers) and the paucity of studies of

effectiveness. Those that had been undertaken had major methodological flaws which limited the interpretation. They were however optimistic that some recent studies had started to provide evidence of effectiveness.

Conclusions

Overall counselling does not appear to cause harm to patients with emotional distress. It is likely that the natural history for most patients receiving counselling is to improve without intervention, although evidence is starting to appear of positive outcomes. Counselling is generally free of side effects, patients are highly satisfied with the result, and monitoring of mental state and compliance are easy for the treating doctor.

Family therapy

“Family therapy may be defined as any therapeutic endeavour that explicitly focuses on altering the interactions between and among family members and seeks to improve the functioning of the family as a unit, or its subsystems, and/or the functioning of individual members of the family.” (93)

This quotation is one of a multitude of definitions for the very diverse field of family therapy. (See (94-99) for other definitions.) The definition quoted above succinctly sets out the basic features of family therapy –

- It is a therapeutic endeavour;
- It explicitly focuses on the interactions between family members; and
- It aims to improve the functioning of any or all of the family, family subsystems or family members.

The following potted history of systemic family therapy is based on articles by Boston (100) and Stierlin. (101) Family therapy arose in the 1950s when the work of Weiner (102) on cybernetic systems and their application to biology was developed by von Bertalanffy (100, 103) into general systems theory. Cybernetics is “... the science of control and communication in animals and machines.” (104) It is particularly concerned with feedback mechanisms. The General Systems Theory proposes that living organisms are “... characterized by two apparently contradictory functions: the homeostatic tendency on one hand, and the capacity for transformation on the other.” (105, page 4) In 1968 Minuchin reported his structural family therapy model (94) which was concerned with the boundaries between, and optimal organisation of the various family subsystems. In 1972 Bateson

(106) developed a cybernetic model for the family and systemic family therapy became an accepted form of therapy.

Two popular models of therapy were the Milan School of Palazzoli and her colleagues (105) and “Solution-Focussed Therapy.” (107) The Milan method promoted the use of teams in therapy and careful exploration of the role of the problem within the family. They were concerned about the paradoxical nature of the symptom in that it maintained the status quo. For instance a rebellious, delinquent adolescent may maintain his or her parent’s marriage through his or her difficult behaviour. When the symptom is removed the parental difficulties often become apparent.

Solution Focussed Therapy is a very brief method that examines when the symptom does not occur and tries to promote those situations. These methods promoted the therapist as an expert who sat outside the system and helped direct the participants to a better way of living. This was known as first-order family therapy.

In the 1980s the work of Maturana and Varela (108) shifted the focus markedly when they proposed that there could not be an independent observer. This understanding shifted the therapist from being an independent expert separate from the family system to a non-expert with his or her own beliefs or feelings who joined with the family system in an attempt to change the system. This became known as second-order family therapy and has become one of the major differences between systemic family therapy and other psychotherapies. Included with second order therapy was a shift of power from the therapist to the patient, recognition of the patient as the expert in the problem and a more collaborative approach to therapy.

Some family therapies however went further and incorporated a post-modern philosophy, (109) where words are seen as creating a reality (social constructionism). (100) Therapy is then seen as creating a space for a conversation about the problem.

The systemic family therapy approach

Systems theory assumes that people live in the context of their family. Symptoms, particularly those seen as psychological or psychiatric, are attributed to family dysfunction. Behaviour is seen as being “circular” and therefore repetitive.

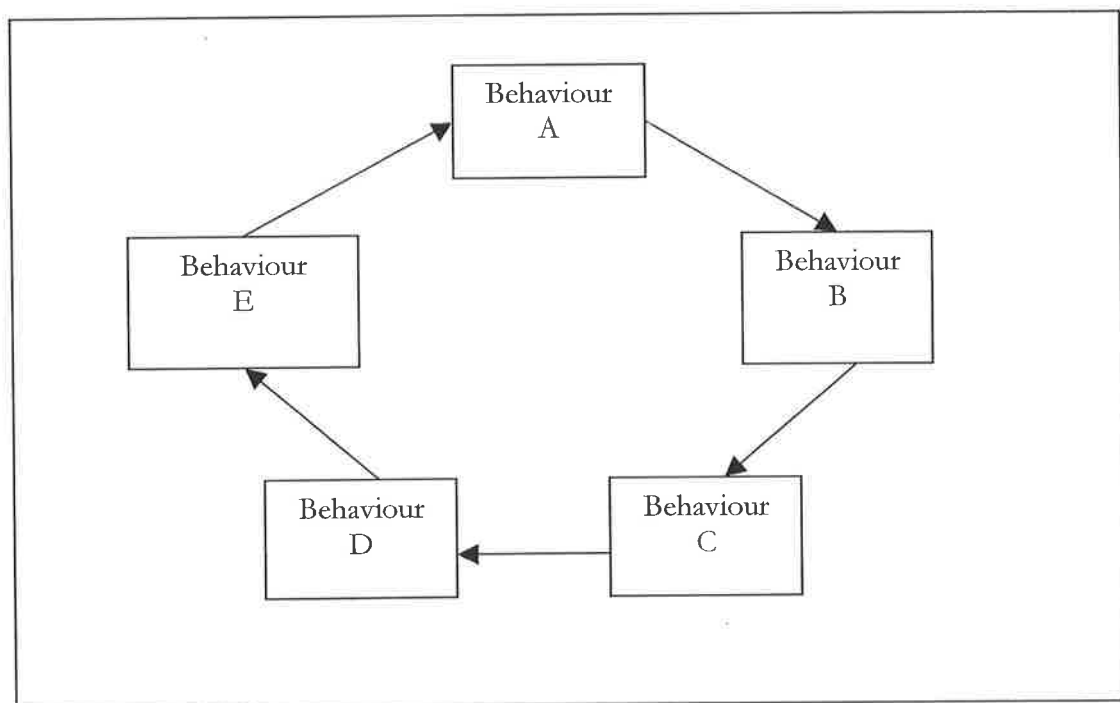


Figure 1 The circular pattern of behaviours

Various styles of questioning are used to discover the pattern. When the pattern is uncovered an intervention can be made at any point in the circle of behaviours. Often

preliminary work is required to develop the family's or patient's understanding of the problem and a repertoire of behaviours to enable the intervention to "stick."

Consider the following example.

David is a ten-year-old boy who has started assaulting fellow students in the schoolyard. As background his parents separated three years ago and David and his younger sister continued to live with their mother. Father now lives with a new partner and her three daughters. Father has recently bought a new car and house. Mother lives on the supporting parent's pension and David and his sister consider themselves to be poor. During the first family interview, which father attends, David is able to express significant anger to his father about father's relative wealth and access to the "good things in life." David feels his father has deserted the family.

It would be possible at this stage to suggest that David is acting out and suffers from a conduct disorder. (110)

A family therapist however, will explore the pattern of behaviour further. In this case, in three hours, spread over two weeks, the following circular pattern was uncovered.

When David hits a fellow student the school rings to inform his mother. Mother then rings father and they meet to discuss what to do about the problem. With mother and father talking David's behaviour improves. Mother and father then stop talking and after a short period of time David hits another student.

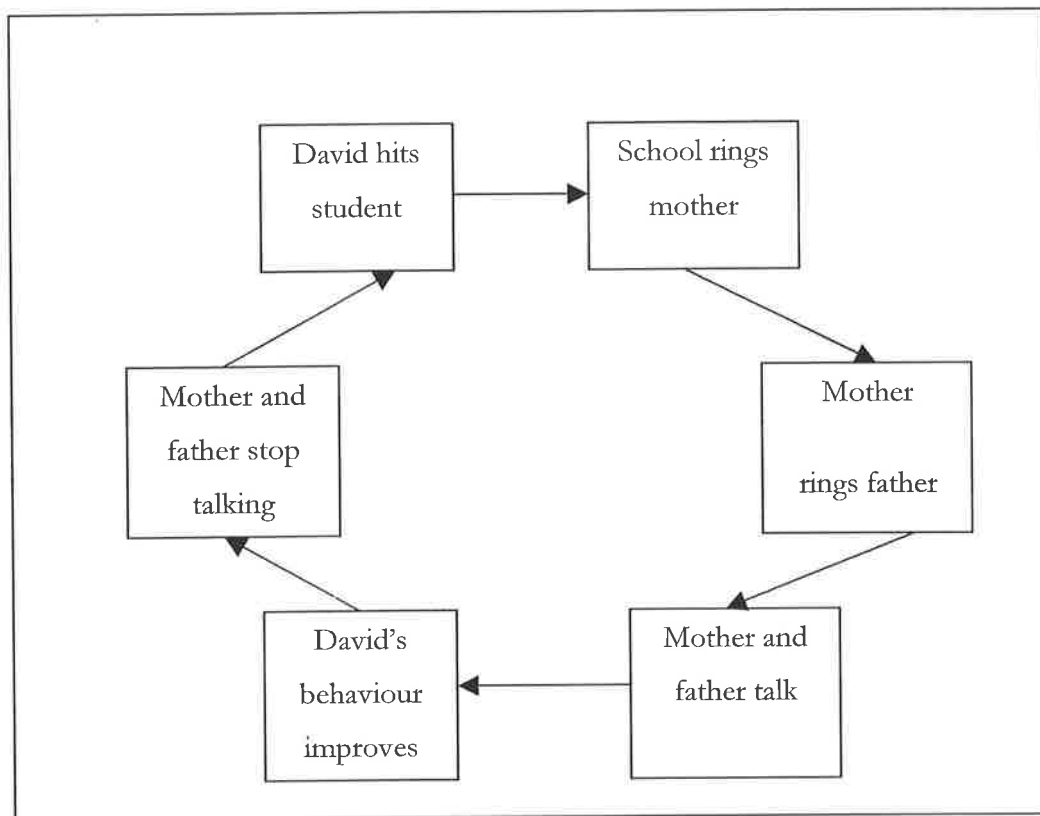


**Figure 2 The circular pattern of
behaviour**

The cycle was also explored at deeper levels, particularly at the level of the meaning of a behaviour or interaction to individual members of a family. It is possible to believe that David felt the talking between his mother and father indicated that there was a chance of reconciliation. It is not however necessary to attribute such intention to David's behaviour and to only acknowledge that the particular behaviour has a particular outcome which maintains that behaviour. (111)

The intervention in this case was then relatively straightforward and it was suggested to mother and father that they finalise their divorce to demonstrate to David that there was

no possibility of their reconciliation. By ensuring that David believed that his parents would not, and could not reconcile, the cycle was broken and the problematic behaviour ceased. There were still some issues around David's anger and financial support for David and his sister, but the parents felt they could deal with these without therapy.

In this case, as in many others, the symptom presented to the therapist was one that tried to maintain the status quo.

The model of therapy used in this study

The model of therapy used in this study is broadly based on the work of the Palazzoli and colleagues, (105) but incorporates second-order methods. That is, the therapist is seen as joining with the family system to explore with them the possibility of change. Families are seen every two to three weeks and most therapy is finished within two to three months. With the exception of teaching and complicated problems, a team approach is rarely used. A method of consultation about therapy has been developed for cases that are not progressing. The overall method was developed by Robinson and Sanders (112, 113) and modified by their experiences in dealing with difficult cases in the workers' compensation system.

Their method, which is continuing to evolve, has the following features:

- It examines as many features of the family, wider systems (such as work, community and neighbours) and effects of the problem as possible. (Unlike the brief therapies it is not symptom focussed, but aims to explore as much of the problem as possible);
- Specific questioning styles are used to elicit the circular pattern of behaviour;

- In addition to behaviour the circular patterns are explored at the emotional and meaning levels;
- Intervention(s) is/are designed to affect as much of the system as possible; and
- Therapy is conducted with as many people who attend.

The author undertook a formal 2-year training program in Family Therapy conducted by Robinson and Sanders.

Family therapy without the family

From the descriptions above it is apparent that family therapy involves a specific approach to problems and is not particularly concerned about the number of “patients” attending. The assumption that family therapy only occurs if the family is in the room has been debated in the literature. Raffa et al (114) used “a minimum of one parent and one child” as part of the criteria for family therapy. Carr (115) however argued that “Effective marital therapy may also be conducted with one partner only under certain circumstances.” Shadish et al (96) included as family therapy those therapies with only “one patient in the room” if the therapy “explicitly focuses on altering the interactions between or among family members” (93)

Stierlin (101) in his review of the directions of family therapy notes that there is increasing tendency for family therapists to deal with the “individual in the system” or the “individual as a system.” Stierlin does note however that “... much conceptual work remains ... to be done before the ... contradiction between the individual and the system can arrive at a reconciliation”

The model of family therapy with one person is starting to gain recognition. A recent (July 2001) article by McGoldrick and Carter (116) examined family therapy with one patient in some detail. They particularly highlighted the work of Murray Bowen who pioneered this style of work the late 1970s. They liken the role of the therapist to that of coach to the individual and the individual's relationship with family members.

The author's experience is that family therapy is easier with the family in the room, but most patients attending general practice expect to be seen on their own. The mind-set associated with family therapy allows a structure to be placed around the process of therapy that enables effective therapy to be carried out no matter how many people are in the room.

Evaluation of family therapy

In 1977 Smith and Glass (117) conducted the first major evaluation of psychotherapy and reported that all forms of psychotherapy had the same outcome. They did not include family therapies within the models of therapy that they investigated. Subsequent studies (118-122) have supported the equivalence of different psychotherapies and this has resulted in discussion of what are the factors that lead to psychotherapy's effectiveness. They are perhaps best summarised in an article by Stiles et al. (119) They explored the possible reasons for research indicating the equivalence of different forms of psychotherapy and proposed the following possibilities.

- The sensitivities of the measures used in the meta-analyses are insufficient to detect any difference.

- There are certain methodologies that are superior for a given patient, with a given problem in a given setting. This is known as the matrix paradigm where the matrix is “treatment x therapist x client x problem x setting.” (119)
- Specification of treatment in studies may be too restrictive to allow for individual variations that could maximise effectiveness.
- Outcome measures may be too imprecise to allow differentiation between methodologies.
- It is possible that there is a common factor in the therapists and this factor is the basis of the effectiveness.
- Perhaps the attitudes of patients who seek help are different and it is their expectations and positive involvement that makes a difference.
- The therapeutic alliance may be the prime reason for change.
- There may be an inclusive methodology that incorporates all methods of psychotherapy.
- Finally, it may be that psychotherapy is too all-encompassing to allow precise evaluation of any changes.

Like psychotherapy, Family Therapy has been subject to evaluation, but methodological difficulties mean that interpretation of the data is difficult. The difficulties include

- The lack of a classification system.

There is not a system of classification of conditions treated in family therapy. It is therefore difficult to ensure comparability of patients. This however is being tackled. (123)

- Difficulty comparing treatment modalities.

Comparison between different treatment methods is subject to bias in that the different arms of the trial may not have the same standard of treatment.

- The difficulty evaluating outcomes.

This has proved a challenging area in most types of psychotherapy outcome research. It is particularly difficult in the Family Therapy area where there are multiple people receiving therapy. For example some studies have shown a significant improvement in family or couple functioning after marital counselling, but little change in marital satisfaction. (124, 125) It is possible that one partner may go into therapy to “save” a marriage while the spouse may want to end it. How is the success of therapy measured in this case? Is the aim of family therapy to keep families together or to allow amicable divorces as an option?

Despite these difficulties there have been attempts to evaluate family therapy

Shadish et al (96) examined 163 randomised trials of marital and family therapy. The 163 trials included 59 dissertations. They concluded that “[m]arital and family psychotherapy clients have a more improved outcome, compared with control clients at posttest.” They found some theoretical orientations appeared superior to others, but these differences disappeared in regression analyses that adjusted for covariates. The only exception to this result was the consistent failure of humanistic therapies to demonstrate significant positive effects. Humanistic therapies included the therapies of Virginia Satir, Carl Rogers and client-centred therapy. If dissertations were excluded the mean effect size was 0.95, but if

dissertations were included it dropped to 0.74. The difference probably represents a publication bias.

In a further analysis of their work Shadish et al (126) confirmed the above findings and also concluded that marital and family therapy is not superior to individual therapy.

Carr (115) recently reviewed the research findings relating to family therapy and found them to be generally supportive of family therapy being effective therapeutically. Other reviews of the literature have been carried out. (99, 114, 125, 127, 128) These articles promote family therapy as an effective treatment modality for most problems.

There has been increasing criticism of family therapy (and other psychotherapies) in that outcomes of carefully controlled trials are different to the outcomes for patients seen in routine practice. Enthusiasts, using a manual to prescribe therapy for well-selected families with only one problem carry out most randomised studies of psychotherapy and family therapy. Shaddish et al (96) did show an effect for allegiance, but this disappeared using multivariate methods.

Weisz et al (129) have demonstrated the difficulties of applying research based therapies in a clinic setting. They compared the outcomes of studies of child and adolescent psychotherapy. They note “.. most studies involved experimental procedures, non-referred subjects, specially trained therapists with small caseloads, and other features that may not represent conventional clinic therapy. Research focussed on more representative treatment of referred clients in clinics has shown more modest effects; in fact, most clinic studies have not shown any significant effects.” They do warn, however “[i]nterpretation of these

findings requires caution; such studies are few and most could profit from improved methodology.”

Shadish et al (126) also discuss this issue and comment that “..psychotherapy researchers have produced an enormous amount of evidence in favour of its efficacy, but perhaps not enough for its effectiveness.” That is, psychotherapy can be shown to be effective in the research setting (efficacy), but there is less evidence to demonstrate positive outcomes in the general clinic setting (efficiency). They also note “.. the general phenomenon of reduced effectiveness when going from the laboratory to the clinic is not at all peculiar to psychotherapy. Rather, it is a general phenomenon that occurs in much of the public health literature.”

Hampson and Beavers (130) examined outcomes in the clinic setting, where various methods of family therapy were used. They found that overall 75% of families showed at least some improvement. They were able to show that the level of family functioning prior to therapy was the best predictor of outcome. There was also a positive association with the length of therapy.

A recent review (131) of the efficacy versus effectiveness argument examined the debate in great detail. The authors felt the ongoing belief of therapists in their own style of therapy conflicted with the research outcomes. They believed a final assessment could only be made after some of the large studies currently under way had been published.

Not all studies have given unequivocal support to family therapy. One of the biggest with a negative outcome is “The Consumer Reports Study.” (118) The study was carried out in USA and relied on a supplementary survey to an annual survey carried out by a consumer

organisation. The survey was sent to 180,000 members. About 22,000 responded and of this group 7,000 responded to the mental health questions.

Three thousand of the respondents had talked to a friend or relative when they “experienced stress or other emotional problems” in the previous three years. The remaining 4,000 consulted a professional therapist. The main results of interest to this study can be summarised as

- “Treatment usually worked.”
- “While all mental health professionals appeared to help their patients, psychologists, psychiatrists, and social workers did equally well and better than marriage counsellors.”
- “No specific modality ... did any better than any other for any problem.”

There are major limitations in this study, with an obvious selection bias (who were members of the organisation – probably white, middle and upper class) and a response bias (who among those who received the questionnaire responded about their emotional problems). There was no definition of the emotional problems, and no reasons were explored for therapy from marriage counsellors being less successful.

A recent paper (132) explored these criticisms in some detail. After comparing with other sources of data they concluded that there is unlikely to have been a response bias. They do note that respondents were more likely to be male, older and better educated than the usual patients who saw mental health professionals. They concluded that the study is quite consistent with prospective studies and there are few inherent biases in the results.

Some of the assumptions used in the comparisons seem to stretch figures to suit their arguments. For instance 32% of people who returned the survey indicated they had sought help for distress in the previous three years. The authors assumed all of those who sought some support for help were mentally ill and equated this with the three-year prevalence of psychiatric problems (35%) in the community. As indicated above almost 50% of those responding indicated they talked with a family or friend. It is unlikely that this entire group had a diagnosable psychiatric condition and thus the 32% is likely to be an overestimate the prevalence of psychiatric conditions. Assumptions such as this diminish the defence of the study.

The study does highlight the general supposition that the method of therapy is generally irrelevant to the outcome, but it raises some questions about marital therapy. It may be that marriage counsellors are only able to please about 50% of their clients. It also needs to be emphasised that family therapy is more than marital therapy.

In 1995 Pinsof and Wynne (128) reviewed the empirical evidence presented in a special edition of the *Journal of Marital and Family Therapy* (Volume 21, No 4) and they concluded that

- Marital and Family Therapy (MFT) works in a large number of conditions;
- MFT is not harmful;
- MFT is more efficacious than standard and/or individual treatments for a number of conditions;
- There are no scientific data to support the superiority of any particular form of marital or family therapy over any other;

- MFT is more cost effective than standard inpatient treatment for schizophrenia and severe conduct disorders and delinquency (very limited number of studies); and
- MFT is not sufficient in itself to effectively treat severe disorders or problems.

The effectiveness of family therapy in management of schizophrenia has been well documented. It is particularly effective in prevention of relapse. Lambert (133) goes so far as to state that “the strength of the evidence for the effectiveness of family psychoeducation in preventing relapse is perhaps second only to that for antipsychotic medications. Despite the evidence ... the literature have suggested that family psychoeducation interventions are highly underutilized.” This echoed by Thornicroft and Susser (134) when they note “One of the most striking aspects of the treatment of schizophrenia is the disjunction between the strength of what is known of the efficacy of family psychosocial and psychoeducational methods of treatment, and the poor availability of these treatments in ordinary clinical settings.”

Overall the differences between the different types of psychotherapy are in process rather than outcome. The choice of therapeutic method therefore becomes more one of personal choice, than of inherent superiority of process or outcome.

Family therapy in general practice

Very little research has been undertaken to examine the use of family therapy in general practice. The Primary mental health care Australian Resource Centre (PARC) project database (135) contains reports of two family therapy projects in Australian general practice. The first (PARC ID 646) reported of a trial of family therapy in a group of general practices in Western Australia. The service saw 75 families and a satisfaction

survey undertaken with 34 families who completed therapy. Interestingly half of the 34 families consisted of just one patient. Seventy percent of clients reported that the problem for which they sought help was reduced or no longer a problem.

The second report (PARC ID 688) concerns a similar service in Queensland. This project was unevaluated, but the report did note that the service was heavily booked, with long waiting times.

Family therapy and cognitive behavioural therapy

Cognitive Behavioural Therapy (136-138) has been subject to the most rigorous of evaluations. It has been demonstrated to be effective in a number of conditions and is currently recognised as the preferred psychotherapy by Australian Psychological Society. (139)

The conditions where CBT is of proven efficacy include

- Phobic anxiety and panic attacks, (140)
- Depression (141) and prevention of relapse in depression, (67)
- Anxiety, (141, 142)
- Bulimia nervosa, (143, 144)
- Chronic pain, (145)
- Social phobia, (146) and
- Chronic fatigue. (147)

Despite the success of CBT in some areas there has been an increasing chorus of doubts about its effectiveness. This was highlighted by an article (148) in a recent “Education and Debate” in the British Medical Journal. Holmes, a consultant psychiatrist and

psychotherapist, argued that CBT produces positive research results because it is targeted at symptoms. He also argued that psychotherapy is more than symptom control and is “essentially concerned with people” and has superior outcomes. Three other psychotherapists (149-151) supported his arguments, while one psychologist (152) wrote passionately about the success of CBT.

The authors limited experience of patients that have seen experienced CBT practitioners is the positive effects while controlling the symptoms are not as pervasive as those achieved by more interpersonal or relationship based psychotherapies. The author’s analysis of the literature leads him to concur with the arguments of Holmes (148) and Bolsover (149) that the evidence base for CBT is limited.

There have been very few comparative studies of CBT and systemic family therapy. Those studies that have been reported indicate the equivalence in outcomes for the two methods. A recent study by Birmaher et al (153) examined the outcomes of CBT, systemic family therapy and non-directive supportive therapy for adolescents with major depressive disorder. They found that the different modalities were equally effective over 2 years. Parikh et al (154) reviewed the literature relating to the use of psychotherapies as an adjunct to the treatment of bipolar disorder. They found the studies to be of limited methodological rigour. They noted in their summary that “[e]vidence is most robust for the efficacy of psychoeducation and family therapy Group therapy, cognitive behavioural therapy, and behavioural family management therapy are supported by weaker evidence.”

Why family therapy in this study?

For general practice, family therapy has a number of distinct advantages.

- Family therapy considers the “patient” in the context of his or her environment and has become closely allied with the biopsychosocial model of general practice. (155) It therefore reflects the processes that already occur in general practice. The general practitioner will already have experience of the family as a unit.
- Because the symptom/problem is conceived in interactional terms the general practitioner is not required to use specialist psychiatric nosologies to define the problem. As pointed out by Goldberg (61) such classification systems are inappropriate in general practice.
- It is generally a brief method of therapy, which is appropriate in busy general practices.
- It does not promote the use of medication.
- Patients can conceptualise problems in interactional terms more easily than in biomedical models.

It can be used successfully as an adjunct in the treatment of severe mental illness. Examples include the maintenance of progress after discharge from hospital after anorexia nervosa, (156) reduction of relapses in schizophrenia (157, 158) and bipolar disorder. (154, 159)

The limitations are relatively few and relate to the differences from the “medical model” of mental health problems as set out in psychiatric nosologies such as the Diagnostic and Statistical Manual (DSM-IV) of the American Psychiatric Association. (110) This can lead to conflict in the diagnostic process. The author has experienced this when certifying illness in terms of the biomedical model, while conceptualising the “disease” and treatment in systemic family therapy terms. It has also been problematic in court and tribunal

settings and has created a difficulty in this study where medical records could not be used to make a DSM-IV diagnosis with any degree of certainty.

Summary

The evidence supports family therapy, when carried out in controlled conditions by psychologists, social workers and psychiatrists, as an effective method for treating individuals, couples and families for most psychological and psychiatric conditions. There have not been any studies of the use of family therapy in general practice or by general practitioners.

The literature does suggest that the model of psychotherapy is unrelated to the success of the therapy. It is some other factor or factors than the model of therapy that determine the outcome. As therapist allegiance may have a role in outcomes, it is important for the therapist to feel comfortable with the method and the constructions imposed by the method. The author, who conducted the therapy in this study, is a trained family therapist who feels comfortable using family therapy and has been impressed by its effectiveness in his hands.

Acute myocardial infarction and breast cancer

In order to determine the significance of any changes detected in the experimental groups it was decided to examine physical conditions that are known to create stress with in family members. The conditions needed to

- have a narrow time window when the condition could be said to have occurred;
- be stressful to other family members;
- occur at an age that provided a good chance of finding a family structure;
- be of sufficient prevalence to produce sufficient cases for analysis; and
- provide a variation in the degree of distress caused.

Myocardial infarction and breast cancer were chosen as they met these criteria.

Consideration was also given to other conditions such as rheumatoid arthritis, colon cancer, cerebrovascular accident, major head injury and diabetes mellitus (type 1), but in each case they did not meet all of the criteria above.

As well as the changes in these two conditions this part of the investigation would also provide a measure of the utility of the DUSOI.

Breast cancer

Lewis et al (160) described their decision to include breast cancer in their study of family functioning when the mother has chronic illness as follows.

“Mothers with nonmetastatic breast cancer were selected because of the expected association of horror, decay, suffering and death typically associated with cancer. Their disease no longer required pharmacological management but did potentially pose an ongoing existential threat.”

The patients in the study of Lewis et al were more than a year past surgery which meant they differed from the current study where patients are in the first year after diagnosis. Breast cancer surgery also leaves noticeable scars which are constant reminder to the patient. This reminder, plus that caused by frequent discussion in the media increase the existential stress for the patient and thus, the author hoped, increase the stress within the family.

There is only a limited literature on the effects of breast cancer on family members. The National Breast Cancer Centre recently published evidence based guidelines (161) on psychosocial needs after the diagnosis of breast cancer, and only mentioned the spouse once, and the family not at all.

Those studies that examine psychosocial issues in the first year after surgery generally examine the issue of support for the patient and communication between the patient and her spouse.

Hoskins (162) examined “... differences in fulfilment of emotional and interactional needs between 128 breast cancer patients and 121 partners ...” at six times during the first twelve months after surgery. Hoskins measured satisfaction with communication, consideration of feelings and sharing of companionship for patient and partner. Seven to ten days after

surgery the partners were more dissatisfied with these characteristics of the relationship than patients. At all other times in the first year patients were more dissatisfied than their partners. All differences were statistically significant. In examining the longitudinal data Hoskins notes "[t]he findings ... support those of investigators who have noted that spousal adjustment may not be as positive as that of patients The crisis of cancer draws attention to the needs of the patient while the spouse may be left to cope with the demands of illness with little or no support."

Neuling and Winefield (163) examined the effect of social support on 58 patients with breast cancer. Patients wanted family members to provide empathic (rather than informational) support. Family members gave a considerable amount of empathic support but patients were generally dissatisfied with it. Friends were also seen as providers of empathic support, but the amount was far less than that from the family, but generally patients were happier with the amount provided. Surgeons were seen as providers of informational support and gave far more than family members. Despite this surgeons were heavily criticised by patients for not providing enough information. Interestingly during hospitalisation, increased support from friends was associated with higher anxiety, but increased support from families was associated with lower levels of anxiety.

Rees et al (164) conducted focus groups with patients and then spouses to determine the information needs after the diagnosis and treatment of breast cancer. The number of spouses in this study was small (nine) and a number were several years after surgery. It is of interest however that spouses seemed to divide into two groups. The first went out of their way to seek more information, sometimes to the point of making themselves unpopular with hospital staff. The other group did not want to know "... anything about

it.” This group wanted to deny the problem and get on with their life. It is interesting that family members like this would be involved in a focus group.

Omne-Ponten et al (165) compared psychosocial outcomes for mastectomy and breast conserving surgery in 99 women during the first thirteen months after operation. They showed that women with breast conserving surgery did consistently better in all psychosocial areas measured except sexual disturbance, which occurred more frequently in the breast conservation group. Women who were married did better. Women who were employed and had radiotherapy did worse at four months, but at 13 months radiotherapy was seen as reassuring.

Rowland et al (166) also compared outcomes for different types of surgery. Although this study examined a large group of women (1,957) recruiting letters were sent to 6,364 identified breast cancer sufferers. For this study three groups were defined, mastectomy, lumpectomy (a breast conserving surgery) and mastectomy with reconstruction. The groups were not directly comparable as the mastectomy with reconstruction group were younger, better educated, more affluent and white. Women in the mastectomy groups had more physical restriction, but there were no differences in emotional, social or role function. Again the only exception to this was that more women in the reconstruction group reported that the cancer had a negative effect on their “sex lives.” In this study however, those women who had lumpectomy had the lowest level of sexual difficulties. The authors noted that the most significant psychosocial changes seen in the first year related to body image and feelings of attractiveness.

A recently published study (167) followed 198 patients for two years following surgery for breast cancer. A total of 73% of patients completed the two-year follow up. They showed

that women who underwent mastectomy with reconstruction had greater mood disturbance ($p = 0.002$) and poorer well-being ($p = 0.002$) than women who had mastectomy alone. This difference persisted to 18 months. Patients who had breast-conserving surgery also had more mood disturbance than those who had mastectomy alone, but the difference was only significant 12 months after surgery. The reasons for these differences are not clear, but may reflect the personality of women who request reconstruction.

An Israeli study (168) examined the coping of 73 women and their spouses, two to six months after the diagnosis of breast cancer. At this stage the patients' distress was greater than their spouses, but the levels of psychosocial adjustment were similar. This research suggested that spouse and dyadic (couple) distress was related to the level of patient distress.

Dorval et al (169) examined the incidence of marital separation following breast cancer. Anecdotally there have been suggestions that there is an increased rate of marital separation after the diagnosis of breast cancer. The study is somewhat confusing with two cohorts from different periods of time. Each cohort was assessed at slightly different intervals. The use of the two cohorts did enable one group to be followed over 5 years. The authors reported that "...marital breakdown is not more frequent among breast cancer survivors ... in the 3-8 years after diagnosis." They also found that those patients who reported a "... poor marital adjustment at the time of diagnosis are the women who are most likely to experience further marital difficulties."

Patient distress has been shown to persist. (170) This study examined 87 patients who had undergone curative surgery for breast cancer. They found reduced quality of life persisted

long after the surgery (> 5 years). The reduced quality of life was particularly seen in the areas of emotional, social and sexual functioning. These areas are particularly likely to impinge on family members.

An Australian study (171) examined 303 women three months after surgery. They found 45% of the women had a diagnosable psychiatric illness. One third of women felt less attractive and most had lost interest in sexual activity.

So although the diagnosis and treatment of a breast cancer is a traumatic event it may not be as existentially threatening as Lewis et al (160) suggest. In their study, which compared patients with breast cancer at least one year after surgery with patients with diabetes mellitus and fibrocystic disease of the breast, they found breast cancer produced least disruption to family functioning. In order to explain why, they conducted individual interviews with the spouses and found the spouses of patients with breast cancer "... had more elaborated explanatory models for their wife's behaviour and affect. Namely, they were able to explain away their wife's behaviour in terms of her illness." This did not occur in the other two groups. This study is different to the ones discussed previously. The families all had to have a child aged 6-12 years and mother's illness had to be stable. Thus patients were younger and further from diagnosis and treatment than the studies reported previously.

Overall the diagnosis and treatment of breast cancer is psychologically and physically traumatic to the patient, but the evidence suggests the psychosocial family problems are limited in severity.

Acute Myocardial Infarction

The evidence around the impact of acute myocardial infarction (AMI) on spouses indicates a higher degree of distress to that seen with breast cancer. There have not been any studies that the author could find that referred to children of patients with AMI.

There is an extensive literature of the psychological and emotional effects of AMI on the patient. This can best be summarised by an Australian study (172) which examined patients four months after discharge from hospital after an acute coronary episode. Despite the large number of participants the recruitment rate was only 58% of patients who survived to four months. In this study there were 356 patients who had suffered an AMI.

The authors found that the four main concerns for the patient at four months were;

- Their physical condition (79%);
- Their emotional reactions (74%);
- Their convalescence (64%); and
- Relating to family and friends (64%).

The authors did note that being married or living as a couple reduced concern about physical symptoms from 84% to 72% ($p = 0.022$). They also noted that severe problems were more likely to be seen in female patients than male patients (see Table 1).

	Female	Male	
Emotional reaction	43%	29%	p = 0.012
Physical condition	46%	30%	p = 0.004

**Table 1 Percent severe reactions in
AMI patients by gender**

The authors noted that their study confirmed previous findings that marriage helped protect men more than women and that overall the outcome for women was worse than for men.

There is a modest literature examining the effects of AMI on the spouse. A number provide qualitative data on the reactions of spouses. These tend to be limited by number of spouses, low recruitment level or methodological issues. Despite this they tend to give consistent results.

Coyne and Smith (173) examined the distress among wives of men suffering an AMI. They approached 70 married patients discharged from hospital after an uncomplicated AMI and recruited 56 couples (80%). Patients and their wives were sent separate questionnaires which were to be returned independently. Validated instruments were used to determine patient functional disability, psychological distress, spouse psychological burden, pre-coronary marital adjustment and other factors not relevant to this study. Six months after their husbands' myocardial infarction, 32% of wives met the criteria for having a psychiatric illness ("psychiatric caseness"). This was between the levels from a previous study by the authors where living with a person with depression produced a level

of 40.5% for psychiatric caseness and living with a person who had previously been depressed (17.4%).

The wives' distress correlated with the patients distress ($r = 0.40$, $p < 0.01$). Lesser, but still statistically significant correlations were found with patient functional disability (positive), patient age (negative) and family income (negative). Marital adjustment prior to the AMI and contact between the wife and the medical profession caring for the patient had significant moderating effects on the wife's distress.

In a study carried out in Australia, Theobald (174) conducted in-depth interviews with 3 spouses (2 female and 1 male) of patients who suffered AMI. The patients had suffered their first AMI and interviews occurred about 1 month after the AMI. Using a qualitative approach Theobald identified 5 major themes;

- Crushing uncertainty;
- Overwhelming emotional turmoil;
- The need for support;
- The lack of information heightened anxiety; and
- The acceptance of lifestyle changes.

Suls et al (175) interviewed 43 of 75 wives (57% recruitment) of male AMI sufferers four weeks and six months after the AMI. They noted a number of associations. As the age of the husband decreased the distress of the wife increased. At four weeks increased distress in the wife was associated with increased patient distress, decreased marital satisfaction and the use of protective buffering as a coping mechanism by the wife. The authors define protective buffering as "... a strategy in which spouses deny worries and hide concerns from their partners and yield to them to avoid disagreements." At 6 months the

associations were the same although the decreased marital satisfaction did not quite reach statistical significance ($p > 0.05$). They did not note any association between a patient using protective buffering and wife distress (or vice versa).

Stewart et al (176) studied 14 couples after the first myocardial infarction. The authors used an unusual technique to perform a qualitative analysis. The couples were enrolled in a twelve-week support group activity shortly after discharge from hospital. Group facilitators kept detailed field notes, recorded after each support group meeting, and couples kept detailed diaries about the support group discussions and these were subject to analysis. The paper does not contain details of the training of the facilitators or the instructions given to the couples. The spouses (1 male and 13 females) indicated the following four primary demands were placed on them.

- Managing lifestyle changes.

The spouses found difficulty implementing the dietary changes and modifying their shopping practices.

- Dealing with the reactions of the AMI survivor.

The spouses found that the survivor's emotional reactions had changed and were less predictable.

- Dealing with the health care system.

Hospital discharge was uncoordinated and often occurred suddenly and without preparation.

- Constancy and vigilance.

About one third of spouses found they were constantly monitoring the survivor. "They worried, watched and listened."

There were also a number of secondary demands on the spouses which involved monitoring their own emotional reactions, reassuring other family members, financial issues and the marital relationship.

Kettunen et al (1977) undertook a questionnaire survey of wives of male survivors of AMI. Fifty-seven (71%) of 80 possible wives took part and were surveyed within two months of discharge. The questionnaire was designed by the authors and does not appear to have been piloted or validated. The questionnaire was designed to measure the shock of the infarct, the fears and symptoms generated in the spouse and some measurement of the support offered by health care professionals. It rated all items on a four point Likert scale, which for fears and symptoms ranged from “not at all” to “very much.”

As in previous studies they reported that younger wives experienced more fears than older wives. The following fears were most frequently reported (at any level from “a little” to “very much.”)

Fears about recovery	(93%)
Fear of a further MI	(88%)
Fear of patient's leisure activities	(86%)
Fear of over-protection	(70%)
Anxiety of significant others	(69%)

The paper does not explain this last item. It is noticeable that financial stress is not mentioned. The authors believe that this may be due to the “solid state welfare system” in place in Finland.

The symptoms generated in wives were fatigue (88%), sleep disturbance (80%), anxiety (79%), tension (79%), depressed mood (76%), and listlessness (70%). These symptoms could indicate depression, although the authors do not comment on the severity or duration of symptoms.

Despite the general poor quality of the studies there is a consistency about the high levels of distress experienced by spouses of patients who suffered an AMI.

Summary

The two comparators chosen for this study appear to provide different levels of distress in the families of patients. Breast cancer would seem to provide a moderate level of distress, while acute myocardial infarction provides a much greater level of distress.

The Duke University Severity of Illness scale

“Which is more severe: a week-long critical illness from which recovery is expected, or a permanent condition that requires some lifelong daily care? What if it shortens life expectancy or changes with age? Does the answer depend on the stage of life, societal or cultural values, or the individual’s perception, values, lifestyle, talents, interests, or career? Clearly different people will reach different conclusions.” (178)

A person’s burden of illness, quality of life and functional status are all inter-related, but each measures a different aspect of that person’s life, illness and disease. Each measurement has its strengths and weaknesses. The method chosen to demonstrate an outcome or change must reflect the outcome being measured. (179-181) This section discusses each of the methods and then examines one instrument in detail.

Quality of life

Measuring the quality of life (QoL) is a very subjective process. A patient’s estimation of his/her quality of life depends on objective factors such as the effects of the disease, and subjective factors as the patient’s perceptions of the disease (illness) and psychosocial factors. (182) Generally QoL is a measure encompassing physical health, physical functioning, social functioning and health, psychological well being, emotional wellbeing and perceptions. (183)

Leplege (181) argues that QoL is a social rather than a medical measure. He notes that "... individuals can consider their quality of life to be good even when there are severe limitations on their physical ability." Muldoon et al (182) propose that QoL is made up of two factors, objective functioning and subjective wellbeing, while Gill and Feinstein (184) see objective functioning as separate from QoL.

Gill and Feinstein (184) examined a structured random sample of published articles that purported to measure QoL. They found 159 different measurements used in these studies to measure QoL. They argue cogently that "... quality of life, rather than being a mere rating of health status, is actually a uniquely personal perception, representing the way that individual patients feel about their health status or nonmedical aspects of their lives."

The subjective nature of QoL measures is perhaps epitomised by multiple reports (185) that patients with cancer do not have a lower quality of life than the normal healthy population. Breetvelt and Van Dam (185) review the literature and discuss this phenomenon in detail. They argue that the baseline from which patients judge their quality of life changes with the passage of time. They suggest that patients will vary their conception of how they are feeling depending on how they thought they might feel.

A number of articles (182, 185) also note that QoL measures correlate more with psychological health than physical symptoms or limitations.

Medical records generally do not contain such qualitative information. The records are written by doctors and represent the doctor's interpretation of patient well being. In this study where the aim is to measure the health of family members, using case note audit, QoL measures are not possible. Fortunately other measures can be substituted.

Functional status

Functional status has been seen as a subset of QoL, (182, 183) although as mentioned above, other authors (184, 185) argue strongly that functional status is quite separate from QoL.

Patrick et al (186) compared the Sickness Impact Profile (SIP), a measure of functional status, with Perceived Quality of Life Scale (PQoL) in 454 persons. They found a modest correlation between the SIP and PQoL. In older persons with chronic illnesses, age, self reported functional status and less depressive symptoms all had significant correlations with the PQoL. In younger persons the correlations were much weaker. The authors conclude that we should not assume that poorer functional status is associated with poorer quality of life.

In a recent editorial, Bradley (187) argues strongly that functional status and QoL are different and should not be confused.

The measurement of functional status has either been by specific measures related to the condition under investigation or generic measures. Often both are used to measure progress or outcome. Generic measures of functional status include general measures such as the Barthel index of activities of daily living (188) and broad multi-dimensional measures such as the Medical Outcomes Study Short Form 36 (sf36) (189, 190) and its derivatives. (191)

The specific measures are numerous and often designed specifically for one study.

It is not always possible to find this data recorded in medical records, and in view of the requirements of this study such measures become inappropriate.

Burden of illness

Burden of illness currently has three meanings. It can refer to

- The burdens associated with an illness.

This can include limitations on work, expenses associated with treatment, loss of quality of life and etc, and can include the burden on the patient, the family and the community. (46, 192)

- The burden of the illness itself.

Also termed severity of illness. (178, 180, 193)

- The burden of the illness to a community.

This is often measured in Disability Adjusted Life Years (DALYs). (194-197)

The requirements of this study mean that the first and third uses of the word burden are not practical. The data in medical records are not sufficiently detailed to enable a calculation of such measures. The second definition relating to the severity of illness is clearly applicable to this study.

Concerns about the variability within Diagnosis Related Groups (DRG), as a method of payment for medical care, (198-200) drove the investigation of the measurement of severity of an illness. Some costs for an episode of inpatient care could be attributed to variations in the standard of care, but others were due to variations in severity of the illness being

treated. (198) Most severity measures arose from these concerns and were therefore designed for hospital use.

Severity scores for hospitals are generally based on one or a combination of

- Physiological parameters,
- Psychosocial factors, and/or
- Economic perspectives. (200)

These methods link the nature of the illness, comorbid conditions and severity. Waite et al (201) reviewed five commercially available measures of burden used in the hospital system to adjust DRGs. All measures scored each primary and comorbid condition with some adjustment for severity.

In primary care there have been few attempts to develop measures of severity and burden of illness. The Duke University Severity of Illness Scale (DUSOI) is one successful method that is widely used. Other attempts, such as that of Krakau (202) seem to confuse functional status with severity. The authors of that article do however note “..the degree of functional impairment was not reflected to any great extent in the biological degree of severity of illness.”

The Duke University Severity of Illness (DUSOI) scale

In 1989 Parkerson et al (36) described, for the first time, the DUSOI, a measure of the burden of illness specifically designed for primary care. Since then the instrument has undergone extensive development and validation. (37, 203-207) A variation is included in the latest version of the classification system of the World Organisation of General

undergone extensive development and validation. (37, 203-207) A variation is included in the latest version of the classification system of the World Organisation of General Practice (WONCA). (193) Despite its name the DUSOI measures the burden of illness.

(1) It calculates a severity score for each illness that a patient reports and adds them in a way that maximises the effect of the most severe illness. Each illness is scored on four factors,

- The symptoms experienced in the preceding week,
- The complications experienced in the preceding week,
- The prognosis, without treatment, over the next six months, and
- The treatability of the condition.

Each factor is scored from zero to four and the scores of each factor are added to give a score out of 16. (A copy of the scoring sheet is seen on page 65.) Each score is then scaled to a score between 0 and 100. The scores are then summed in a manner that emphasises the major illnesses.

$$\text{DUSOI score} = \text{DX1} + ((100 - \text{DX1}) / 100)(\text{DX2} / 2 + \text{DX3} / 4 + \dots + \text{DXn} / 2^{n-1})$$

(DX1 = highest score, DX2 = second highest score, etc)

This method of addition results in a score between 0 and 100, with higher scores indicating greater severity (or burden) of illness.

	None	Questionable	Mild	Moderate	Major
1 Symptoms (past week)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2 Complications (past week)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Disability

	None	Mild	Moderate	Major	<u>Threat to life</u>
3 Prognosis (next 6 months without treatment)	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Need for Treatment

Expected Response to Treatment

	No	Questionable	If Yes	Good	Questionable	Poor
4 Treatability	☐ 0	☐ 1	→	☐ 2	☐ 3	☐ 4

Figure 3 Chart used for scoring DUSOI

Consider the following case scenario:

Mr J is a 45-year-old man who has had non-insulin dependent diabetes mellitus treated with diet and metformin for 3 years. His diabetes is well controlled and he shows no evidence of complications. He also suffers from mild hypertension that is also well controlled with an ACE inhibitor. He presents today with a severely sprained ankle that occurred when he was jumping while playing basketball with friends. The ankle is very swollen and bruised and he is unable to weight bear. An x-ray does not reveal any fracture and he will be treated with strapping, rest, elevation and the limited application of ice. He will spend 3-4 days using crutches and will be referred to physiotherapy.

His DUSOI score is calculated as follows

Condition	Symptoms	Complications	Prognosis	Treatability	Score (16)	Score (100)
Diabetes Mellitus	0	0	2	2	4	25
Hypertension	0	0	0	2	2	12.5
Sprain	3	0	1	2	6	37.5

Table 2 Example of scoring

$$\text{DUSOI score} = \text{DX1} + ((100-\text{DX1})/100)(\text{DX2}/2 + \text{DX3}/4 + \dots + \text{DXn}/2^{n-1})$$

$$\text{DUSOI score} = 37.5 + ((100-37.5)/100)(25/2 + 12.5/4)$$

$$= 37.5 + (0.625)(12.5 + 3.125)$$

$$= 37.5 + 9.77$$

$$= 47.27$$

If the diabetes was poorly controlled and he had a hypoglycaemic episode in the last week the scoring for diabetes may have been symptoms 2, complications 4, prognosis 4, and treatability 2. This results in a final score for the diabetes of 75. The diabetes then becomes DX1.

$$\text{DUSOI score} = \text{DX1} + ((100-\text{DX1})/100)(\text{DX2}/2 + \text{DX3}/4 + \dots + \text{DXn}/2^{n-1})$$

$$= 75 + 0.25(37.5/2 + 12.5/4)$$

$$= 75 + 5.47$$

$$= 80.47$$

In the first scenario the sprained ankle provided 79.3% of the final score while in the second scenario the same injury provided 5.8%. Thus the severity of a condition adds variable amounts to the burden of illness depending on the severity of other conditions.

Reliability

As set out in the manual (1) there have been a number of studies of reliability. For casenote auditors, over 4 studies, interrater correlations ranged from 0.54 to 0.79. In each study the number of raters was very small (2 or 3). When providers (physicians) and auditors were analysed correlations ranged from 0.57 to 0.77. The figures were generated

in three studies with 6 to 23 raters. When 3 auditors compared their independent scores before completing the rating the correlation was 0.85.

In the same publication Parkerson examines the intrarater reliability, by calculating correlations for 3 individual scorers. Intrarater reliability ranged from 0.68 to 0.89.

In a separate study by Shields et al (208) using 33 raters (27 general practitioners and 6 consultants) of fourteen patient records the intraclass correlation coefficient was 0.43. The authors recommend that strategies should be adopted to maximise the reliability of the instrument.

A large international study (209) using 27 general practitioners in 16 countries showed interrater intraclass correlations (ICC) of 0.45. The authors did report that intrarater reliability was better but did not report any figures. They do note that "... the limits of clinically acceptable variability has not been established for a measure like the DUSOI."

Fleiss (210) recommends that the correlations should be greater than 0.75 to indicate excellent agreement. Parkerson (1) argues that the inherent variability of severity and its subjective nature means the 0.75 cut off should not apply to the DUSOI. While accepting the argument of the subjective nature of severity, the results are lower than is acceptable and indicate that the reliability needs to be evaluated in each study.

Validity

Parkerson (1) argues for the validity of the measure on the following basis.

There is interdiagnosis variation of scores in line with expected severity.

There is intradiagnosis variation of scores that appear to reflect clinical experience.

Scores are higher in hospital patients than in primary care patients.

In a study (207) comparing patients hospitalised with end-stage renal disease and primary care patients there was a large difference in mean DUSOI scores (74.7 vs. 43.4 $p = 0.0001$). There are positive correlations with measures of disability. (203) The DUSOI has the ability to predict health care costs in the ensuing 18 months. (206)

A factor in the studies used to justify inter- and intra-diagnosis variation is the wide score range for a given diagnosis (intradiagnosis variation). In one study, (204) the research group scored 414 primary care patients. The authors found 803 conditions. They reported in some detail the 21 most prevalent problems. Sprains and strains had the highest mean score (43.0) and a range of scores of 18.8 to 56.3. Alcohol abuse on the other hand had a mean of 33.8 and a range of 0.0 to 93.8.

This range is used by Parkerson et al (1) to validate the instrument. This argument is repeated in the larger international study. (209)

One issue that has not been discussed is a limitation that applies in that it records only those conditions that the treating doctor has knowledge of, or in casenote audit, has recorded.

Application to this study

The DUSOI is a practical, easy to apply measure of the burden of illness that uses data that can be extracted from the medical record. In this study the DUSOI is modified so that it

provides a measure of the burden of illness in a family over a twelve-month period. The modified family DUSOI has therefore been subject to an analysis of its validity, reliability and responsiveness (see page 105) and is shown to be an acceptable measure.

Given the inability to use other measures and the significant ethical issues introduced by a prospective study and the unmeasurable and uncontrollable biases due to combining research and service delivery, the DUSOI provides the most acceptable, if not the only practical, measurement tool for this particular project.

Summary

The literature supports the contention that a mentally ill family member produces an increased burden of illness in a family, but does not resolve the issue of whether this applies in general practice. The research on counselling would suggest that this will not be the case, but there is no firm evidence one way or another. Whether patients treated by psychiatrists in public psychiatric service outpatients or private practice, have any effect on the health of family members has not been evaluated. The literature supports the use of family therapy as an effective method of counselling, but there has not been any evaluation of its use in general practice or by general practitioners.

Breast cancer and acute myocardial infarction are revealed to have different levels of stress associated with them, so they are appropriate comparators for the patients in this study. The Duke University Severity of Illness scale is an appropriate measure of illness burden in general practice. Its modification to measure illness load over a full year has not been attempted previously. Validation of this process will be an essential part of this study.

This review suggests the research (null) hypotheses should be rejected by this study.

Hypothesis 1

A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a family member is treated for mental health problems with either of two levels of severity, those requiring counselling in general practice and those requiring referral to a psychiatrist.

Hypothesis 2

A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a family member suffers from either of two severe physical illnesses, breast cancer or myocardial infarction.

Chapter 2

Method

This chapter details the method used in this study. It provides a brief overview of the method followed by a detailed description. Chapters three and four provide details of the subjects of the study and the validity and reliability of the modifications made to the Duke University Severity of Illness scale (DUSOI).

Overview

The study was carried out in a large general practice in suburban Adelaide, Australia.

Four groups of 20 patients and their families with the index events described below were followed for 12 months prior to the event and for 12 months after the event using medical record review. A modification of the DUSOI was utilised which had the advantage of allowing the scores to reflect the number of conditions seen over a year. For each group the scores for the year prior to an index event were compared to the year after the event. In addition comparisons between the groups were also carried out. The four groups of patients were

1. Patients who had received family therapy from the author as the sole treatment of a mental health problem;
2. Patients who were referred to a psychiatrist by any doctor in the practice for the treatment of a mental health problem;
3. Patients who suffered an acute myocardial infarction; and
4. Patients who were diagnosed breast cancer.

Groups three and four were the comparator groups.

As set out above, each family was scored for the year prior to the index event, and the year following the event. Comparisons were made between the pre and post scores for each group and between groups using parametric and non-parametric statistical methods, one-sample t-test and Wilcoxon Signed Ranks Test for within group comparisons, and independent-samples t-test and Mann-Whitney U test for between groups comparisons.

As previously outlined the research hypotheses are that in each group there will not be a difference in the modified family DUSOI scores between the two years.

Adaptations to the DUSOI to fit the needs of the study

The unmodified DUSOI measures the burden of illness in a person at a point in time. It does not take into account repeated consultations. As pointed out by Leach et al (29) mental distress can result in an increased frequency of consultation in general practice among some family members. It was therefore decided to modify the DUSOI to reflect the effect of frequency of consultation.

Frequency of consultation or number of conditions?

As a proxy for frequency of consultations it was decided to use the number of conditions seen in a given time. While this does not take into account an increased frequency of consultation for a given condition, it will reflect an increase in the number of conditions presented to a doctor. In the first twenty families in the study (group 1) the mean number of consultations by all family members (with the patient excluded) was 3.04 consultations per year.

By using the number of conditions seen in a given period of time the basic structure of the DUSOI is maintained. In effect the DUSOI is calculated over a period of three months

rather than at a point in time. The number of consultations for a condition would be difficult to factor in to the score. It would produce a scoring system that would require much larger numbers to validate and it is unlikely, because of the small numbers of consultations, to materially affect the analysis.

Interval of measurement

A number of options were considered. It was decided to use a three-month interval as the basis of calculation because it provided a range of consultations that provided a broad dispersion of scores. It was also feasible to implement while reviewing case notes.

Medical records do not contain sufficient information to allow calculation of the DUSOI on a more frequent basis such as weekly or fortnightly. Records contain information such as

- “otitis media amoxil”
- “persistent cough o/e NAD doryx 10/7”
- “Several months abdominal pain IBS dietary advice.”

Such records would not allow calculation over such a short time interval.

Longer periods, such as six months and one year would lead to a reduction in the influence of the number of conditions on the final score. Where records contained more than five or six conditions in a given time period any condition beyond that number had only a very small effect on the overall score.

The overall score however was calculated over a twelve-month period. Two scores were to be calculated, one for the year prior to the index event and one for the year after. The final

choice of a year interval was a pragmatic choice. It is worth noting that Starfield et al (211) in preparing and analysing Ambulatory Care Groups used one year as the unit of measurement. This length of time allowed them to develop predictive tools and measures.

Method of Scoring

The method of calculation became:

1. For each family member the notes were reviewed and 3-month intervals defined for the year prior to and the year after the index event.
2. Each condition documented in the medical records in a three month period were noted and scored using the standard DUSOI scoring method.
3. Each 3-month period was treated as a point in time and the individual DUSOI scores was added using the method described by Parkerson et al, (1) for each family member.
4. The mean of the family members' scores for a 3-month interval became the family score for that interval.
5. The mean of the four family scores prior to the index event became the family's score for that year.
6. The mean of the four family scores after the index event became the family's score for that year.

Validation of changes

Validation of the changes was undertaken by

1. Reviewing the face validity;
2. Examining the content validity; and

3. Examining the construct validity by comparing the scores with DUSOI scores taken at the time of the index event.

The latter was carried out by comparing the modified annual DUSOI scores for five families in group 2 with the DUSOI measured at the time of referral to a psychiatrist.

Reliability

The test-retest reliability was measured by re-scoring the first five families 18 months after first scoring and the results compared. Inter-observer variability was not assessed as one person (the author) carried out all the scoring. As discussed previously the inter-rater reliability is less than hoped for and the use of one scorer minimises this problem.

Subject Selection

Each of the four groups of patients was randomly selected from the patients seen within the author's general practice. The method of selection and the process of randomisation are described below.

Group 1 – Patients who received family therapy

Records of patients who had received counselling prior to July 1995 were identified and the counselling records examined. July 1995 was chosen as the cut-off date as the author ceased keeping separate counselling records from that date. The author commenced training in family therapy in late 1989. The effective period of recruitment became 1 January 1990 to 30 June 1995.

Exclusion criteria were developed in order to ensure consistency of treatment method and a degree of homogeneity of condition and severity. The exclusion criteria developed were

1. The patient lived alone – a family score could not be calculated;
2. Therapy consisted of a method other than family therapy;
3. The patient suffered from schizophrenia or other psychotic illness where psychotherapy is not appropriate as the sole therapeutic method;
4. The patient received counselling for a physical illness or symptom; or
5. The author or any referring doctor had used psychotropic medication.

The computerised database of administrative details and the medical record were then examined and patients further excluded if

6. Any member(s) of the family had not attended the practice for medical treatment; or
7. Any family member(s) had ceased attending the practice during the year prior to or after the commencement of therapy.
8. A member of the family was having psychotherapy from someone other than the author.

A genogram (family tree) is used during family therapy and allowed accurate details concerning family size and structure. This led to a high degree of confidence that full family details were obtained.

Where a family member had not attended a doctor at the surgery during the two years under investigation, but had attended prior to and after the two years under investigation it was assumed that the patient was an ongoing patient of the practice and the family included in this study.

A list of patients and their families was produced by this method. A random starting point was chosen. Family medical records were examined in order from the list starting at the random starting point and examined to confirm the above criteria were met. The first twenty family records that were free of exclusion criteria were selected.

Group 2 – Patients referred to a psychiatrist

A manual search of randomly selected casenotes was undertaken to identify patients that had been referred to a psychiatrist for treatment. Randomisation was achieved by selecting various starting points in the case-note storage and examining sequential notes for 2 hours and then commencing at another point.

Patients from those that were referred to a psychiatrist were excluded if

1. The patient lived alone;
2. Family records were incomplete;
3. The referral took place prior to 1 January 1990 or after 30 June 1995 – to provide some consistency with group 1;
4. The records did not extend for one year prior to or after referral; and
5. The author had provided counselling to a member of the family.

The first 20 records that were not excluded by these criteria became Group 2.

Group 3 – Breast cancer

The computerised practice records were searched to find entries relating to breast cancer. The computerised records were coded using ICPC-2 (212) and the appropriate code was used for the search. In order to maximise the chances of finding patients with families the

list generated by the search was examined from youngest to oldest until twenty appropriate families were identified. Computerised and hand-written records were examined and the database searched by address to ensure complete families were selected. Patients were excluded if

1. The patient lived alone;
2. Family records were incomplete; or
3. The records of all family members did not extend for one year prior to or after the diagnosis of the breast cancer.

The first 20 records identified became Group 3.

Group 4 – Acute myocardial infarction

An identical process to that used to identify breast cancer was used for identification and selection of 20 patients who had been diagnosed as suffering from acute myocardial infarction.

The first 20 records identified became Group 4.

Index events

Because the study examined adjacent years it was necessary to determine the point that separated the years.

Group 1 – Family therapy

There are a number of points that could be used to define the years. The date at which the treating doctor became aware of the issue could be used. This date is not always precise, as

notes do not always indicate the thought processes of the doctor. The doctor may suspect psychological distress but may try to exclude organic conditions first. This may not be apparent from the medical record.

A number of patients self refer for counselling and their treating doctor may not become aware of the emotional distress or psychological difficulties until after a communication from the counsellor.

It was therefore decided to use the date of first family therapy session as the indicator date for this group. This was easily determined from the counselling records.

Group 2 – Psychiatric referral

A referral to specialists in the Australian medical system requires documentation. However this is not always included in the medical record and the date of referral is not always apparent. The date of first appointment with a psychiatrist was therefore chosen as the indicator date for this group.

In four cases it was uncertain if the patient had attended the psychiatrist. In view of the belief that the recognition of a mental illness was therapeutic (see page 20) it was decided that the act of referral was important and these four patients should not be excluded. In these situations the date of referral was available and this was used.

In another four cases the letter from the psychiatrist only indicated broadly when he or she had first seen the patient. In such situations it was possible to narrow this time to a period of three weeks. In these cases an estimate of the date was made that used information from the referral letter, information in the written record and the information contained in

the letter from the psychiatrist. At its worst the error in estimating the date of first consultation would be two weeks.

The use of the date of referral was contemplated, however details of the referral were also sparse. Written records often did not contain reference to referral. Sometimes there was a letter of referral, but often there was only a letter from the psychiatrist to indicate such a referral had taken place.

Group 3 – Breast cancer

A number of options were available to choose an index date. It would be possible to choose the date of first presentation to a doctor, the date of tissue diagnosis by biopsy, the date of referral to a surgeon for definitive treatment or the date of surgery. A significant proportion of breast cancers is now diagnosed through BreastScreen South Australia and the specific dates of diagnosis are not included in the medical record. It was therefore decided to use the date of surgical intervention as the indicator date.

It proved very difficult to determine the day of operation. One patient did not have an operation, but in this case the day of diagnosis was explicit and was the date used. In another seven cases the letters from specialists and hospitals indicated the date of surgery to within one week. In one additional case it was only possible to determine the month of operation and in this case the middle of the month was chosen. At most the error was 3 weeks.

For similar reasons the day of diagnosis was also extremely difficult to determine. It was decided to retain the day of surgery as the index event.

Group 4 – AMI

The date on which an infarct occurred should have been easy to define from the records and was chosen as the indicator date.

However once again it proved difficult to ensure a precise date for an infarction. For patients diagnosed by the general practitioner or treated in a public hospital the date of occurrence was usually well defined. For patients treated in private hospitals there was often no documentation of the date. Often letters from cardiologists referred to “recent infarction.” Using dates from the written record, dates when letters were sent and hospital discharge summaries it was possible to narrow down the time interval in which the infarction occurred to plus or minus one week.

Data collection

The author collected all data. Data were collected in the following sequence

1. Group 1 – Family therapy (collected June – August 1999)
2. Group 2 – Psychiatric referral (collected November 1999 – March 2000)
3. Groups 3 and 4 concurrently (collected May – September 2000).

For the family therapy group the list of patients was developed and the patients determined. Counselling records were examined for exclusion criteria and a final list of patients and families drawn up. The list, because of the way it was developed was in partial alphabetic order. A random starting point in this list was chosen using the random function of the database.

The patients and their families were examined sequentially from the random starting point until twenty satisfactory records were obtained. Scoring took place as records were selected.

Of the 457 potential records numbered sequentially from 1 to 457, the following case numbers were selected.

180 185 191 209 214 219 220 281 287 297 339 340 344 354 355 356 367 382 388 389

As the records were in crude alphabetic order, this selection tended to miss patients with surnames beginning with A to G and S to Z. It is unlikely, however, that this created any bias in this group. These records then formed Group 1.

Manual searching of the written records was used to select patients referred to psychiatrists. Records were retrieved in batches of 20-30 from the storage shelves and examined sequentially. Each batch was in alphabetical order.

Each record cover was examined to see if the file represented a family and the years in which a doctor had seen the family. If the record was not excluded then the correspondence section of the record was examined to determine if there were any letters to or from a psychiatrist. If there was such a letter the record was more closely examined to determine if there were any other exclusion criteria applying. If not, the record was scored and then returned to the storage shelf. This was continued until 20 records had been scored.

For the breast cancer and acute myocardial infarction the same process was used for each group. The computerised record base was searched using the ICPC (212) codes for breast

cancer and myocardial infarction. The lists generated were then sorted by age (youngest to oldest) and the records (written and/or computerised) examined. As records were accepted they were scored in the usual way.

Initial scoring was to paper chart, which were then converted to 3-month DUSOI scores using a small Excel (Microsoft 1997) spreadsheet. A second Excel spreadsheet was used to calculate the pre and post annualised scores. Data were then entered and analysed in SPSS version 10 (Statistical Package for Social Sciences 2000).

Primary Statistical analysis

The results consisted of a mix of normal and non-normal distributions and both parametric and non-parametric methods were used. For the before and after studies where the data were paired the one sample t-test (parametric) was used to compare means and the Wilcoxon signed ranks test (non-parametric) was used to compare medians.

For comparisons between groups where the data were not paired the Mann-Whitney U test was used to compare medians. Because of the mix of distributions this was the only method used for these comparisons.

Secondary analyses

Secondary analyses were carried out using a number of techniques. The individual scores (out of 16) for each condition were placed in an SPSS database and two other scores calculated, the number of conditions per family and the mean score per condition for each family. Figures were generated for the year prior to the index event and the year after. These figures were used to determine whether the differences discovered above could be

due to a change in the number of conditions, a change in the severity of conditions or a combination of both.

Wilcoxon signed ranks test was used for direct comparisons between the years and univariate ANOVA (for normally distributed data) was used to examine the contribution of severity and the number of conditions on the difference in the scores. In the univariate ANOVA the difference in the mean family DUSOI scores was entered as the dependent variable, with the difference in the conditions per family and the difference in the severity of the conditions per family (both continuous variables) were entered as covariates.

Conditions were coded using ICPC-2. (212) This classification is standard to general practice and conveniently classifies each condition as either a diagnosis or a symptom. This allowed the proportion of symptoms to be examined by using 2×2 tables and χ^2 .

Conditions were also classified as either psychosomatic or organic. Psychosomatic conditions were those conditions generally seen as have a psychological basis for their causation. The conditions so classified are detailed in Appendix A. This allowed the proportion of psychosomatic conditions to be examined by using 2×2 tables and χ^2 .

In order to investigate the effects of gender on the difference in scores the results were examined by classifying each year of each group as a high stress year or a lesser stress year. A high stress year was taken as that year when the group condition under investigation was active. That is the high stress years were the years prior to the use of counselling for a psychological problem, the year prior to referral to a psychiatrist for a mental illness, and the years after the diagnosis and treatment of breast cancer and the occurrence of a myocardial infarction. The lower stress year score was then subtracted from the high stress year score.

Comparisons were made between gender, group and difference between the years by univariate ANOVA. Because gender and group are categorical variables they were entered as factors.

Simple correlations were undertaken using Spearman's ρ for non-parametric distributions.

Level of significance and power of study

Because of the limited number of comparisons to be made $\alpha < 0.05$ was set as the level of significance. It could be argued that as the study is exploratory that $\alpha < 0.10$ is acceptable. However this could lead to the criticism that random effects may have overpowered the effects being studied. It was decided to retain the smaller value. Where multiple comparisons were undertaken Bonferroni correction was applied. (213)

Sobieraj et al (2) found that, at the time of diagnosis of depression the mean DUSOI score of the family was 35.1 and that of control groups was 16.4. Their study used an older version of the DUSOI that was based on a twelve point score and not sixteen as used in this study. That study also used the DUSOI averaged across a family at a point in time. The scores in this study could be expected to be of a similar order.

Using values approximating those of the above study produced the following power calculation.

With $\mu_1 = 20.0$ (s.d.₁ = 20.0) and $\mu_2 = 35.0$ (s.d.₂ = 25.0) and allowing for pairwise analysis and double sided α the sample size calculations provided the following results. (214)

Alpha	Power			
	0.6	0.7	0.8	0.9
0.1	5	7	8	10
0.05	7	9	10	13
0.01	12	13	16	19
0.001	18	20	23	27

Table 3 Sample size calculations

For an $\alpha = 0.05$ and a power of 0.80 a sample size of 10 is required. Because the calculation is based on a paper that is using a slightly different methodology it was decided to examine 20 families in each group.

Ethical approval

The Human Research Ethics Committee (HREC) of Adelaide University granted approval for this research on 27 August 1997. The main concern was the auditing of casenotes without patient permission. Rogers and Braunack-Mayer (215) have discussed the ethics of general practice case-note audit in detail. They concluded that case note audit by a medical practitioner does not require patient consent if that doctor is auditing his or her own case notes. That situation applied in this study.

A recent paper by Hohmann-Marriott (216) reviewed the Ethical Guidelines of the American Association for Marriage and Family Therapy (AAMFT) for marriage and family therapy research. They outlined ten issues to be considered in managing research related to family therapy. Each of the ten issues is discussed in relation to this study.

Minimise potential risk to participants

This was a major issue in planning this study. The author has had experiences where the sudden awareness that a member of a family had received counselling resulted in negative consequences for the patient. The study was designed so that this would not occur.

Review research with qualified neutral professionals

Ethical approval was sought from and accepted by the HREC of Adelaide University and supervised by experienced researchers.

Inform potential participants and obtain their consent

This is discussed above.

Avoid deception

Direct interaction with patients did not occur and thus there was no deception.

If comparison groups are necessary, ensure that both receive equitable treatment

In this study all patients received appropriate care from their usual doctors. The counselling group received counselling from the author.

Keep participants anonymous and their data confidential

All records were kept at the medical centres. Patient record numbers were used to identify records. These could only be converted to identifying detail by access to records held only in the medical centre.

Avoid dual relationships

This study was carried out using information obtained retrospectively. At the time the data was recorded there was not any intention to carry out research. Dual relationships were not possible in this situation.

Collect data with accuracy

Every effort was made to ensure data accuracy.

Report research with integrity

Every effort has been made to ensure the integrity of the data and the manner in which it is presented.

Minimise the effects of researcher bias

Throughout this study a number of steps have been taken to ensure the minimisation of bias.

In summary this study meets all the requirements for an ethical study and has undergone evaluation by the appropriate ethics committee prior to commencement.

Chapter 3

Subjects

This section sets out details of the patients and their families that were the subjects in this research project. Details of the method of the selection are contained in the Method section (page 77).

The Practice

All patients and their families attended either of two branches of a suburban practice in Adelaide, South Australia. The practice is a large multi-doctor practice, which at the time of the study used a mix of written and computerised records. The two branches of the surgery are 2.5 km apart and patients readily attend either branch for medical care.

“Adelaide: a social atlas” (217) describes the area surrounding the practice as consisting of a mix of established regions and rapidly growing areas with a relatively high proportion of young people. The people are predominantly Australian or United Kingdom born. Less than 1% of the population is non-English speaking. A high proportion of households (> 41% in most areas) have a weekly income in excess of \$1000 a week. Unemployment is comparatively low. A majority of the population (> 51% in most areas) are buying their own homes. Many families (39 – 50%) consist of couples with dependent children.

Overall it could be said to be a middle-class area.

Group 1 – Index patients received counselling

The patients in this group consisted of 19 females and one male. The age of the patients ranged from nine to sixty with a mean of 37.25 and a median of 36. The size of the family ranged from two to six members.

		Family Size						
Age Range	Male	Female	2	3	4	5	6	Total
5 – 14 Years		1			1			1
15 – 44 Years	1	13	1	4	5	3	1	14
45 – 59 Years		4	3	1				4
60 – 74 Years		1	1					1
Total	1	19	5	5	6	3	1	20

**Table 4 Age, gender and family size
of counselling group**

Table 4 indicates that 70% of patients were aged 15 - 44 years and 80% came from families with two to four members. There were three patients aged less than 30 years and one aged 60 years. The remainder (80%) were in the 30 to 59 age range. Younger patients tended to come from larger families.

Because the counselling records were recorded in a way that reflects family therapy, it was not always possible to provide a strict psychiatric diagnosis as set out in the Diagnostic and Statistical Manual (DSM IV) of the American Psychiatric Association. (110) However the descriptions are mostly consistent with adjustment disorders. A brief description of each of the patients can be found in Appendix B.

The following table sets out the number of cases in each broad diagnostic category.

Diagnosis	No
Adjustment disorder	13
Mixed anxiety and depression	1
Depression	2
Conduct disorder	1
Dysthymia	3

**Table 5 Summary of diagnoses in
counselling group**

The following definitions have been used to classify the patients.

An adjustment disorder is a mental disorder in response to a recent (< 6 months) event.

It may take on the nature of any of the mood disorders.

Dysthymia is a minor depression that has been present for more than 2 years.

Depression is a mood disorder with, as a minimum, low mood, lack of motivation and loss of the ability to enjoy oneself.

Mixed anxiety and depression is a mood disorder with features of both depression and anxiety.

Conduct disorder occurs in children when they deliberately behave, to a pathological degree, in a way to upset people around them.

In summary there are 13 patients with adjustment disorders, six with mood disorders, and one with a conduct disorder. The author re-iterates that these diagnoses are not based on a strict interpretation of current nosologies of mental illness, but reflect the reality of trying to use a classification system designed for specialist psychiatric practice to categorise patients whose records reflect the principles of family therapy.

Group 2 – Index patients referred to a psychiatrist

As indicated in Table 6 the patients in this group consisted of eight females and twelve males. The age of the patients ranged from three years to 68 years with a mean of 37.75 and a median of 42.5. The size of the family ranged from two to six members.

		Family Size						
Age Range	Male	Female	2	3	4	5	6	Total
0 – 4 Years	1				1			1
5 – 14 Years	3				2	1		3
15 – 44 Years	5	3	3	2	2		1	8
45 – 59 Years	2	5	4	1	2			7
60 – 74 Years	1		1					1
Total	12	8	8	3	7	1	1	20

**Table 6 Age, gender and family size
of psychiatric referral group**

Sixty percent of patients were less than 45 years and 90% lived in families with two to four members. Once again younger age of patient is associated with larger family size.

The cases examined were as set out in Table 7.

Diagnosis	Number
Anxiety and related disorders	6
Mood disorders including mixed anxiety and depression	4
Behaviour problems (child)	3
Adjustment disorder	2
Alcohol related disorder	1
Personality disorder	1
Impotence	1
No record of diagnosis	2

Table 7 Psychiatric diagnoses in psychiatric referral group

Further details of individual cases are contained in Appendix C.

Eleven of the diagnoses were obtained from the psychiatrist letters while seven came from the referral letter or medical records of the general practitioner. Eight patients were

prescribed psychotropic medication, four were not and the records were not clear in another eight cases.

Replies from psychiatrists following referral were of poor quality and did not always include a diagnosis. Nine (45%) patient records did not contain a psychiatric diagnosis from a psychiatrist. In four records it is impossible to say if the patient attended the psychiatrist, as there was not a letter from a psychiatrist. Two patients (10%) required inpatient treatment.

Comparison of groups 1 and 2

Table 8 compares the psychiatric diagnoses of each group.

Diagnostic category	Counselling	Psychiatric referral
Adjustment disorder	13	2
Mood disorders	3	4
Anxiety disorders		6
Childhood disorders	1	3
Dysthymia	3	
Other		3
Unknown		2

**Table 8 Comparison of diagnoses in
the counselling and psychiatric
referral groups**

It is difficult to be certain of relative severities, but in usual use, adjustment disorders and dysthymia are considered to be less severe than mood and anxiety disorders. This would suggest that the patients in the psychiatric group were more severely ill than in the counselling group. This is supported by the rate of prescription of psychotropic

medication (11 of 20 patients) in the psychiatric referral group. The counselling group only contains people that the treating doctor did not consider such medication clinically indicated. The fact that group 2 patients were referred to psychiatrists also suggests that the conditions were towards the more severe end of the spectrum. Discussions with the doctors within the practice indicated they referred the less severe cases to the author for treatment. The evidence supports the psychiatric referral group of patients as being more severely ill than the counselling group.

Group 3 – Index patient with breast cancer

As indicated in Table 9 the patients in this group consisted of 20 females. The age of the patients ranged from 38 to 62 with a mean of 49.20 and a median of 48. The size of the family ranged from two members to 5 members.

Family Size						Total
Age Range	2	3	4	5	6	
15 – 44 Years	1	3	2			6
45 – 59 Years	6	3	1	1		11
60 – 74 Years	3					3
Total	10	6	3	1		20

Table 9 Age and family size of breast cancer group

Only 30% of this group were less than 45 years of age. Eighty percent of families had two or three members.

All patients but one had surgery. The one patient who did not have surgery underwent a biopsy followed by radiotherapy. Of the 19 patients who had surgery, 17 (89.5%) also received chemotherapy and/or radiotherapy.

Group 4 – Index patient suffered an acute myocardial infarction

The patients in this group consisted of two females and 18 males. The age of the patients ranged from 38 to 73 with a mean of 54.35 and a median of 54.50. The size of the family ranged from two members to 5 members.

			Family Size					Total
Age Range	Male	Female	2	3	4	5	6	
15 – 44 Years	3			1	1	1		3
45 – 59 Years	13		10	1	2			13
60 – 74 Years	2	2	4					4
Total	18	2	14	2	3	1		20

**Table 10 Age, gender and family size
of AMI group**

Only 15% of patients were less than 45 years of age and 70% of families consisted of 2 members.

The two female patients were in the 60-74 years age group and as would be expected the younger patients had the bigger families (Table 10). All patients survived the twelve months after infarction. This reflects the selection method as patients who die are removed from the computer system and do not appear in any search.

Cross group comparisons

The groups are dissimilar. This is demonstrated in Table 11.

	Age range (patient)	Mean age (Std Dev)	Family size range	Mean family size (Std Dev)	Percent female patients
Counselling	9 – 60	37.25 (13.25)	2 – 6	3.5 (1.19)	95%
Psychiatric referral	3 – 68	37.75 (18.74)	2 – 6	3.2 (1.20)	40%
Breast Cancer	38 – 62	49.20 (7.56)	2 – 5	2.75 (0.91)	100%
AMI	38 – 73	54.35 (8.82)	2 – 5	2.55 (0.94)	10%

Table 11 Comparisons of patient and family characteristics in each group

Table 11 demonstrates the marked variation in the percentage females in the groups as well as the variations in the age of patients and family size. The gender distribution is not directly consistent with the literature. For mild to moderate disability proportionally more women than men attend general practitioners for psychological problems, and more men attend psychiatrists, (218) however the BEACH study (225) indicates that in

Australian general practice women are referred to psychiatrists in greater absolute numbers than men. The figures relating to breast cancer and myocardial infarction reflect clinical experience.

Summary

This section details the subject families and provides descriptions of the nature of the illnesses suffered. It also indicates the differences in families and patients between the groups.

Chapter 4

Assessment of the validity and reliability of the modified family DUSOI.

As set out in the methods section (page 74) it was decided to modify the Duke University of Illness score (DUSOI) so that it provided a measure of illness burden over twelve month period. This section sets out the process and results of the validation of the changes made to the DUSOI.

Background

The DUSOI is detailed in Chapter 1 (page 59). In summary it is a well-documented instrument designed specifically for use in general practice. It measures the total burden of illness in each patient. For a given patient, the DUSOI scores each condition suffered by a patient and adds them in such a way to give a score between 0 and 100. Each condition is scored on four scales that reflect the symptoms and complications (both over the previous week), prognosis (without treatment), and treatability.

Modifications

As set out in the Methods section the modifications used for the method of calculation in this study are:

- For each family member the notes were reviewed and 3-month intervals defined for the year prior to and the year after the index event.
- Each condition documented in the records in a three month period was noted and scored using the standard DUSOI scoring method.
- Each 3-month period was treated as a point in time and the individual DUSOI scores was added for each family member in the method described previously (see method).
- The mean of the family members' scores for a 3-month interval became the family score for that interval.

- The mean of the four family scores prior to the index event became the family's score for that year.
- The mean of the four family scores after the index event became the family's score for that year.

Process of validation

The process of assessing an instrument for validity and reliability has been set out by Cumming. (219) He describes validity as the "... the extent to which an instrument measures what it is supposed to measure ..." and reliability as the "... the ability of an instrument to produce the same results when used repeatedly on the same person under the same circumstances." Reliability and validity are separate measures and high levels of both are required for an effective instrument. Cumming indicates four measures of validity (face, content, criterion and construct). Each of these and reliability will be discussed in turn. He also raises the issue of "responsiveness to change", that is does the instrument produce different scores for different conditions. The substance of this research project will demonstrate this.

Face validity

"Face validity describes the degree to which an instrument looks as if it will measure what it was designed to measure." (219) In this study the instrument is required to provide a measure of burden of illness over a twelve-month period.

As mentioned above the DUSOI is a well-documented instrument. The changes have not interfered with the basic soundness of the measure. In essence the changes have shifted the measurement from a point in time to a period of three months. The scores have then

been averaged across the family and across the year in question. At a face validity level this seems appropriate.

Content validity

“Content validity describes the degree to which an instrument covers the full range of items that make up whatever is being measured.” (219) The modifications made do not alter the content of the DUSOI and it still measures all conditions disclosed to the doctor and recorded in the medical record. The DUSOI does not measure symptoms suffered by patients, but not reported to, or recorded by the doctor. There are not any instruments that are capable of doing this.

The proportion of patients who do not indicate their distress to the doctor can be a large. A study by Horder and Horder reported by McWhinney (220, page 30) revealed that only about one third of adult patients with symptoms in any given month consult a doctor. Even if patients have symptoms, they do not necessarily reveal them to the doctor. For example Robinson and Roter (89) examined 308 audiotapes of consultations of emotionally distressed patients with their physicians. On only 157 (51.0%) of the recordings did the patient disclose their distress.

In a large study Mojtabai et al (221) followed 1792 individuals with at least one common mood, anxiety or substance disorder for 12 months. Only 571 (32%) of this group perceived the need for professional help and only 59% of the 571 actually sought help. Overall only 19% of patients in this study sought help. While there are some reported limitations in this study, the relevance to this study is clear. Despite significant distress only a small percentage of patients will seek help.

In another very large study (222) (>10,000 randomly selected patients) the rate of help-seeking varied primarily with severity, although there were significant effects from epidemiological variables. For men, 26.3 % of men with a neurotic illness sought help, while for women it was 39.8%. The only notable exception in the epidemiological variables that did not affect help-seeking behaviour was socio-economic status.

There will be obvious problems for the study if there is a differential bias in reporting one or more of the conditions before and after the index event. While this issue is dealt with in more detail in the results section there is nothing to suggest such a bias is likely to exist.

Criterion validity

“Criterion validity describes the extent of agreement between the instrument ... and some ‘gold standard’ measure of the same thing.” (219) A search of the literature has not revealed any gold standard for the measure of burden of illness of a family over a twelve-month period. It was therefore decided to proceed with an evaluation of construct validity.

Construct validity

“Construct validity describes the extent of agreement between the study instrument and other instruments that are supposed to be measuring the same underlying theoretical construct.” (219) There are not any measures that are structured in the same manner to measure burden of illness over twelve months. However, in the study by Sobieraj et al, (2) discussed previously, the instrument used was the mean family DUSOI measured at the time of diagnosis of depression.

The twenty families where a family member was referred to a psychiatrist were chosen to assess construct validity. The mean family DUSOI measured at the time of referral was

compared to the score for the year prior to referral. The data for the DUSOI scores were not normally distributed.

	Median	Minimum	Maximum
Year Family Score	20.15	0.0	44.7
Mean DUSOI	15.65	0.0	56.3

**Table 12 Comparison of family DUSOI score at referral
with modified family DUSOI score for year prior**

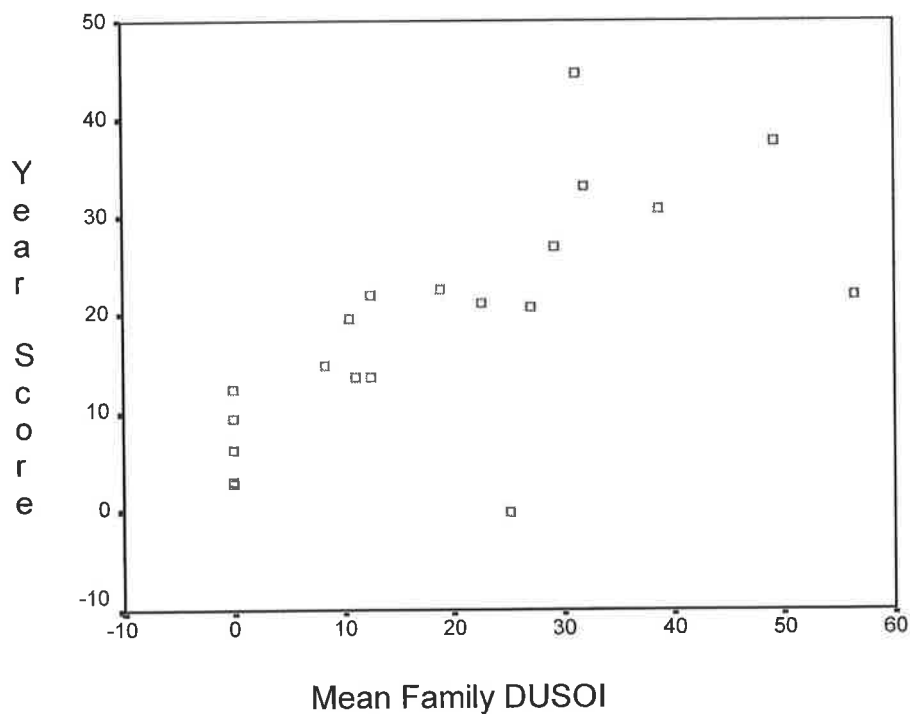


**Figure 4 Scatter plot of DUSOI at referral and
modified family DUSOI for year prior**

Correlation (Spearman's *rho*) is 0.785, which is significant (2-tailed) at the $p = 0.001$ level. This is greater than the level (0.75) recommended by Fleiss (210) as indicating excellent agreement. This result indicates that the modified family DUSOI produces similar results to the mean family DUSOI, which has previously been shown to be an effective measure. Within the limited available measures these results suggest that the construct is valid.

Reliability

Reliability is “the extent to which an instrument agrees with itself.” (219) The test-retest method is used to assess reliability in this study. The first five families in the counselling group were re-scored. The author carried out all scoring, and the time interval between the test and retest was 18 months. Comparisons were made over both years and the eight 3-month periods in those two years. The data were not normally distributed.

	Median	Minimum	Maximum
Year Scores	3.8	0.00	31.00
Year Scores - Retest	4.1	0.00	31.30

Table 13 Test - retest year scores

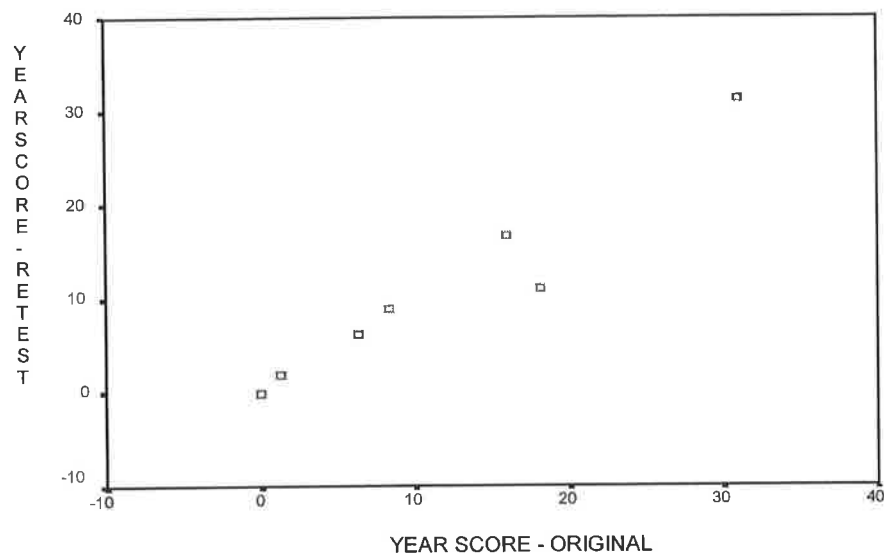


Figure 5 Test-retest year scores

The correlation (Spearman's *rho*) of 0.987 ($p < 0.0005$) indicates a high degree of test-retest reliability.

To further analyse the reliability the 3-month scores were compared. Within the forty quarters compared, twenty consisted of zero at both test and retest. Zero scores reflect the absence of consultations in those quarters and thus do not influence the person undertaking the scoring. Correlations with the zero scores included and excluded are reported. Once again the data were not normally distributed.

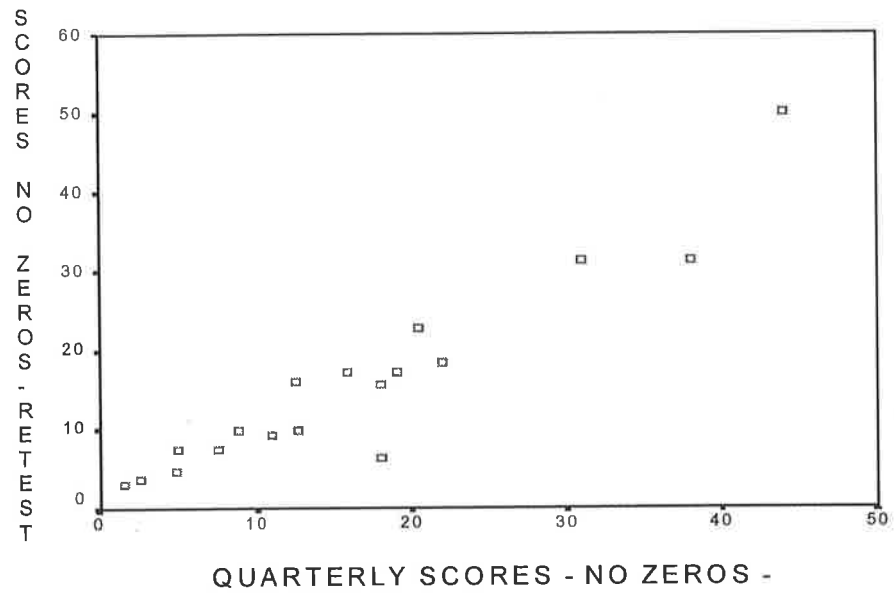


Figure 6 Test - retest quarterly scores

	Median	Minimum	Maximum
Quarterly scores - initial	0.75	0.00	44.00
Quarterly scores - retest	1.55	0.00	50.00
Quarterly scores – no zeros - initial	17.14	1.50	44.00
Quarterly scores – no zeros - retest	16.54	3.10	50.00

Table 14 Test – retest using quarterly scores

The correlations (Spearman's ρ) of 0.990 with all scores included, and 0.932 with zeros excluded, confirm the high degree of test-retest reliability.

As only one scorer was used it was not possible to undertake inter-rater correlations. Table 14 does reveal the significance of the zero scores on the final result. The difference in medians with zeros included and excluded is large.

Responsiveness to change

Cumming (219) indicates that a measurement must be able to reflect change over time and between patients and conditions. It is vital that the measurement does this and the results of this thesis will demonstrate the responsiveness or otherwise of this instrument.

Summary

The modifications to the DUSOI to enable it to measure a family's burden of illness over a twelve month period have been demonstrated to provide a valid and reliable instrument suitable for use in general practice. The method of casenote audit for scoring provides an ethical and practical way of scoring families burden of illness.

Chapter 5

Results

In this chapter the data obtained in this research and their analysis are presented. In turn it examines the results from each group of subjects, followed by inter-group comparisons. Secondary analyses, undertaken in an attempt to discover the possible reasons for the results from the within-group analysis, are also reported.

Overview of results

The data demonstrate that the burden of illness decreased for a family after referral of a family member to a psychiatrist and the burden increased in the year after a family member suffers a myocardial infarction. The data do not demonstrate any significant differences between the years before and after counselling for a mental illness or diagnosis of a breast cancer. The results are summarised in Table 15.

Exploration of reasons for these findings revealed that the number of conditions presented to a doctor by family members decreased in the year following referral to a psychiatrist, but this only played a small part in the overall difference. Following an AMI there was a complex interaction between the severity of the conditions and the number of conditions that lead to the increase in the burden of illness. The prime contributor to the increase was the severity of the conditions for which family members sought consultation, followed by the number of conditions and then an interaction between severity and number. This model explained almost 70% of the difference.

Year	Mean Family DUSOI score		Mean Number of Conditions per Family		Mean Score / Condition / Family Member		Proportion of Symptoms		Proportion of Psychosomatic Conditions	
	Prior	After	Prior	After	Prior	After	Prior	After	Prior	After
Counselling	16.06	16.31	6.45	7.15	4.41	4.07	0.20 ^e	0.21 ^e	0.11	0.06
Psych referral	21.63 ^a	17.76 ^a	8.65 ^c	6.80 ^c	4.89	4.35	0.18 ^e	0.22 ^e	0.08	0.11
Breast Cancer	17.41	16.47	5.85	4.55	4.29	3.74	0.37 ^d	0.21 ^{d,e}	0.10	0.10
AMI	18.11 ^b	24.82 ^b	5.10	6.00	3.85	4.27	0.35	0.42 ^e	0.08	0.14

Table 15 Summary results

a = difference significant $p < 0.015$; b = difference significant $p < 0.03$; c = difference significant $p < 0.005$;

d = difference significant $p < 0.05$, e = proportion of symptoms significantly different to year after AMI $p < 0.05$

Group 1 – Counselling group

The counselling group consisted of twenty patients and their families, where, as set out previously, the patients (plus or minus other family members) received family therapy based counselling from the author as the sole treatment for a mental health problem.

This group of patients was selected from 456 records of treatment. After the application of the exclusion criteria 127 records were retained. In Table 16 the reasons that patient records were excluded are detailed. Only the first reason that led to exclusion is recorded.

Reason for exclusion	Number
Psychotic illness	2
Unable to identify patient	3
Problem was not a mental health problem	7
Other members of family having psychotherapy from a person other than the author	21
Medication used	53
A therapy other than family therapy used	61
Medical record of family member incomplete	80
No family or no family record	102
Total	329

**Table 16 Counselling group - Reason
for exclusion**

From a random starting point in the list of patients, patient records were extracted from the filing system and examined for exclusion criteria, until twenty appropriate family records were found. A total of 36 records were examined before the 20 were identified. The sixteen excluded records included nine which were not available because they were stored off-site, and seven that, on close examination were subject to the exclusion criteria.

The 20 subject patients and their families appeared different (Table 18) from the overall group of potential subjects, especially in relation to family size and the percentage of patients who were female.

	Total	Age of patients		Family size		% Female	
	N	N	Mean	N	Mean	N	%
All identified patients	456	400	35.9	436	3.03 ^a	436	72.5 ^d
All potential subjects	127	115	35.0	125	3.42 ^{a,b}	115	73.0 ^c
Subjects	20	20	37.3	20	3.75 ^{a,b}	20	95.0 ^{c,d}

**Table 18 Comparison of Subjects
with overall patient base**

a = All patients, potential subjects, subjects - difference significant $p < 0.0005$; b = Potential subjects, subjects - no significant difference; c = Potential subjects, subjects - difference significant $p < 0.025$; d = All patients, subjects - difference significant $p < 0.02$.

These results suggested that there might be a difference between the groups, particularly in relation to gender. In order to compare the groups, three separate groupings were defined.

1. Counselling Group 1 = all identified patients – all potential subjects = all excluded patients
2. Counselling Group 2 = all potential subjects – subjects = included patients – selected patients
3. Counselling Group 3 = subjects = all selected patients

For ease of understanding these groups will be labelled C-Groups to avoid confusion with the four major groups.

Some of the data were not normally distributed so non-parametric methods were used. Comparison between the three C-groups was carried out using the Kruskal-Wallis test. The results were as follows.

Age:	$\chi^2 = 1.073$	df = 2	p = 0.585
Family size:	$\chi^2 = 16.507$	df = 2	p < 0.0005

These results indicate that while there was not a significant difference in age between the three C-groups there was a significant difference in family size.

This latter difference was not unexpected as C-Group 1 contains a number of people who lived alone. C-Groups 2 and 3 consisted of people who lived in family situations and thus the minimum size of the family was two for these counselling groups.

The Mann-Whitney U test was used to explore comparisons about family size between individual C-groups. The results were

C-Group 1 v C-Group 2	Z = -3.360	p = 0.001
C-Group 1 v C-Group 3	Z = -2.637	p = 0.008
C-Group 2 v C-Group 3	Z = -1.264	p = 0.206.

These results indicate that the family size of C-Group 1 is significantly different to the other two groups but there was not a significant difference between the potential subjects (C-group 2) and the subjects (C-group 3). The differences found between C-group 1 and the other two groups were explained by the exclusion criteria relating to family size.

Table 17 suggests that C-Group 3 differed from the other groups on the basis of gender. This was investigated using Crosstabs and Pearson's χ^2 . The results for the comparisons of the three groups were

Pearson $\chi^2 = 5.540$	df = 2	p = 0.063.
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This result does not quite reach statistical significance at the $p < 0.05$ level, so individual comparisons were undertaken using the same method. The results were

C-Group 1 – C-Group 2	Pearson $\chi^2 = 0.003$	df = 1	p = 0.953
C-Group 2 – C-Group 3	Pearson $\chi^2 = 5.137$	df = 1	p = 0.023
C-Group 1 – C-Group 3	Pearson $\chi^2 = 5.522$	df = 1	p = 0.019.

These results indicated that the gender distribution of C-Group 3 (the subjects) was significantly different from the group of all possible subjects, and all counselled patients, with a higher number of females in C-group 3. The significance of this result is discussed later.

The family scores of burden of illness, as measured by the mean modified family DUSOI score, are shown in Table 18.

	Year prior	Year after
Mean	16.06	16.31
Median	11.45	11.70
Mode	0.0	0.0
Std Dev	18.03	15.37
Minimum	0.0	0.0
Maximum	68.5	63.5

**Table 18 Counselling group –
modified family DUSOI scores**

The results showed little change in the burden of illness in the year following counselling. The mode of zero and the standard deviation being larger than the mean indicated a markedly skewed distribution. (223)

The distributions of the modified family DUSOI scores are shown in Figure 7 and Figure 8.

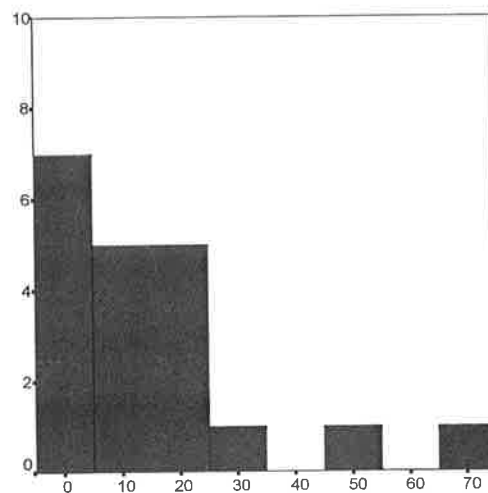


Figure 7 Counselling group - frequency of modified family DUSOI scores for year prior

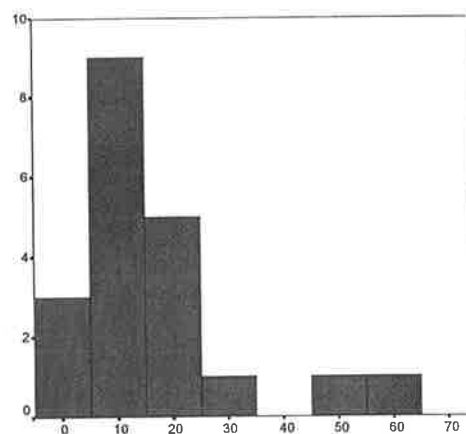


Figure 8 Counselling group – frequency of modified family DUSOI scores for year after

The scores were obviously positively skewed and attempts at transformation were unsuccessful. The distributions appeared similar and this was confirmed by similar variances (variance for year prior = 325.0 and for year after = 236.1). Because of the non-normal distributions and the similar variances Wilcoxon Signed Ranks test would be appropriate for testing for differences in medians.

In order to examine the data further the modified family DUSOI score for the year prior was subtracted from the modified family DUSOI score for the year after the commencement of counselling. As a higher score indicates a larger burden of illness, a positive difference indicates an increase in the burden of illness. A negative difference indicates a decrease in the burden of illness.

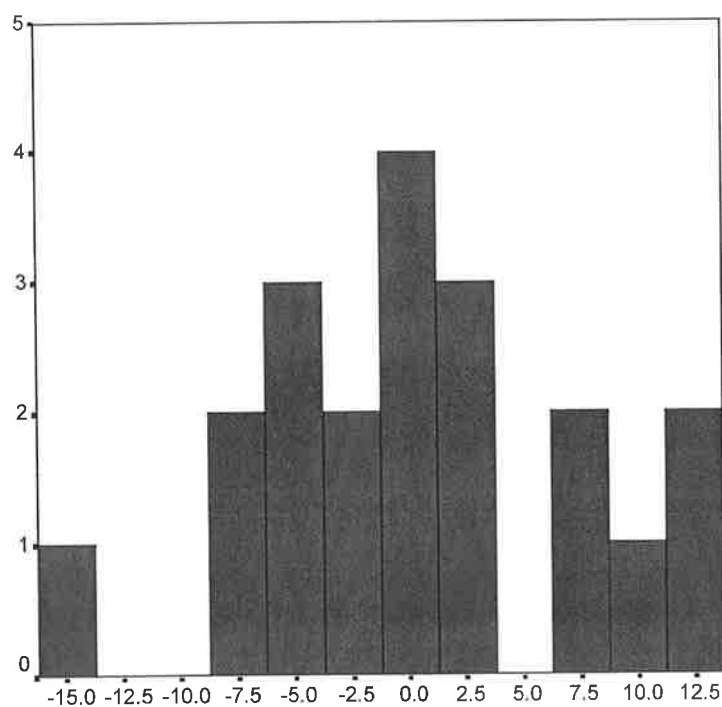


**Figure 9 Difference of mean modified family
DUSOI scores - Counselling group**

For the counselling group the difference of the mean modified family DUSOI scores took on a far more normal distribution.

Skewness (0.070) and kurtosis (-0.107) were both within the limits of acceptability¹.

A box plot of the difference in the modified family DUSOI scores did not reveal any outliers. With a normally distributed difference the one-sample t-test was therefore appropriate. The one-sample t-test is more powerful at detecting a difference than the Wilcoxon Signed Ranks test and was therefore used in this analysis.

The mean difference of the mean modified family DUSOI scores in the counselling group (0.25, 95% CI -2.20 to 3.41) was not statistically significant (one sample t-test $t = 0.162$, $df = 19$, $p = 0.87$).

A family's burden of illness did not show any significant change in the years before and after the commencement of counselling.

¹ If the absolute value of each of skewness and kurtosis is less than $1.96 \times$ absolute value of the standard error of measurement for the parameter then the data can be examined by parametric methods. Some authors (213) argue that with small samples this figure should be increased to 2.58, however 20 families was an intermediate number and a pragmatic decision was made to use 1.96 during the analyses.

Group 2 – Psychiatric referral

Approximately 5000 family records were examined to find 126 where there was evidence of a referral to a psychiatrist. From these 20 were suitable for this study. The records of 106 patients were excluded from analysis for the reasons set out in Table 19.

Reason	Number
Date of referral outside range	27
Author had provided counselling to a family member	31
Living alone	39
Incomplete family records	9
TOTAL	106

Table 19 Reasons for exclusion of psychiatric referral patients

A detailed description of the patients is included in the Methods chapter (see on page 96) and a comparison with the other three groups is detailed below (see on page 145).

In the Method section the author indicated that the date of the first consultation with the psychiatrist was chosen as the index event. As indicated there was some difficulty in determining the date of referral, but the largest error in estimating the date of first consultation could only be two weeks.

The results are detailed in Table 20.

	Year prior	Year after
Mean	21.63	17.76
Median	19.95	13.15
Mode	6.90	9.40
Std Dev	11.32	11.60
Minimum	6.90	0.00
Maximum	52.90	42.00

**Table 20 Psychiatric referral group –
modified family DUSOI scores**

The results indicate a decrease in the family burden of illness in the year after referral to a psychiatrist.

The distributions of the mean modified family DUSOI scores are shown in Figure 10 and Figure 11.

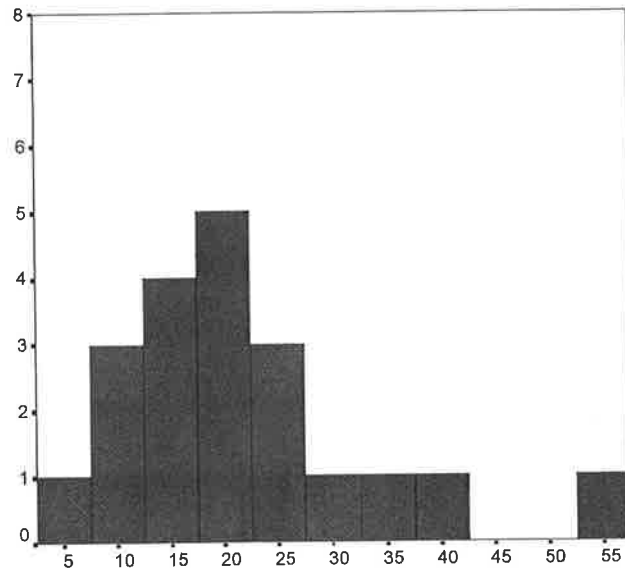


Figure 10 Psychiatric referral group - frequency of modified family DUSOI scores for year prior

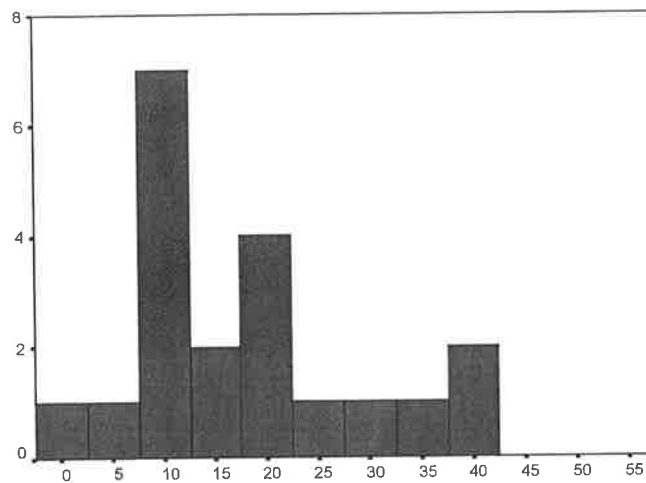


Figure 11 Psychiatric referral group - frequency of modified family DUSOI scores for year after

The scores for the year prior to psychiatric referral showed a positive skew (1.26). The Shapiro-Wilk test ($p = 0.042$) confirmed the non-normal distribution of the scores for the year prior to referral.

The variances of the scores for each year were similar (prior variance = 128.1 and after variance = 135.1).

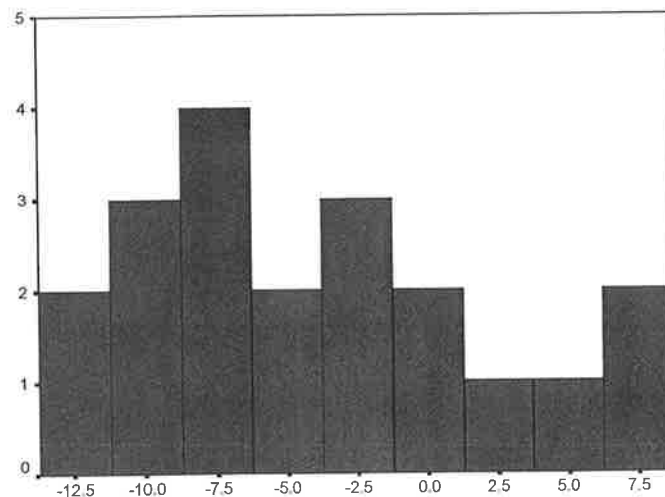


**Figure 12 Difference of modified family
DUSOI scores - Psychiatric referral group**

When the mean modified family DUSOI scores of the year after referral were subtracted from the scores of the year prior to referral the resultant scores had a normal distribution (Figure 12) with a skewness (0.444) and kurtosis (-0.605) which are within acceptable limits.

The boxplot did not show any outliers. The one-sample t-test was therefore used to examine for significant difference.

The mean difference of the mean modified family DUSOI scores in the psychiatric referral group between the years prior to referral and the year after referral (-3.88, 95% CI -1.04 to -6.72) was statistically significant (one sample t-test $t = -2.860$, $df = 19$, $p = 0.010$).

Thus, for families where a member was referred to a psychiatrist the scores for the family burden of illness in the year prior to referral were significantly larger than those in the year following referral.

Group 3 – Breast cancer

A total of 83 records were identified by searching the practice database for the ICD-10 code for breast cancer. The patients were sorted by age and examined from youngest to oldest. A total of 51 records were examined for exclusion criteria to find twenty appropriate families. Thirty-one were unsuitable for the reasons detailed in Table 21.

Reason	Number
Incomplete family record	14
Lived alone	11
Selected in Counselling group	2
Personal relationship with author	2
Breast cancer occurred within 12 months of commencement of project	2
Total	31

**Table 21 Reasons for exclusion in
breast cancer group**

Further details of the patients are contained in the description of subjects (see on page 101).

As previously reported there was some difficulty with determining the date of surgery, but at most the error was two weeks.

The modified family DUSOI scores for the breast cancer group are shown in Table 22.

	Year prior	Year after
Mean	17.41	16.47
Median	11.45	11.75
Mode	0.0	0.0
Std Dev	19.60	19.35
Minimum	0.0	0.0
Maximum	73.9	74.8

**Table 22 Breast cancer group –
Modified family DUSOI scores**

The results show a very small decrease in the mean family burden of illness in the year following diagnosis of breast cancer. The standard deviations are higher than the means suggesting skewed distributions.

The distributions of the scores are set out in Figure 13 and Figure 14.

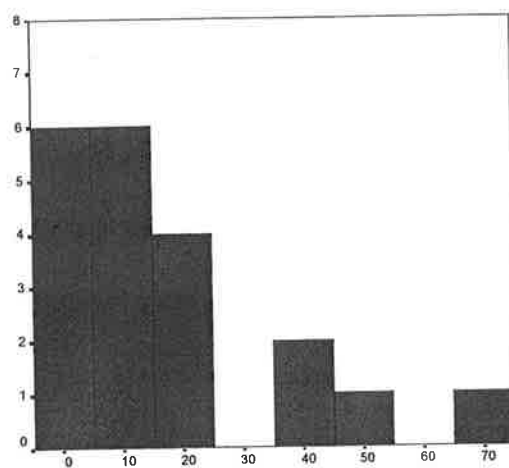


**Figure 13 Breast cancer group -
frequency of modified family DUSOI
scores for year prior**

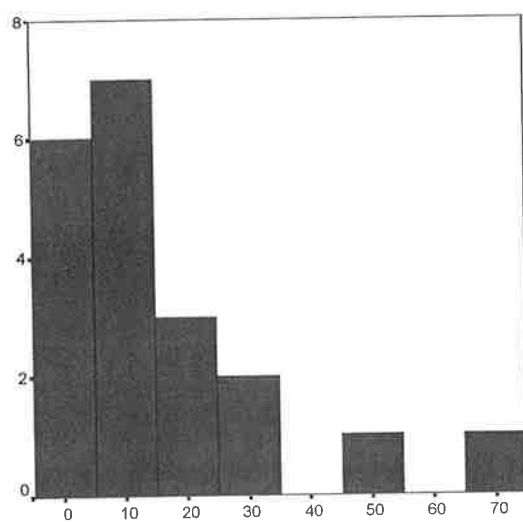


**Figure 14 Breast cancer group -
frequency of modified family
DUSOI scores for year after**

Once again the crude scores appear to have a non-normal distribution. Transformation was unsuccessful. Variances were very close (384.0 and 374.3).

The difference in mean modified family DUSOI scores had a peaked distribution centred on a mode of zero. The skewness (0.283) was acceptable for a normal distribution, but kurtosis (2.898) was outside acceptable limits.

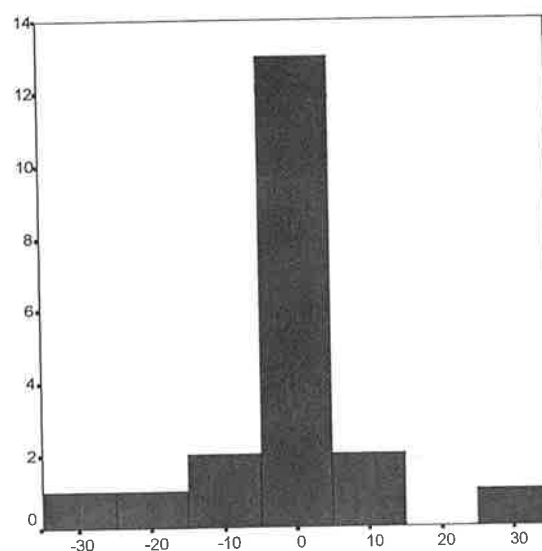


**Figure 15 Distribution of Breast Cancer
family difference scores**

The boxplot (Figure 16) showed three outliers. Examination of these cases did not reveal any error of scoring or calculation. With the outliers excluded from the analysis the difference figures became normally distributed (skewness = -0.778 and kurtosis = 0.728). The results will be presented with and without the outliers.

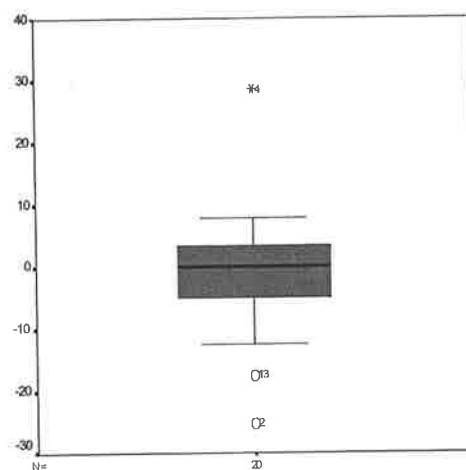


Figure 16 Boxplot modified family DUSOI
Difference scores - Breast cancer group

With all 20 subject families included the difference between groups as calculated by the Wilcoxon Signed Ranks test were not significant ($Z = -0.454$, $p = 0.650$.)

With the outliers excluded the mean difference of the mean modified family DUSOI scores in the breast cancer group (-0.28 , 95% CI -3.10 to 2.54) was not statistically significant (one sample t-test $t = -0.208$, $df = 16$, $p = 0.84$).

In summary the data for the breast cancer group are as follows.

	All families		Outliers excluded	
	Year prior	Year after	Year prior	Year after
Mean	17.41	16.47	15.68	15.40
Median	11.45	11.75	10.40	9.40
Mode	0.0	0.0	0.0	0.0
Std Dev	19.60	19.35	19.84	20.50
Minimum	0.0	0.0	0.0	0.0
Maximum	73.9	74.8	73.9	74.8

**Table 23 Breast cancer group,
Summary results**

The mean modified family DUSOI scores for the breast cancer group do not significantly alter after the diagnosis of breast cancer.

Group 4 – Acute myocardial infarction

A total of 55 records were identified by searching the practice database for the ICD-10 code for myocardial infarction. The patient list was sorted by patient age and a total of 42 records were examined for exclusion criteria to find twenty that were appropriate. Twenty-two records were excluded for the reasons detailed in Table 24.

Reason	Number
Incomplete family record	14
Lived alone	6
AMI within 12 months of scoring	2
Total	22

**Table 24 Reasons for exclusion of
AMI patients**

More details of the patients can be found in the description of subjects (see on page 102) and in the cross-group comparisons below.

As mentioned in the method it proved difficult to ensure a precise date for an infarction. It was possible to narrow down the time interval in which the infarction occurred to plus or minus one week.

The mean modified family DUSOI scores are detailed in Table 25.

	Year prior	Year after
Mean	18.11	24.82
Median	14.15	23.50
Mode	0.00	0.00
Std Dev	16.74	17.09
Minimum	0.00	0.00
Maximum	54.1	49.6

**Table 25 AMI results – modified
family DUSOI scores**

There was a large increase in the burden of illness among family members after the occurrence of a myocardial infarction. The modes of zero suggest skewed distributions, as all scores are positive.

The distribution of the scores is detailed in Figure 17 and Figure 18.

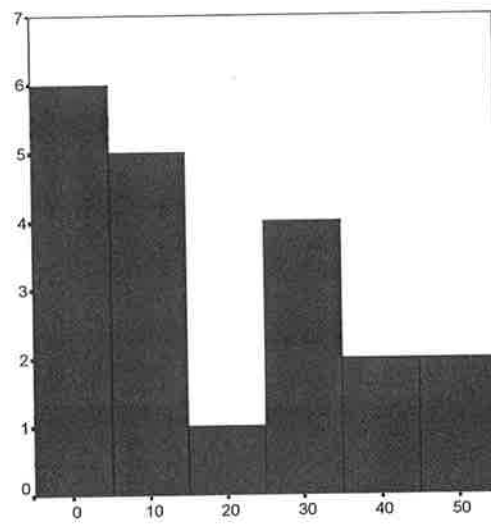


Figure 17 AMI group - frequency of family scores for year prior

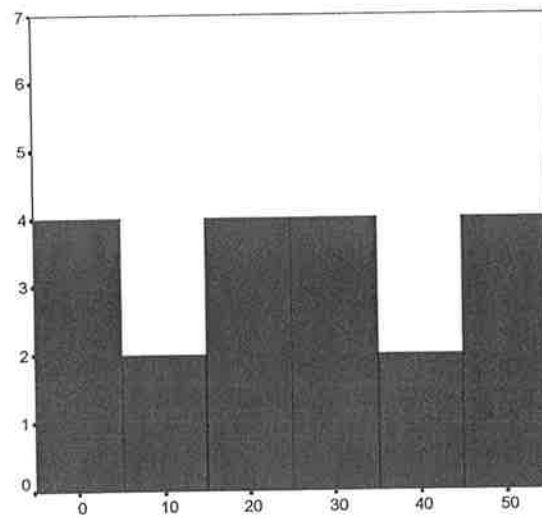


Figure 18 AMI group - frequency of family scores for year after

Once again the crude scores appear to have a non-normal distribution, although the degree of skew and kurtosis are within acceptable limits. For the scores in the year prior to the index event skewness = 0.621 and kurtosis = -0.640. For the year after the figures are -0.035 and -1.389 respectively. Variances are similar (prior = 280.2 and after = 292.1).

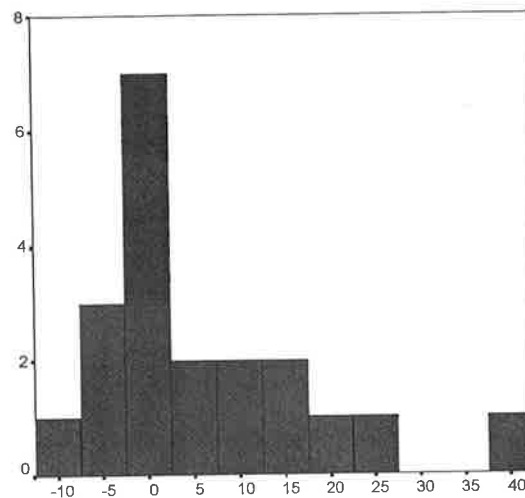


**Figure 19 Difference score AMI
group**

The difference in modified family DUSOI scores appeared skewed (Figure 19). Skewness was greater than acceptable (1.193). Figure 19 also suggested there might be an outlier. The boxplot (Figure 20) confirmed the outlier, and as with previous data this was not due to a mistake in the scoring or calculation. With the outlier excluded from the analysis the difference data were normally distributed (skewness = 0.772 and kurtosis = -0.094). It should be noted that with the outlier excluded from the analysis the specific tests for normality provided conflicting results. The Kolmogorov-Smirnov test (with Lillefor's correction) indicated a non-normal distribution (p for difference from a normal distribution = 0.034), while the Shapiro-Wilk test did not indicate a difference from a

normal distribution (p for difference = 0.168). Generally the Shapiro-Wilk is accepted as being more accurate than the Kolmogorov-Smirnov. (213, page 51)

The results will be presented with the outlier included and excluded.

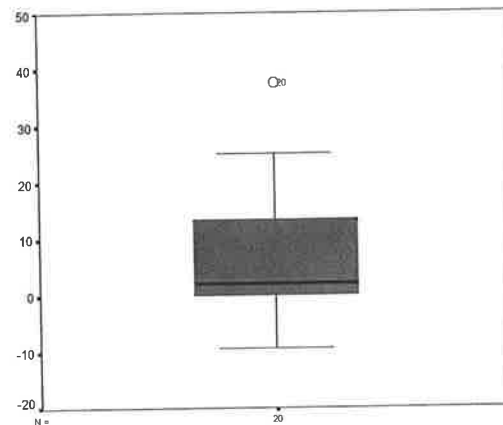


**Figure 20 Boxplot modified family
DUSOI difference scores - AMI group**

With all 20 families included the difference was significant (Wilcoxon Signed Ranks test $Z = -2.287$ $p = 0.022$).

With the outlier excluded the mean difference of the mean modified family DUSOI scores in the counselling group (5.08, 95% CI 0.62 to 9.55) was statistically significant (one sample t -test $t = 2.390$, $df = 18$, $p = 0.028$).

In summary the data for the acute myocardial infarction group set out in Table 26.

	All families		Outlier excluded	
	Year prior	Year after	Year prior	Year after
Mean	18.11	24.82	19.06	24.14
Median	14.15	23.50	14.70	21.90
Mode	0.0	0.0	0.0	0.0
Std Dev	16.74	17.09	16.63	17.28
Minimum	0.0	0.0	0.0	0.0
Maximum	54.1	49.6	54.1	49.6

Table 26 AMI group modified family

DUSOI scores - Summary results

With either the outlier excluded or included the data revealed that the mean modified family DUSOI scores for the AMI group for the year following the infarction were significantly greater than the scores in the year prior to the infarction.

Summary of within-group comparisons

The results are summarised in Table 27 which contains the p values for a difference between the scores for year prior to the index event and the scores for the year following.

These results indicate a significant decrease in the burden of illness for a family following referral of a family member to a psychiatrist and an increase in the year following a myocardial infarction.

Group	N	Year prior	Year after	Test statistic	p
Counselling - All families	20	15.60	14.54	t-test df = 19	0.873
- Means				t = 0.162	
Counselling - All families	20	11.75	9.90	Not applicable	
- Medians					
Psych Ref - All families -	20	18.88	15.23	t-test df = 19	0.010
Means				t = -2.860	
Psych Ref - All families -	20	20.15	12.00	Not applicable	
Medians					
Breast Ca - All families -	20	17.41	16.47	Not applicable	
Means					
Breast Ca - All families -	20	11.45	11.75	Wilcoxon	0.650
Medians				Z = -0.454	
Breast Ca - No outliers -	17	15.68	15.40	t-test df = 16	0.838
Means				t = -0.208	
Breast Ca - No outliers -	17	10.40	9.40	Not applicable	
Medians					
AMI - All families -	20	18.11	24.82	Not applicable	
Means					
AMI - All families -	20	19.06	24.14	Wilcoxon	0.022
Medians				Z = -2.287	
AMI - No outliers -	19	19.06	23.50	t-test df = 18	0.028
Means				t = 2.399	
AMI - No outliers -	19	14.70	21.90	Not applicable	
Medians					

**Table 27 Summary of within groups
data**

Between group comparisons

As set out in Chapter 3 (on page 103) the groups were dissimilar in structure so it was possible there may also be differences in illnesses experienced and/or behaviour. However because of the unmatched nature of the data it was unlikely that with twenty families in each group there was sufficient power to detect any meaningful differences. Using data from Group 4 (Table 26) which had the largest differences, power calculations indicated that with $\mu_1 = 19$, $\mu_2 = 24$, (SD = 17), $n = 20$ and $\alpha = 0.05$ then power = 0.20. (214) This was very small and indicated little likelihood of demonstrating differences, even if they existed.

On examination of the data on means and medians (Table 27) there appear to be substantial differences between some figures.

It was decided to undertake the following comparisons.

1. Year prior of Groups 1 and 2
2. Year after of Groups 1 and 2.
3. Year prior of Groups 3 and 4.
4. Year after of Groups 3 and 4.
5. Year prior of Groups 1 and 2 with year after of Groups 3 and 4.
6. Year after of Groups 1 and 2 with year prior of Groups 3 and 4.

Such comparisons looked at similar periods of time. The year prior of Groups 1 and 2 and the year after of Groups 3 and 4 could be seen to be years of higher distress in the families. Similarly the year after of Groups 1 and 2 and the year prior of Groups 3 and 4 could be seen as years of lesser distress.

The modified family DUSOI score of the groups were compared using a one way ANOVA with the contrasts set out above. Because some of the scores were not normally distributed the scores were converted to ranks and these were used for the ANOVA.

The level of significance (α) was reset using the Bonferroni correction for multiple comparisons to 0.05/12 or 0.004. In the Bonferroni correction the level of significance is divided by the number of comparisons (k). In this case $k = 12$.

The ANOVA for between group comparisons was not significant ($F = 1.348$, $df = 7$, $p = 0.232$).

None of the comparisons achieved a significant level of difference. This may reflect the low power in this part of the study or could indicate that there is not a difference. The values are contained in Appendix D (on page 252).

Summary

There were not any statistically significant differences in the burden of illness between groups.

Secondary analyses – Analysis of the reasons for the differences

Number and severity of conditions

The data relating to Groups 2 (Psychiatric referral) and 4 (AMI) were further analysed to explore the reasons for the differences. The individual scores (out of 16) for each condition were placed in a database and two other scores calculated: the number of conditions per family and the mean score per condition for each family. Figures were generated for the year prior to the index event and the year after. These figures provided some ability to determine whether the differences discovered above were due to a change in the number of conditions, a change in the severity of conditions or a combination of both. The results are displayed in Table 28 and the Wilcoxon Signed Ranks test results are in Table 29.

	Psychiatric referral		AMI	
	Number of families	Median (Range)	Number of families	Median (Range)
Number of conditions / family in year prior	20	9.00 ^a (1 – 23)	20	5.00 (0 – 14)
Number of conditions / family in year after	20	5.00 ^a (0 – 22)	20	6.00 (1 – 12)
Score / condition/ family in year prior	20	4.69 (2.61 – 14.00)	19	4.20 (0.33 – 5.50)
Score / condition/ family in year after	19	4.20 (2.50 – 7.00)	20	4.24 (0.00 – 7.00)

**Table 28 Comparison of number of
conditions and severity**

a = statistically significant difference $p < 0.005$

N is less than 20 for some of the calculated scores because the count of conditions for a family can be zero, and dividing by zero for the score/condition produces an undefined result.

	Count/family Difference between years	Score/condition Difference between years
2 Psych referral	Z = -2.890 p = 0.004	Z = -0.845 p = 0.39
4 Acute MI	Z = -1.625 p = 0.10	Z = -0.523 p = 0.60

Table 29 Statistical significance of differences using Wilcoxon Signed Ranks Test

These results indicate that, for Group 2 (Psychiatric referral) the change in the modified family DUSOI scores between the years may have been related to a decrease in the number of conditions (consultations) per family in that year.

In order to investigate this further, the number of conditions per family and the severity of the conditions (score/condition) were entered into a univariate analysis of variance (ANOVA). The dependent variable was the difference in the modified family DUSOI scores and the independent variables were calculated scores, the difference in number of conditions per family and the difference in score per condition and an interaction between the two. In all cases the differences were calculated by subtracting the score for the year after the index event from the year prior to the index event. Because these data were continuous they were entered into the univariate ANOVA as covariates.

Group 1 – Counselling and Group 3 – Breast cancer

Analyses of the Counselling and Breast cancer groups did not reveal any significant effects.

Group 2 - Psychiatric referral

The first model tested used the difference in modified family DUSOI scores as the dependent variable and entered the difference in number of conditions, difference in severity of conditions and an interaction between these two items as covariates. This model was not significant ($F = 2.328$, $df = 3$, $p = 0.318$). Analysis of the results suggested that the difference in the number of conditions was significant ($p = 0.045$) while the interaction did not appear to have a significant effect ($p = 0.485$).

The analysis was repeated with the interaction removed. The result was not significant ($F = 1.874$, $df = 2$, $p = 0.186$). The difference in number of conditions was almost significant ($p = 0.072$), while the difference in severity was not significant ($p = 0.377$).

The analysis was repeated with only the difference in number of conditions as covariate. This again produced a non-significant result ($F = 3.045$, $df = 1$, $p = 0.098$).

Examination of the parameters generated in the analysis did not reveal anything that would affect the validity of the ANOVA result.

If the last result had been significant the adjusted R^2 is small (0.097) indicating that the difference in number of conditions between the years has only contributed a small portion (9.7%) of the overall difference in modified family DUSOI scores.

The overall results, the univariate ANOVA combined with the results of the Wilcoxon Signed Ranks test (Table 29), indicate that the difference in number of conditions is significant, but only had a very small effect on the difference in the modified family DUSOI scores. The limitation of the results of the ANOVA could be overcome by a larger sample size.

Group 4 – Acute myocardial infarction

As one of the conditions for this analysis is that the dependent variable is normally distributed, in the case of group 4 (AMI) the outlier was excluded before analysis. With the outlier excluded the parameters become

Parameter	
Skewness	0.772
Kurtosis	-0.094
Kolmogorov-Smirnov with Lillefor's correction	p = 0.034
Shapiro-Wilk	p = 0.168

**Table 30 AMI pattern (outlier
excluded from calculation)**

The visual appearance of the histogram appeared normal with a mild positive skew, but the skewness measure is acceptable. As mentioned previously, the Shapiro-Wilk is generally more accurate than the Kolmogorov-Smirnov and thus the univariate ANOVA is an appropriate test.

The data were entered in the same way as in the psychiatric referral group. The first model used consisted of entering the difference in the number of conditions and the difference in severity of the conditions as main effects combined with an interaction between these two items. This model was highly significant ($F = 13.824$, $df = 3$, $p < 0.0005$). The adjusted R^2 was high at 0.694, indicating that this model explained 69.4% of the difference in the modified family DUSOI scores.

Examination of the test parameters did not reveal any difficulties with the analysis.

The parameter estimates indicated a significant effect for all covariates. These are indicated in Table 31.

Parameter	β	t	p	95% CI	Eta ²
Intercept	4.835	3.334	0.005	1.725-7.964	0.443
Interaction	0.823	2.735	0.016	0.178-1.469	0.348
Difference in number	1.760	3.303	0.005	0.617-2.902	0.438
Difference in severity	4.061	5.488	< 0.0005	2.744 - 5.648	0.683

**Table 31 Parameter estimates for
ANOVA in AMI group**

Examination of Table 31 indicates that the difference in severity of the conditions had the largest effect (Highest β , lowest p and largest effect size eta²). Further analysis, entering

individual covariates did not improve the model. These results indicate that nearly 70% of the difference in the modified family DUSOI scores can be attributed to the difference in number of conditions, the difference in the severity of the conditions and an interaction between these two measures.

Summary

From these results it appears that for the psychiatric referral group the difference was due to unidentified factors, with a small effect from the decrease in the number of conditions. For the AMI group the difference was largely due to an increase in the severity of the conditions associated with a smaller effect from the number of conditions and a small effect from an interaction between these two measures.

Effects of age, gender and family size

The effects of the age and gender of the patient, and family size on the results of each group were analysed by bivariate correlations of each item with the mean modified family DUSOI scores for the year prior to and year after the index event, and the difference in these scores. Each group was examined individually. Because of the non-parametric nature of the data Spearman's ρ (rho) was used.

There was a significant correlation was between mean modified family DUSOI score in the year after myocardial infarction and family size (Spearman's $\rho = -0.601$, $p = 0.005$). There is a lower correlation in the year prior to infarction (Spearman's $\rho = -0.437$, $p = 0.054$). None of the other groups show such a significant degree of correlation. These results suggest that the larger the family the lower the burden of illness in the families of patients who have a myocardial infarction, although the correlation is modest in size. The implication of this result is discussed later.

There were no significant correlations in any other groups. It is reassuring that in all four groups there was a strong negative correlation between age and family size.

There was a significant correlation between the difference in mean modified family DUSOI scores and the age of the patient in the counselling group (Spearman's $\rho = -0.536$, $p = 0.015$). This indicates that, in the counselling group, as the age of the patient increases the difference in means decreases, although the level of correlation is only modest.

In order to explore the effect of gender in more detail the results were classified as coming from a stressful year or a less stressful year. A stressful year was defined as the year prior

to counselling or referral to a psychiatrist or the year after the detection of breast cancer or the occurrence of a myocardial infarction.

There were 31 male patients and when the scores for the stressful and less-stressful years for each family were compared the data were not normally distributed. The medians of the family's burden of illness for the stressful year (21.10) and the less-stressful year (14.70) were significantly different (Wilcoxon signed ranks test $Z = -2.498$, $p = 0.013$).

There were 49 female patients and once again the family scores were not normally distributed. The medians of the family's burden of illness for the stressful year (13.80) and the less-stressful year (11.80) were not significantly different (Wilcoxon signed ranks test $Z = -0.813$, $p = 0.416$).

To investigate further, the differences in family scores between the stressful year and the less stressful years were calculated. Graphical analysis suggested there was a slight degree of skew and kurtosis. The standardised variance for the difference data appeared to be acceptable for ANOVA.

The data were therefore entered into a univariate ANOVA. The difference scores were the dependent variable, while gender and group, being categorical values, were entered as factors in the analysis. For the first analysis the gender and group were entered as main effects and as an interaction. This model was not significant ($F = 1.953$, $df = 6$, $p = 0.084$). The analysis suggested that the interaction was the least significant effect.

The analysis was repeated with the interaction removed. This model was significant ($F = 2.597$, $df = 4$, $p = 0.043$). However the adjusted R^2 was low (0.075), which indicates that this model explains only 7.5% of the difference in scores.

The analysis was then repeated, entering gender and group independently. For gender alone the model was not significant ($F = 2.817$, $df = 1$, $p = 0.097$). For group alone the model was significant ($F = 3.113$, $df = 3$, $p = 0.031$). Once again the adjusted R^2 was low at 0.074, or 7.4% of the difference in scores.

In all analyses Levene's test for the equality of variance did not indicate a significant deviation from equal variances across groups.

These results indicate that there was not a significant effect from gender and that group (or disease) had only a small effect on the difference.

Nature of conditions

In order to analyse the reasons for the differences further, the nature of the conditions being scored were entered into a database and classified using the main groups of the ICPC-2. (212) ICPC classifies conditions into one of 17 system-based clusters. Within each cluster there are two large groupings – diagnoses and symptoms. In order to analyse this data the conditions in the database were classified as diagnosis or symptom and entered into four 2 x 2 tables for analysis.

	Counselling		Psych Ref		Breast Ca		AMI	
Year	Prior	After	Prior	After	Prior	After	Prior	After
Symptoms	26	29	32	30	41	19	36	52
Diagnoses	103	110	149	105	81	71	65	73

Table 32 Number of Symptoms and Diagnoses in each group

The results of comparing the proportion of symptoms within each group are shown in Table 33.

Group	χ^2	df	p	Significance
Counselling	0.021	1	0.89	N.S.
Psych Ref	1.012	1	0.31	N.S.
Breast Ca	3.985	1	0.046	Lower year after
AMI	0.834	1	0.36	N.S.

Table 33 Significance of change in proportion of symptoms

N.S. = not significant

All χ^2 values were calculated by TABCHI. (224)

These results indicate that in the breast cancer group in the year after developing breast cancer there was a significant decrease in the number of symptoms for which family members sought consultation.

In an attempt to provide further clarity the diseases were classified as psychological and/or psychosomatic, or “organic”. A complete list of the 29 conditions that were classed as psychological and/or psychosomatic are detailed in Appendix A. Individual diagnoses were classified rather than ICPC codes as this allowed greater precision.

For each group a 2x2 table was generated which compared the figures across the two years.

	Counselling		Psych Ref		Breast Ca		AMI	
Year	Prior	After	Prior	After	Prior	After	Prior	After
Psychological	14	9	15	15	12	9	8	17
Organic	115	130	166	120	110	81	93	108

**Table 34 Number of psychological
and organic conditions in each group**

Group	χ^2	df	p	Significance
Counselling	1.634	1	0.20	N.S.
Psych Ref	0.718	1	0.40	N.S.
Breast Ca	0.002	1	0.97	N.S.
AMI	1.830	1	0.18	N.S.

**Table 35 Significance of change in
proportion of psychosomatic
diagnoses**

N.S. = not significant

All χ^2 values were calculated by TABCHI. (224)

It is apparent on examining the figures that there was a large variation in the number of conditions between groups. This is particularly obvious in the number of conditions in the year prior to the index event.

Two by two tables of the number of symptoms and the number of psychosomatic conditions were prepared for comparisons between groups in the years prior to and after the index event for each. Because of the multiple comparisons a Bonferroni correction was applied. Because of the 6 results in each set of comparisons α was set at $0.05/6$ or 0.0083.

The following results were obtained. (There was one degree of freedom in each comparison.)

Comparison	χ^2	p	Significance
Counselling – Psych referral	0.303	0.58	N.S.
Counselling – Breast cancer	5.798	0.016	N.S.
Counselling – AMI	6.902	0.009	N.S.
Psych referral – Breast cancer	10.109	0.0015	sig
Psych referral - AMI	11.432	0.0007	sig
Breast cancer – AMI	0.101	0.75	N.S.

Table 36 Significance of difference in proportion of symptoms in year prior to index events

(N.S. = not significant)

In the year prior to the index event there was a significantly lower proportion of symptoms in the families of the psychiatric referral group than in either of the breast cancer and AMI groups. The corollary is that there were more diagnosable conditions in the families in the psychiatric referral group. The results for families in the counselling group in comparison to the families in the breast cancer and the AMI groups almost achieved significance.

Comparison	χ^2	p	Significance
Counselling – Psych referral	0.075	0.78	N.S.
Counselling – Breast cancer	0.002	0.96	N.S.
Counselling – AMI	13.307	0.0003	sig
Psych referral – Breast cancer	0.039	0.84	N.S.
Psych referral – AMI	11.287	0.0008	Sig
Breast cancer – AMI	9.931	0.0016	sig

Table 37 Significance of difference in proportion of symptoms in year after index events

In the year after the index event there was a significantly greater proportion of symptoms in the families in the AMI group than in families of any of the other groups.

The biggest difference was between the proportion of symptoms in the year prior to referral to a psychiatrist and the year after suffering an acute myocardial infarction ($\chi^2 = 21.24$ $df = 1$ and $p < 0.000005$). This is despite the years in question both being considered stressful.

There were no significant differences in relation to the psychosomatic conditions.

Summary

The data did not reveal any significant differences in relation to psychosomatic conditions during within-group analysis. However, there was a decrease in the proportion of symptoms for which family members sought consultation in the breast cancer group in the year after detecting the breast cancer.

In the year prior to the index event there were proportionately more diagnosable conditions in the families of those referred to a psychiatrist than in the breast cancer and AMI groups. In the year after the index event there were proportionately more symptoms in families where a member suffered an AMI than in the families in the other groups.

Comment on validation of the modified family DUSOI

In the validation section (on page 105) it was noted that the DUSOI did not take into account conditions not presented to the doctor. In the psychiatric referral group (Group 2) there was an increase in the number of conditions presented to the doctor, suggesting, that in this group, patients sought consultations for a greater number of conditions. For the AMI group (Group 4) there is an interaction between the number of conditions and their severity which results in the difference. In this group they sought more consultations, and were also sicker. Despite concerns expressed earlier, the instrument can be seen to reflect the increased number of consultations as each of these is attributed to a condition or symptom which produces a measurable difference.

The results indicate that the instrument is responsive to changes and is capable of being used in research such as this.

Analysis by psychiatric condition

Within groups one and two there were a number of similar conditions as set out in Table 38.

Condition	Number
Adjustment disorder	15
Depression	7
Other	18

**Table 38 Number of
psychiatric conditions**

An analysis of each group was carried out. The power calculation carried out a priori (see on page 85) indicated that there would be sufficient power to show a difference if it existed for the adjustment disorder group and the “other” group, but would probably be insufficient for the group with depression.

It is also important to remember that the diagnostic categories, particularly from Group 1 did not necessarily conform to established nosologies. (See page 93)

Adjustment disorder

The data for the difference in the mean modified family DUSOI scores for the adjustment disorder group were normally distributed. The mean difference of the mean modified family DUSOI scores in the adjustment disorder group (-0.81, 95% CI -4.96 to 3.34) was not statistically significant (one sample t-test $t = -0.420$, $df = 14$, $p = 0.68$).

Depression

The data for the difference in the mean modified family DUSOI scores in the depression group were normally distributed. The mean difference of the mean modified family DUSOI scores in the depression group (-0.77, 95% CI -5.25 to 3.71) was not statistically significant (one sample t-test $t = -0.421$, $df = 6$, $p = 0.69$).

Other psychiatric conditions

The data for the difference in the mean modified family DUSOI scores in the “other” group were normally distributed. The mean difference of the mean modified family DUSOI scores in the “other” group (-3.06, 95% CI -6.38 to 0.26) was not statistically significant (one sample t-test $t = -1.945$, $df = 17$, $p = 0.069$).

Summary

The results of this study have demonstrated that when patients were referred to a psychiatrist for a mental illness there was a reduction in the burden of illness for the rest of the family in the subsequent year when compared to the year prior to the referral. The factors associated with the decrease in burden are not revealed in this study other than there appeared to be a slight effect from a decrease in the number of conditions presented to the general practitioner by the family.

When a patient suffered a myocardial infarction the burden of illness of family members increased in the subsequent year when compared to the year prior to the infarction. A large part of the increase appeared to be due to an increase in severity of the conditions, an increase in the number of conditions and an interaction between these two factors.

There was no change in the burden of illness for a family when a patient has general practitioner counselling for a mental illness or when a woman suffered a breast cancer. It was interesting to note that there was a decrease in the proportion of symptoms in the family after a patient suffered a breast cancer.

When individual psychiatric diseases were analysed there was no detectable change in family burden of illness for adjustment disorders, depression or a grouping of the remainder of the psychiatric conditions.

While there appears to have been a significant effect due to the gender of the patient with a significant difference between the years when the patient is male, evidence has been presented which suggests that this was due to the nature of the conditions rather than gender.

Chapter 6

Discussion

The results presented in the previous chapter provide an interesting insight into the effects of mental illness on the health of a family. The study also confirms that the modified DUSOI, despite some weaknesses, is a suitable tool for measuring change in response to events occurring in the family. This chapter discusses the results in detail and examines the strengths and weaknesses of the study. It provides suggestions for further investigation of the phenomena associated with a mental illness in the family and examines the clinical significance of the findings. It examines the research hypotheses in light of the results presented in the previous chapter, and makes recommendations related to clinical general practice.

Overview of the study

This study describes the effect of four different “events”, (counselling for a mental health problem, referral for treatment of a mental illness, the occurrence of breast cancer, and the occurrence of an acute myocardial infarction) on four different groups of families. The families were four groups of 20, selected because of the illness suffered by a family member. Selection was carried out in a way that minimised bias. All data collection was carried out retrospectively.

Each of the four independent studies examined a different disease process and each needs to be interpreted independently. The descriptive nature of the study allows an exploration over time of families when a significant life event occurs. The secondary analyses reveal some interesting differences when the years before and after the index event are compared and provide insights into some of the primary results. The study lacks the power to confidently demonstrate differences between groups and this limits the ability of this study to comment on the relative levels of burden of illness between groups and to compare

these with “normal” families. The consistency of the results however strongly supports differences in these areas.

The results are summarised in Table 39, a repeat of Table 15.

Year	Mean Family DUSOI score		Mean Number of Conditions per Family		Mean Score / Condition / Family Member		Proportion of Symptoms		Proportion of Psychosomatic Conditions	
	Prior	After	Prior	After	Prior	After	Prior	After	Prior	After
Counselling	16.06	16.31	6.45	7.15	4.41	4.07	0.20 ^e	0.21 ^e	0.11	0.06
Psych referral	21.63 ^a	17.76 ^a	8.65 ^c	6.80 ^c	4.89	4.35	0.18 ^e	0.22 ^e	0.08	0.11
Breast Cancer	17.41	16.47	5.85	4.55	4.29	3.74	0.37 ^d	0.21 ^{d,e}	0.10	0.10
AMI	18.11 ^b	24.82 ^b	5.10	6.00	3.85	4.27	0.35	0.42 ^e	0.08	0.14

Table 39 Summary results

a = significant difference $p < 0.015$; b = significant difference $p < 0.03$; c = significant difference $p < 0.005$;

d = significant difference $p < 0.05$ level; e = proportion of symptoms significantly different from year after AMI $p < 0.05$.

The major results can be summarised as follows.

Counselling group

This group did not show any significant alteration in the family burden of illness across the two years.

Psychiatric referral group

There was a significant decrease in the mean family burden of illness in the year after referral to a psychiatrist when compared to the year prior to the referral. The study is unable to determine reasons for the difference. There was a decrease in the number of conditions for which the family sought help from the general practitioner in the year after referral, when compared to the year prior to referral.

Breast cancer group

This group did not show any significant alteration in the family burden of illness across the two years, however there was a significant decrease in the proportion of symptoms in the year after the diagnosis of breast cancer when compared to the year before.

AMI group

The families of patients that suffered an AMI had a significant increase in their burden of illness in the year after the AMI when compared to the year before. A large proportion (approximately 70%) of this difference was found to be due to a mixture of increase in the severity of conditions occurring in the family, an increase in the number of conditions in the year following the infarction and an interaction between these two factors. While not statistically significant the proportion of symptoms doubled in the year after the infarction.

Group 1 – Counselling

As indicated in the introduction to this research (page 20), there is a substantial literature to support the safety and efficacy of counselling as a method of treatment for mental health problems in general practice. This study was not able to demonstrate any improvement in family health as a result of counselling, but neither has any deterioration occurred.

The counselling group patients were selected from a list of possible subjects by choosing a random starting point (see Method) and then examining records sequentially until twenty that did not have any exclusion criteria for the study were found. This method was designed to minimise bias in the selection process.

The patients in this group were predominantly female, and while it is not unexpected that women would predominate as patients in this group, (218) the proportion (19 out of 20) is greater than expected. It is possible that husbands respond less to distress (see page 198) and this may have produced some reduction in the effect size. The small size of difference in the results, however, suggests that a gender distribution more in line with that seen in the group of potential subjects would not have lead to a significantly larger difference. In this study there are 19 female patients. If the number of females was reduced to 15, the proportion would have been near the expected level. In a study examining groups of patients of this size such a difference is too small to significantly affect the measured difference.

Unfortunately the computer system in the general practice was not able to give an age-gender or family size breakdown of the total practice patients at the time of the study. It was impossible to do a direct comparison of the counselling group families, or any of the other groups, with the practice population. The author was unable to find any data on

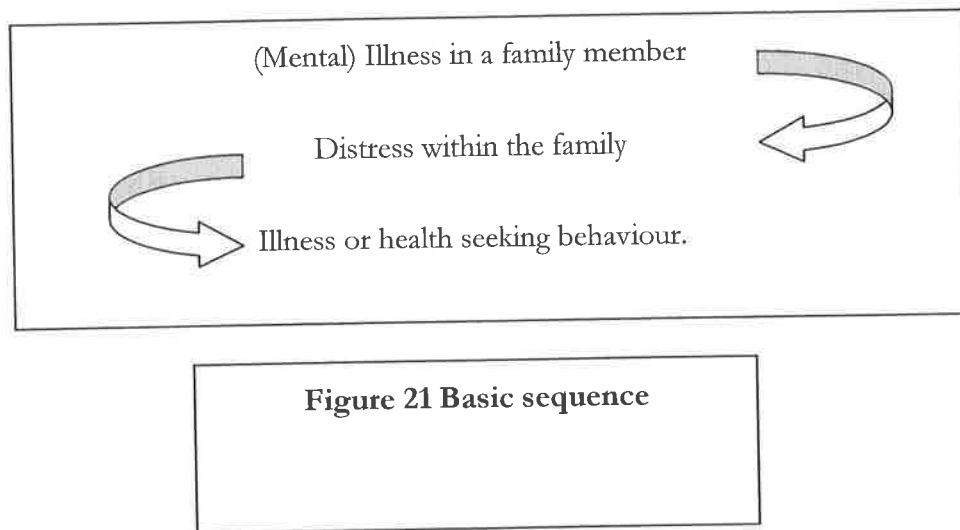
family size in relation to attendance in general practice, but the BEACH study (225) of Australian general practice showed that 57.7% (95% CI = 57.0 to 58.4) of general practice consultations in Australia are with female patients. In summary the proportions are detailed in Table 40.

	General Practice (BEACH)	All Patients Counselling	All Patients Counselling Only	All Patients in Study
N		457	126	20
% female patients	57.7%	72.5%	73.0%	95.0%

Table 40 Comparison of proportion of female patients in study and BEACH

The largest group of patients in this group suffered from adjustment disorders and while these conditions are distressing to individual patients, they are generally regarded as less severe and are more short lived than the conditions seen in the group where the patient was referred to a psychiatrist. It could thus be postulated that one of the reasons for this result is the insufficient time for a low distress condition to produce any effects within the family.

Underlying this research is the supposition that



This model is supported by the literature review (on pages 7 et seq) and is thought to explain the interaction between severe and persistent mental illness and illness in the family. It would also be expected that families would react to the stresses in a measured way. That is, it would be expected that the duration and the intensity of the distress would modify the development of family based response. The author can only remember one instance where there was an instantaneous physical response to a family stress.

The patient was a 71-year-old, anxious grandmother who suffered a myocardial infarction while being informed that her favourite grandson was homosexual. The patient subsequently underwent coronary angiography which did not reveal any stenoses of the coronary arteries. This is in keeping with a stress related coronary vasospasm.

The interaction between stress and performance and the General Adaptation Syndrome (GAS) also support the supposition that the duration and intensity of the distress are important in the development of symptomatic behaviour. The interaction between stress

and performance is generally represented by stress performance curves as shown in Figure 22. They are based on the work of Yerkes and Dodson ((226), quoted in (227)) which compared arousal with learning. There have been studies that have confirmed that the inverted-U curve does apply to the perception of stress and performance. (228)

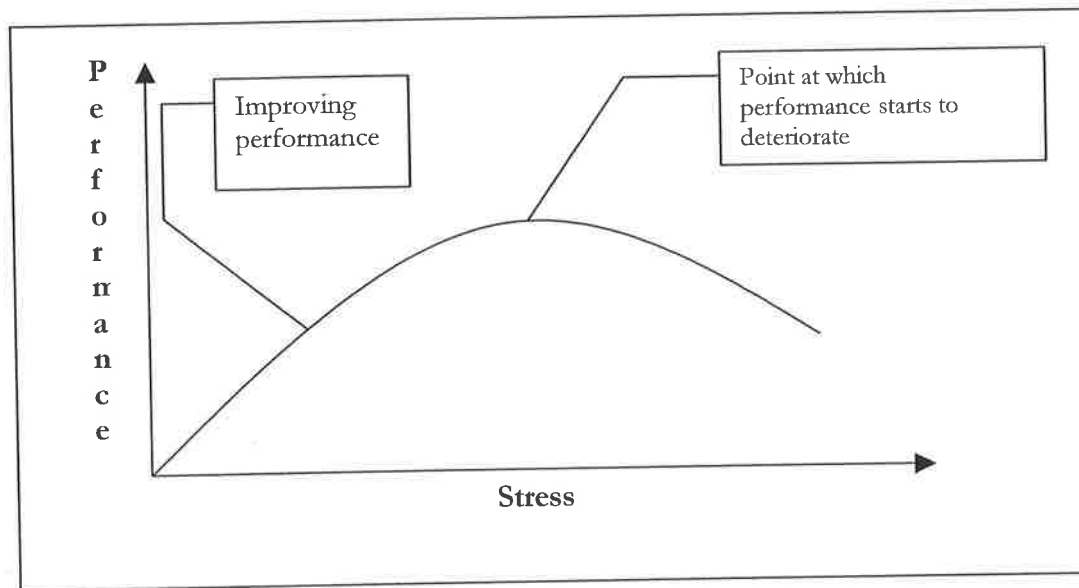


Figure 22 Stress - performance curve

This curve represents the belief that as stress in an individual increases, the performance of that person increases until a crucial point is reached. Beyond this point performance deteriorates. The reduction in performance becomes a stressor in its own right, and the deterioration in performance can be rapid.

The GAS is a model developed by Selye (229) to explain the reaction of individuals to ongoing stress. It is also usually presented graphically as in Figure 23.

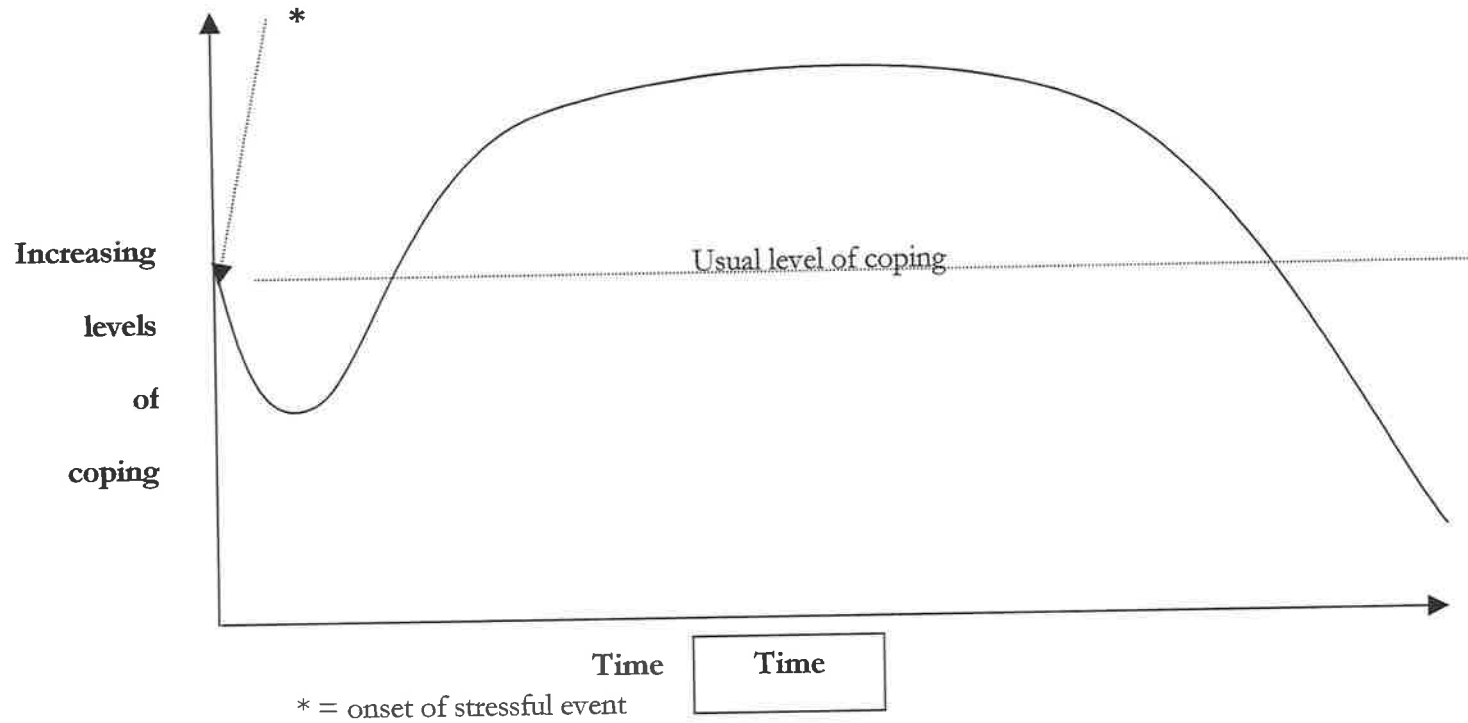


Figure 23 General adaptation syndrome

This model was developed for animals subjected to injection of toxic agents, and indicates three phases in the response to a stressful event. Initially there is an "alarm response" where an animal produces stress hormones and develops signs of acute distress. If the animal survives this initial phase it develops a "stage of resistance". The persistence of the stressor however, eventually results in the "stage of exhaustion". During this last phase the animal's health deteriorates.

When applied to humans experiencing a stressful event a similar sequence is noted, and in particular, while there are specific physiological responses, the pattern can be interpreted as alterations in coping ability. During the last phase where coping skills fatigue the development of symptoms of other illnesses occur.

These models suggest that the duration of the illness and its severity would be expected to affect the response of families. It is likely therefore that the family burden of illness will show little change for the short-lived, comparatively minor conditions seen in the counselling group. To the individual these conditions are distressing.

It would be expected that family members do respond to a change in the mental health of a family member. The initial expectation would be that the change in the patient would be temporary. It is only with the passage of time that the nature and extent of the condition becomes apparent, that a significant response develops in family members. Initially this would take the form of distress, and it is only if the distress is of sufficient severity (ie. affects the social and family role of the members) that illness, or at least help seeking behaviour, develops sufficiently to cause the family member to attend a general practitioner.

Additionally, as discussed in the literature review, the systemic view of a family indicates that families are self-supporting and stabilising. Through this families have a “natural resistance” to distress.

With the less severe conditions of short duration seen in the counselling group than in the psychiatric referral group, it is less likely that they would generate an effect in family members. Even if distress within the family had a rapid onset it is likely that there would be a delay between the onset of distress and seeking help for that distress. In that time the condition creating the distress may have settled.

Alternative interpretations of the lack of change in the family burden of illness in the counselling group, are to assume that counselling is ineffective or the instrument is incapable of measuring the change. The author's impression, supported by the literature, is that counselling does produce positive results, but it is not possible to assert this with any degree of certainty. Patients receiving counselling often just discontinue therapy. This could be interpreted as being dissatisfied with what is happening or that they have improved. Anecdotally in discussions with patients or referring doctors some time after the patients withdrew from therapy, they comment on the success of counselling. Unfortunately this has not been documented in the clinical record and so is unable to be verified. The literature (as discussed earlier) indicates that counselling by lay counsellors in general practice is well received by patients and the patients would see the results as positive, but the overall outcome is not different from a control group of usual general practitioner care. This is consistent with the results in this group.

The next section on the psychiatric referral group the ability of the instrument to measure small changes in family health is demonstrated. It is unlikely therefore that the instrument is incapable of measuring any changes.

In summary

1. the conditions suffered by patients in the counselling group tend to be of lower severity and persistence, (see page 99)
2. the modified family DUSOI scores are at the lower end of the range seen in the various groups in this study,
3. anecdotal evidence suggests that patients find positives from counselling, and
4. the literature supports a positive effect of counselling on the patient.

The study demonstrates that the data from the counselling group is consistent with the conditions suffered by the patients not having sufficient severity and/or duration to generate distress within the families to produce symptoms or illness. This is supported by items 3 and 4 above.

Unfortunately this does not allow any comments to be made about the success or otherwise of counselling as a treatment modality. It does however indicate that it is a benign modality without demonstrable negative effects.

The first research hypothesis stated "A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a family member is treated for mental health problems with either of two levels of severity, those

requiring counselling in general practice and those requiring referral to a psychiatrist.” This is supported in relation to counselling.

Group 2 – Psychiatric referral

Unlike the counselling group the psychiatric referral group showed a significant decrease in the modified family DUSOI score after the referral of an ill family member to a psychiatrist. This is despite the fact that it is suspected that four (20%) of the patients did not attend their appointments with the psychiatrist.

It was interesting to note the poor quality of the records relating to psychiatric illness. For two patients it was not possible to come to a diagnosis. In each case it was noted that the patient was referred, but there is not any indication of the reasons for this. Reports from psychiatrists, if they existed, were of variable quality. This resulted in some uncertainty as to the diagnosis and on seven occasions the diagnosis recorded in the notes was that given by the general practitioner. Some the general practitioners’ diagnoses were not supported by the recording of expected symptoms.

For the psychiatric referral group, selection was by searching blocks of medical records. As such there may be some clustering, however the low return rate suggested that this was unlikely to be significant.

The conditions suffered by patients in this group are generally more severe than those seen in the counselling group. The fact that they were referred to a psychiatrist and the rate of prescription of psychotropic medication indicates the severity of the conditions. The conditions in this group vary widely with anxiety related and mood disorders making up 50%

of the group. The remainder were a mixture of other conditions. There were not any psychotic illnesses in the group.

The difference in the scores was approximately 3.9 per family. Calculations indicate that this is the equivalent to a reduction of two conditions of minor severity per family in the year after referral.

The negative correlation (Spearman's $\rho = -0.536$) between patient age and the difference in the mean modified family DUSOI scores cannot be explained by this study. The level of correlation is modest and most likely represents a chance association.

The decrease in the number of consultations in the year after referral is as expected, however this was not due to statistically significant decreases in the number of psychosomatic conditions or symptom presentations. The univariate ANOVA is unable to throw any light on the reasons for the reduction in consultations and burden of illness. In particular it did not support the difference in burden as being attributable to differences in number of conditions and severity of conditions. It is likely that this represents an effect of the method by which the DUSOI is calculated. The difference in the number of consultations would therefore appear to reflect a change in help-seeking behaviour in the family. The sequence outlined previously therefore becomes

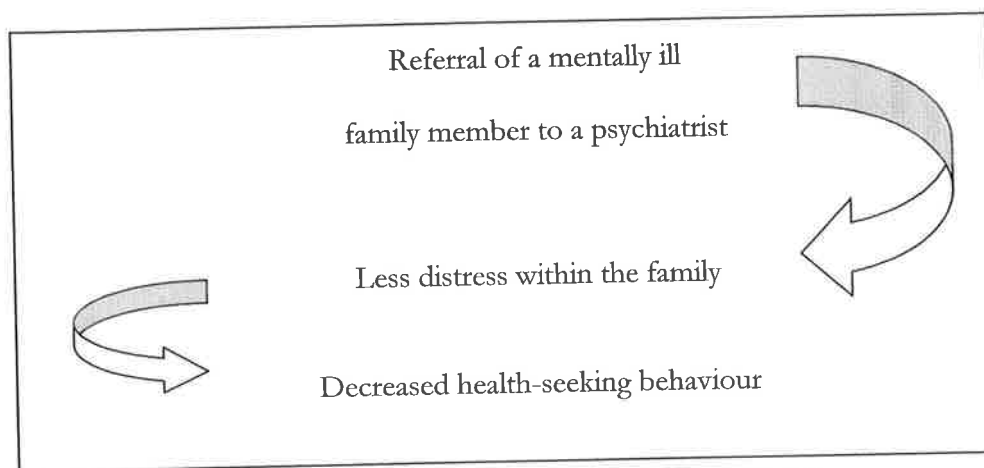


Figure 24 Sequence of events for psychiatric referral families.

The greater proportion of diagnoses in the year prior to the referral when compared with the breast cancer group and AMI group is interesting. It might have been expected that during a stressful time patients might present with more symptoms and psychosomatic conditions. This appears to have occurred in the year after AMI. The reaction by family members to mental illness may be different to that seen in physical illness. Family members of patients with mental illness present with a greater proportion of diagnosable conditions than “normal” families and families after an acute myocardial infarction. An alternative explanation is that the duration of the psychiatric illness allows the development of more diagnosable conditions. In reality it is likely that both duration and the nature of the illness affect the outcomes. Further research will be required to clarify this supposition about the reasons for these findings.

From these results we can say that after referral to a psychiatrist the burden of illness in a family decreases. From this it is possible to assert that the level of distress in the family has decreased. It has not been possible to demonstrate any statistically significant cross-group differences, however the level of distress in the year leading up to the referral is higher than in

non-distressed families. Despite the lack of statistical support the differences are sufficient to suggest that in the year prior to referral the family burden of illness is higher than that seen in non distressed families. As pointed out in the literature review there is evidence for this in relation to severe and persistent mental illness (see page 10).

Psychiatric diseases

When the counselling and psychiatric referral groups were combined it was possible to define three groups of patients, adjustment disorders, depression and "other". It was suspected that depression might have been the driving factor in the difference seen in the psychiatric referral group. However none of the groups showed a significant difference. The small number of depressed patients (seven) reduced the chances of finding a difference, however the difference (-0.771) was small and did not even trend towards significance ($p = 0.689$). The differences detected could not be attributed to the effects of any particular psychiatric diagnosis.

It is unfortunate that a separate group of families where a patient had been treated for depression with an antidepressant had not been established. This would have allowed a more graded comparison.

The first research hypothesis stated "A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a family member is treated for mental health problems with either of two levels of severity, those requiring counselling in general practice and those requiring referral to a psychiatrist." This hypothesis is not supported in relation to referral to a psychiatrist.

Group 3 – Breast Cancer

The results from this group of families were the most unexpected findings. While the literature suggests that male spouses do not overtly respond to distress it was unexpected that there would not be a detectable significant difference between the years prior to and after the development of breast cancer. A possible explanation for the lack of difference is discussed below.

When selecting patients for this part of the study two patients were excluded and their records not examined because the author was or had been their employer. Examination of such records would be ethically unacceptable. Two further patients had had their breast cancers treated within the 12 months prior to the case-note scoring and were therefore excluded.

The low rates of detection of breast cancer from the practice records suggest that there may be biases in the recording of this diagnosis and that the patients selected may be from a small group of doctors in the practice who coded using ICD codes. It is impossible to be sure as the medical records indicate that most of the patients saw multiple doctors within the practice and in all but a few patients it was impossible to determine who was the primary treating general practitioner and who recorded the data on the database.

The list of breast cancer patients was examined from youngest to oldest so as to ensure the greatest chance of discovering patients with families. Notes were examined sequentially until 20 were found that were free of exclusion criteria. In order to achieve twenty subject families 49 of the 83 identified records were examined.

Once again the quality of the data contained in the medical records was poor. The difficulty in determining the date of operation was unexpected. The process of averaging scores across the

family every three months and then averaging the scores across the year means that it is highly unlikely that a shift of a few weeks would make major changes to the score. It is possible that a major medical event in a family member could have altered the scoring if it occurred at the beginning or end of one of the years. This is unlikely, and a review of the case notes did not indicate that this occurred for any family member in any of the four groups.

Thirteen of the families showed little change of score between the years. In three of these cases family members had not visited the general practitioner in either of the years under investigation. Two of these three families consisted of husband only, while the third was husband and adolescent daughter.

Three outliers in the distribution of the difference data were detected and the final analysis reported levels of significance with their scores included and excluded. The two extreme cases remained extreme when the difference data from the four groups were examined together. All three were examined in detail. The two most extreme outliers are discussed here.

The first patient was 42 years old when she was treated for breast cancer. In the year prior to the development of the cancer her husband suffered a prolonged (9-month) episode of sciatica which severely disabled him. He recovered from this just prior to his wife being diagnosed with breast cancer. In the year following he suffered from three minor conditions only.

The second patient was 61 when she was treated for breast cancer. Her husband visited the general practitioner for two minor conditions in the year prior to the breast cancer. In the year after he suffered a number of minor conditions, a major side effect to a drug prescribed for a minor condition, a lacerated thumb and a migraine requiring systemic medication.

It would appear from these descriptions that their results are outliers only in the sense they represent extremes of normal help seeking behaviour.

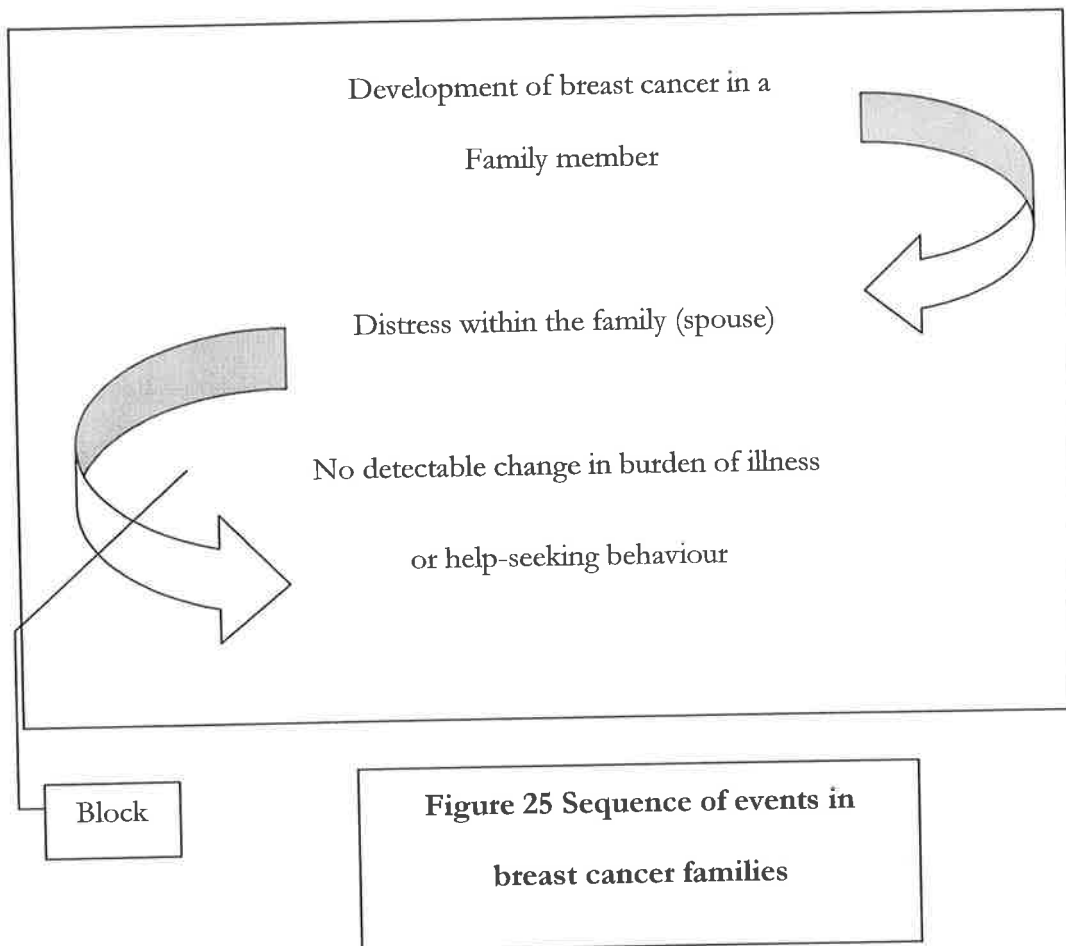
Alternative methods of handling outliers, such as altering the outlying score to the mean or some other arbitrary score, were not used as the inclusion or exclusion of the outliers did not affect the significance of the results.

This group did not show any significant change in the burden of illness after the diagnosis and treatment of breast cancer. This is consistent with the literature which perhaps can best be summarised as indicating that husbands respond to the diagnosis of breast cancer in their wife either by withdrawal or by over-involvement in the care of their wives (see page 47). It was expected that there would be a detectable difference as the literature relating to the perceptions of patients and spouses suggests.

The result may also reflect the gender of the family members (predominantly males). Ten of the twenty families consisted of husband only and a further six families consisted of husband and one child. Males are renowned for poor attendance for medical consultation (230-232) and it may be this rather than a lack of distress that the results reveal. The article by Corney (232) in particular indicates that psychosocial distress does not lead to an increase in help-seeking behaviour in men. It is perhaps confirmatory that there is a significant reduction in the proportion of symptoms presented by family members to the general practitioner in the year following treatment of a breast cancer.

It seems that the results indicate that either stress does not occur in the family with the development of breast cancer in a family member or that the family is not overtly reacting to the distress. The literature and clinical experience support the latter interpretation.

The sequence of events appears to be



Despite the reduction in the proportion of symptoms, the proportion in the year after diagnosis and treatment did not differ from those seen in the year after counselling or referral to a psychiatrist. This suggests that the husbands of women with breast cancers were not responding to the distress with an increased number of symptoms.

A recent review by Kiss and Meryn (233) drew together the literature on this issue. They examined the response of spouses to breast and prostate cancer. The authors reported that women were more distressed by their husbands prostate cancer than the men actually suffering from the cancer. The reverse situation has not been specifically studied. They also noted that

men in support groups prefer to share information while women prefer to share emotion and that female partners had a “more accurate understanding of their husband’s experience with prostate cancer than male partners had of women’s breast cancer experience.” In general the paper supports the assertion that men refrain from showing or seeking help for their distress.

The second research hypothesis stated “A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a family member suffers from either of two severe physical illnesses, breast cancer or myocardial infarction.” This is supported in relation to breast cancer.

Group 4 – Acute myocardial infarction

While the psychiatric referral group provided an unexpected result the AMI result was as predicted. The secondary analyses provided the most accurate description of where the changes arose.

This group showed the largest difference between the years and the change was in the expected direction, with an increase in the year after the infarction. The families in this group were smaller and the patients older than the other three groups. Not unexpectedly the patients were predominantly male (90%). In line with usual clinical experience the female patients were in the older age group.

It is interesting that only 55 patients who had suffered a myocardial infarction could be detected by use of the computerised record system. At the time of the search there were over 35,000 patients recorded in the database. This reflects the highly variable use of the coding system by the general practitioners, however it is extremely unlikely to have produced a bias in the families and their response to the event. The computer system did not allow for searches

except by ICD codes and few of the general practitioners in the practice consistently coded in this way.

The comments made in relation to the selection of patients in the breast cancer study (see page 184) apply to the selection of patients in this study.

The presence of an outlier did not affect the results. The patient in the outlying family was a 56-year-old man at the time of infarction. His wife, aged 52, developed a number of disabling conditions in the year after the infarct. She developed globus hystericus shortly after the infarct and plantar fasciitis produced a prolonged period of disability. Later in the year she developed recurrent, severe, disabling, migraine headaches. This spouse demonstrated the expected outcome of a person stressed by a family illness, with an increase in psychosomatic conditions. Although this result is statistically an outlier, it can be seen as an archetype of the expected reaction in distressed families.

Using the same method as in the psychiatric referral group the increase in family score in the year after the myocardial infarction is one condition with a score of 8 (out of 16). Conditions that scored 8/16 included moderate depression, an acute exacerbation of osteoarthritis of the knees and non-insulin dependent diabetes mellitus requiring admission to hospital. The difference was thus the equivalent of one additional condition of moderate severity in the family in the year following the infarction.

The univariate ANOVA indicated that almost 70% ($R^2 = 0.699$) of the difference in family DUSOI scores can be explained by a difference in severity of the conditions, the number of conditions and an interaction between the two. Logically it would be expected that the difference in family burden of illness is reflected by these two factors, however the mechanism

by which the DUSOI is calculated will reduce direct association. In the psychiatric referral group there was not a significant effect.

The proportion of “psychosomatic” conditions in the year after the infarction was almost twice that in the year prior, however this difference was not statistically significant. Similarly there was not a significant increase in the number of symptoms, although the proportion of symptoms was significantly higher than the proportion of symptoms in either years of the Counselling and Psychiatric Referral groups. Overall it can be said that the proportion of psychosomatic conditions and symptomatic presentations by family members increased in the year subsequent to the infarction.

The negative correlation between family size and mean modified family DUSOI scores is unexpected and clinically inexplicable. There were modest positive correlations between the scores in the year prior to and the year after the index event and also modest negative correlations between age and family size in all groups. Neither of these correlations is unexpected. In the adult age groups being studied younger families tend to be larger. As parents age, children leave home and family size decreases. The correlation between the two years reflects the narrow band of time over which this study occurred.

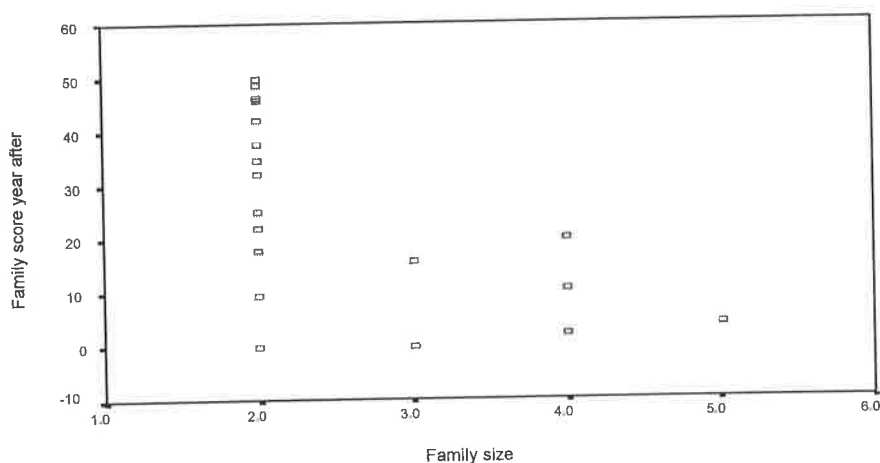


Figure 26 Scatterplot of family score by family size in the year after AMI

A scatter plot (Figure 26) provides an explanation of the reason for the negative correlation between family size and score.

This reveals that the large number of high scores for spouses (family size = 2) produced a negative slope to the regression line and result in a negative correlation. There are limited numbers of families with three or more family members. Thus the distribution of scores are more constrained in these groups. Examination of scatter plots for the other groups revealed that the scores for spouses were lower and the scores for the larger families were more variable and more frequent than in the AMI group. This suggests that the correlation is a result of the increased number of spouses as sole family members in this group. It is highly likely that this correlation would disappear with an increased number of study families.

These results suggest the sequence of events was as follows.

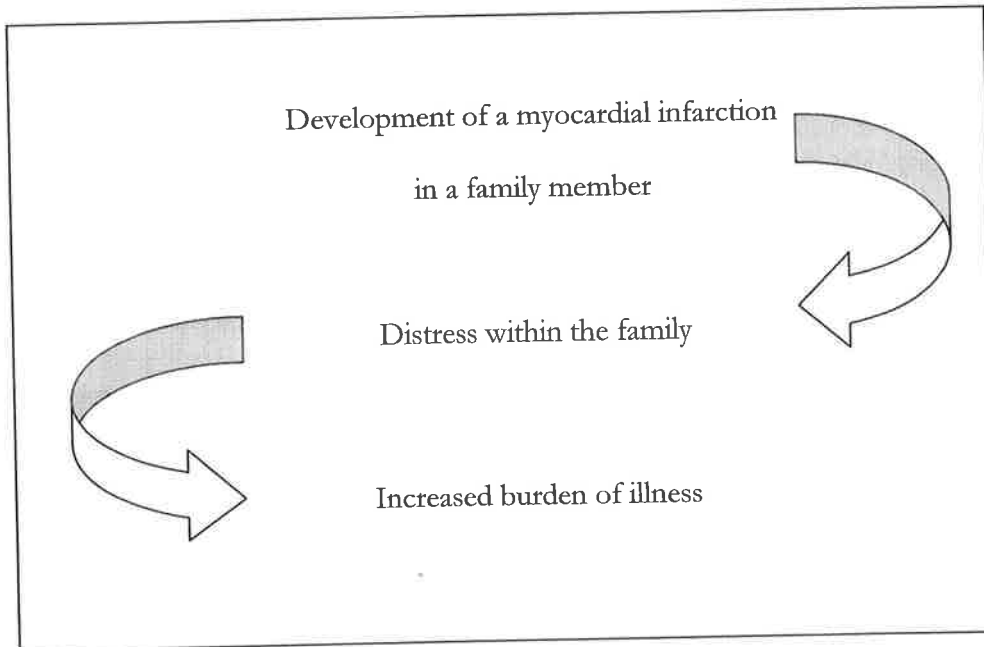


Figure 27 Sequence of events for AMI families.

Despite this group not showing a statistically significant increase in the proportion of symptoms or psychosomatic conditions, the proportion of symptoms was much higher in this group than any other group. This particularly contrasts with the decrease in the proportion of symptoms in the families with a mentally ill member. The lack of significant change within the group is perplexing. It suggests that in families where a member suffers a myocardial infarction there is an increased proportion of symptoms presented to the doctor in the year prior to the infarction. This may represent family distress that “results” in infarction, that prior to infarction there are changes that impinge on the family, or a statistical anomaly relating to this particular sample.

Some studies have suggested that in the lead up to a myocardial infarction patients display “vital exhaustion”, (234) other psychosocial difficulties such as type-A behaviour and

depression, (235) or are affected by difficult work situations. (236) Perhaps the families are responding to one of these issues.

An alternative, and perhaps more likely interpretation is that the lack of difference is related to the small number of families in this study. That is, there are insufficient numbers to enable the demonstration of a difference. The raw figures suggest a difference, but this does not reach statistical significance. A larger group of families may have increased the chances of demonstrating a significant difference.

These results could also be interpreted as indicating that the proportion of symptoms increases with age or decreasing family size. However this is not confirmed by analysing all four groups together (see below).

While it is not possible to argue statistically that the distress in a family after a myocardial infarction in a family member increases beyond that seen in non-distressed families, the differences are marked and consistent across the various groups. The author believes there is sufficient evidence in this study and the research literature to support the belief that the burden of illness in a family after a member suffers a myocardial infarction is greater than that seen in "normal" families.

In this study, although it was not a criterion the index AMI was a first AMI for all patients. Two patients had preceding crescendo angina. It would be interesting to compare the effects of a first infarction with a second or subsequent AMI.

The second research hypothesis stated "A modified family Duke University Severity of Illness scale will demonstrate that the burden of illness of family members does not alter when a

family member suffers from either of two severe physical illnesses, breast cancer or myocardial infarction.” This is not supported in relation to acute myocardial infarction.

Comparisons between groups

The means of the groups are detailed in Table 41, which has been extracted from Table 27

Group	Year prior	Year after
Counselling	16.06	16.31
Psychiatric referral	21.63	17.76
Breast cancer	17.41	16.47
Acute myocardial infarction	18.11	24.82

Table 41 Means for each year in each group

The two groups that did not show a significant change (counselling and breast cancer) have similar scores. The two groups that show a change have larger scores in both years than the groups that do not show a change, however these differences are not statistically significant. The lack of significance probably reflects the low power of the comparison due to small sample size, and because of the low power it is impossible to reach any conclusions.

As shown in Table 42, the only significant differences between the groups were seen

- in relation to the structure of the groups (age and gender of patient and family size),
- the consistency of diagnosis within groups,
- the nature of the factors affecting the differences in the scores for the psychiatric referral and AMI groups, and
- the proportions of symptoms and diagnosable conditions.

	Counselling	Psych Ref	Breast Ca	AMI
Mean patient age	37.3	37.8	49.2	54.4
Mean family size	3.5	3.2	2.8	2.6
Proportion female patients	0.95	0.40	1.00	0.10
No of diagnoses	4	7	1	1
Year prior prop symptoms	0.20	0.18	0.34	0.36
Year after prop symptoms	0.21	0.22	0.24	0.42
Determined factors for difference	Not applicable	No	Not applicable	Yes

Table 42 Cross groups differences

The differences between the groups as far as age, gender and family size are concerned reflect the diseases being investigated. Breast cancer is extremely rare in males, while AMI is uncommon in younger females. As has been previously documented (218) for mild to moderate disability due to mental illness, women are far more likely to attend general practitioners for help, while males are more likely to see a psychiatrist. However this study is based on referrals and more women than men are referred to psychiatrists by general practitioners. (225)

It is interesting to note that the conditions where male patients predominate are the conditions that show a significant difference. Where males predominated as spouses there was a lack of change. This was reflected in the scores when patients were selected by gender and the high stress year was compared to the lower stress year. As set out in the Method, a high stress year

is defined as the year in which the family member is likely to be more ill, ie. it is the year prior to counselling or referral to a psychiatrist, or the year after the occurrence of breast cancer or AMI. For female patients there was not a significant difference in the family score across the two years (difference in medians = 2.00, $Z = -0.813$, $p = 0.416$). For male patients however there was a large difference between the years with the more stressful year having significantly higher scores (difference in medians = 6.40, $Z = -2.498$, $p = 0.013$).

For a more detailed discussion of the effect of gender on the score see the discussion on page 198, where the analysis suggests the difference is more likely due to the condition under investigation than the gender of the patient.

As mentioned above it is hypothesised that the lack of help-seeking behaviour in men led to there not being a detectable difference in burden in the breast cancer group.

While the diagnostic categories in the breast cancer and AMI groups were consistent there was a high degree of variability in the counselling and psychiatric referral groups (see Table 5, Table 7 and Table 42). While the psychiatric referral group showed an overall significant change, it was not possible to attribute this to a single disease category. Similarly the diversity of diagnosis in the counselling group decreases the likelihood of finding a consistent change. It is interesting to speculate on whether a repeat of the study on counselling would show any differences if there were consistent diagnostic categories in different groups.

In this study there was an inability to show any changes when the cases were divided into psychiatric groups. This may reflect the small numbers in each group, but even within those groups there was a high degree of variability. For example, depression is primarily treated in general practice, so it is highly likely that the two cases in the psychiatric referral group were of

significantly greater severity. This cannot be discerned directly from the medical records, and as referral reflects a number of extraneous factors, such as patient or family request, it is impossible to be certain that the severity was greater. In retrospect it would have been interesting to have another group that consisted of patients treated with antidepressants.

Exploration of the reasons that the psychiatric referral group and the AMI group each showed a difference in score produced conflicting results. The decrease in the score in the psychiatric referral group seemed to be partly due to a decrease in the number of conditions in family members seen by the general practitioner.

On the other hand the increase in scores in the AMI group was primarily due to an increase in the severity of the conditions, an increase in the number of conditions presented and an interaction between these two factors. It is difficult to understand why this difference should occur. It could possibly relate to the conditions under investigation, the age of the patient and family size, and the length of time that the stress has been evident.

Gender

As discussed earlier (page 192) the positive results are seen in the groups where men predominate as patients. One possible interpretation of the results is that they represent an effect of the gender of the spouse. However, closer analysis reveals this difference is unrelated to gender and only modestly related to disease process.

The univariate ANOVA of group and gender indicates that there is a modest effect ($F = 3.113$, $df = 3$, $p = 0.031$) from group of origin (or disease). This is equivalent to 7.4% of the difference of the scores between the years. Gender did not have a significant effect ($F = 2.817$, $df = 1$, $p = 0.097$) on the size of the difference in scores, although the size of the p value

suggests that an increased sample size may have led to a statistically significant result. This result indicates that the difference between the years is more likely related to other factors such as family structure, ongoing medical illness and random effects.

The results seen in relation to gender are symptomatic of the differences between the groups. The groups were not matched in any way and in the unlikely event there had been significant cross group difference in scores there would be large doubts about the clinical significance of the differences.

However it is highly likely that the results seen in the breast cancer group could be attributed to a gender effect. As indicated previously (page 184) it appears that men do not frequently attend doctors for emotional distress. (232) This is supported to some extent by a study from Peleg-Oren and Sherer (237) who examined patients with cancer and their spouses. The patients were Israeli and had a potentially curable cancer, were undergoing active treatment, and were at least three months from diagnosis. The response rate was 70%. The finding of relevance to this discussion was that men (patients or spouses) usually experienced more psychological distress (fear, anxieties and depression about illness and medical treatment) than their female partners, but expressed their reaction more in behavioural terms than with affective changes. The authors note that "as spouses, it could be that men more than women use denial mechanisms when dealing with life-threatening event. This could be related to ... the 'traditional' male role as guardian and protector."

An additional interpretation is suggested by Norcross et al. (238) They were able to demonstrate that men were 2.4 (95% CI 1.4 to 4.3) times more likely to be influenced by a member of the opposite sex to seek health care than vice versa. It could be postulated that

with their wives being focussed on their own medical care one of the drivers for men to seek medical care is missing.

Overall the effect of gender is likely to be one of the factors affecting the outcomes of the study, but only in relation to certain disease processes. It will however be important to be aware of the possible interaction in any future use of the modified family DUSOI.

The modified (family) DUSOI

The instrument used in this study, a modification of the Duke University Severity of Illness scale, was subject to a rigorous validation that indicated that it was a reliable instrument for this study and that it appeared to measure the burden of illness in a family. As indicated in Figure 21 (page 174) this research relies on the supposition that illness within a family produces distress, which results in illness or consultation seeking behaviour in other family members. It appears from these results that this occurs provided the distress reaches a certain level of intensity, and presumably duration, and the outcome is not modified by gender.

Using a before-after study the modified family DUSOI has great power to demonstrate changes within a group of patients. It is, however very underpowered when looking at direct comparisons between groups of patients.

In order to be able to demonstrate differences from “normal” families it will be necessary to use a much larger number of families. Using the figures from the AMI group, in order for this instrument to have a statistical power of at least 0.8 at the $\alpha = 0.05$ level would require approximately 300 families in each group. (214) This will be most practical in multi-doctor studies of common conditions, as it is unlikely that sufficient patients could be found in one practice unless the practice was extremely large and the condition extremely common. To

compare conditions with this instrument will require a large numbers of patients and is likely to need data from a number of practices.

The major limitation is the poor quality, in research terms, of the medical records. The records only contain what the patients tell the doctor and the doctor decides to record. Evidence was presented previously of the limitations patients have about disclosing distress to doctors. As mentioned in the results there are also significant limitations on what the doctors' record. In the results it was indicated that some referrals to psychiatrists had no information other than referral had occurred, or alternatively there was not a record of a referral being made, but a letter from the psychiatrist indicated that such referral had occurred.

Similarly, important data such as the date of infarction or of breast surgery was not included. This was most noticeable when the patient had seen a specialist in the private health system and the letters to the general practitioners did not include this information.

From a research perspective a significant weakness was the poor recording of conditions in the computerised record. The system in place at the time of the study was relatively easy to use and did not require much effort to record the information. However, it was poorly carried out. Since this study a new, even easier to use system has been installed. This has lead to a small increase in the recording of diagnoses in a manner that can be retrieved. Additionally, the new system allows easier search routines. The recording of data is dependent on the interest of the doctor.

The limitations revealed by this study may also apply to the original DUSOI score. As pointed out earlier the DUSOI only measures those conditions that a patient brings to the general practitioner. It would appear from the literature and this research that gender and the nature of

comorbid conditions may modify the process that causes patients to consult doctors. It will be important therefore when using the DUSOI that comparisons only occur between groups of consistent gender and diagnosis. Having said this however it is important to point out that the lack of a response to a distressing event in a family is a valuable finding and worthy of further investigation.

Clinical significance

This study provides clinical insights in the areas of counselling, referral to psychiatrists, response of families to distress, spouses' responses to breast cancer, medical records, and the bio-psychosocial paradigm. Each will be discussed in turn.

Counselling

This study used the family therapy (systemic) model of therapy and adds to the literature indicating that counselling does not harm patients, or for that matter their families. Unfortunately it was not able to show a positive benefit from counselling, but this may reflect the limitations of the measurement instrument used in this study. This result, combined with the literature indicates that family therapy may be more appropriate treatment for minor mental illness than medication. It has positive effects without the side-effects of medication.

Referral to psychiatrists

Referral to a psychiatrist has been shown to produce positive benefits for the family. This would suggest that it produces benefit for the patient. It has not been possible to separate out the act of referral from therapy and to determine which has the most effect on the wellbeing of the family.

Families' responses to increased distress

Generally the response of families to increased distress of significant magnitude, as seen in this study is to present to the doctor with an increased burden of illness. This was seen in the stressful years prior to referral of a patient for a mental illness, and after a patient suffered a myocardial infarction. Across each of these groups the differences were small, however the variation was marked and for some families the distress manifested itself as an increased rate of consultation. If practitioners notice such an increase in consultations or severity, discussions about family illnesses may be appropriate.

Spouses responses to breast cancer

The proposed family response does not apply to all distress caused by illness. In the families where a breast cancer occurred there was not, across the group, an increase in illness burden. There were however some spouses who did have an increased rate of consultation. It would be interesting to investigate the reasons that cause some husbands to present more frequently. It may be that this group of men have a more dependent role in their families and are being "asked" to take on a new role in the family.

Medical records

General practitioner medical records are widely used for medical research and audit. This study confirms a number of other studies that indicate that medical records are deficient in certain areas. For example Hassey et al (239) showed that records in a fully computerised ("paperless") practice showed high degrees of validity for some conditions (such as diabetes) and low levels in other areas (such as asthma and ischaemic heart disease). This study was later criticised for poor use of statistics, (240) however the basic thrust of the original article, that electronic patient records have reasonable validity, in some areas, still held.

Similarly Mant et al (241) showed only moderate agreement between patient records and questionnaires with $\kappa = 0.50$ for smoking and $\kappa = 0.52$ for alcohol use. The variability evident in these two studies is confirmed in the current study.

It was also noticeable in this current study that computerised records did not improve the situation, apart from readability. It is also apparent that searches that rely on coding systems will limit the discovery of patients with the illness under investigation. Unless doctors are prepared to code effectively this will always be a problem.

The use of search routines that allow the whole record to be searched stand a much better chance of finding all records. Medic-GP (242) is a database that allows such searches and as yet unpublished research (243) indicates that this method detects far more cases. Each detected record requires examination to determine if the search word applies to the patient or to some other person being discussed. In an ongoing study of depression approximately 40% of detected references to "depression" (or synonyms) referred to relatives of the patient, a past history of the disease, or the absence of depression. (243) Medic-GP could not be used in this current study, as it was impossible to link family members.

The bio-psychosocial paradigm

The study does highlight the power of a systemic view of illness (the family therapy model) in explaining events such as those demonstrated in this study. Viewing a family as a system, where a problem arising in one part of the system, "causes" changes in another is a powerful explanation of the results of this study. Even within the breast cancer group it provides an insight to an explanation. A woman's breast cancer "results" in a change in the husband's behaviour. As indicated by the literature, he either withdraws from the family, or, he takes over and tries to control the situation. Taking a systemic view of illness would help general practitioners predict changes within a family in response to illness and disability.

General practice has a long history of reflecting the biopsychosocial model of illness. This study emphasises the significance of that approach to practice. Integrating care to include the biological, psychological and the social is of the utmost importance in providing appropriate care to patients and their families.

Future directions

This research raises numerous further questions. As a first step however this study needs to be confirmed by similar results in studies carried out in different settings in different communities. This study has been limited to one group of patients, in one general practice, in a suburban area of a state capital in Australia.

Repeating the study would also help overcome one of the other methodological issues relating to all scoring being carried out by the author. The results in relation to the research hypotheses suggest that this did not produce significant biases, but repetition of the study would reduce any suggestion that bias exists.

A list of possible research proposals arising as a result of this project are detailed in Appendix E.

The two areas that seem high priority relate to the modified family DUSOI and the AML.

If the modified family DUSOI is to be of value in further research it must be characterised for normal and abnormal families. The range of normal values in relation to the age of family members and the sensitivity to specific diseases needs to be determined. It will also be important to characterise the effect of the gender of the patient on the scoring process.

The deterioration in health of the family after the occurrence of a myocardial infarction was significant. The effect on the outcomes for family members is important to determine, and of prime importance is to determine whether intervening with the well spouse affects the outcome for that spouse and/or the patient.

Chapter 7

Conclusions

This study set out to explore the effect of mental illnesses on the health of family members. The research (null) hypotheses were confirmed for two conditions, counselling for a mental health problem and diagnosis of breast cancer, and rejected for two conditions, psychiatric referral for a mental illness and the occurrence of an acute myocardial infarction.

The study demonstrated that the level of illness burden was low in families where counselling was chosen as the sole treatment for a member with a mental health problem. Counselling was shown not to have a detrimental effect on the family and the literature supports that it has a positive effect on patients.

It demonstrated that the health of a family improved after referral of a mentally ill family member to a psychiatrist. The results were also consistent with such families having a higher burden of illness than "normal" families. A small part of the reduction in illness burden in the family was due to a decrease in the number of conditions presented to doctors by family members, but it was not possible to define the reasons in any greater detail. From a clinical point of view this research suggests that practitioners may need to explore family issues in detail if members of a family appear to present to the practitioner with an increased number of medical problems. The results were reassuring in that they indicated that referral to a psychiatrist produced a positive benefit for the family.

The physical illness comparators used in this study provided conflicting and perhaps the most interesting results. Firstly, the study was not able to demonstrate any change in burden of illness of a family in the year after the diagnosis of breast cancer in a family member. Such a result was consistent with the literature which supports the belief that men do not seek help from doctors for psychosocial distress. This belief was supported by

the finding that there was a significant decrease in the proportion of symptoms that family members presented to their general practitioners in the year after the diagnosis of the breast cancer. The study raises questions about the effects of the family's behaviour on the outcomes for the patient with breast cancer and whether any intervention would affect the response of family members.

The study was able to demonstrate an increase in the burden of illness in a family in the year after a family member suffers an acute myocardial infarction and that this was primarily due to an increase in the severity of the conditions, the number of conditions, and an interaction between severity and number. The increase was significant and raises the question of the effect this may have on the outcome of the myocardial infarction. A project to examine an intervention to reduce the effect of the AMI on family members could be undertaken to include an exploration of the effects of the family's distress on the outcome of the infarction. Practitioners need to be aware of the effect of myocardial infarction on the family and, where appropriate intervene to minimise the impact.

The modified family Duke University Severity of Illness scale performed well, but its sensitivity to small changes is suspect. Relying on conditions reported to and recorded by the doctor imposes limitations that decrease its sensitivity to change. It is possible that daily or weekly recording of symptoms or illnesses may provide a more sensitive instrument. Such an instrument may have been able to detect changes in the counselling and breast cancer groups. These limitations also apply to the individual DUSOI score and it may be that a measure that relies on patient's report is of limited sensitivity.

From a clinical point of view a number of issues arise. Some of these are mentioned above, but will be reiterated here for completeness.

1. Counselling is a treatment method for mental health problems that did not reveal any detrimental effects on the family.
2. Referral to a psychiatrist for treatment of mental illness had a positive outcome for the family.
3. Families where a member has a mental illness show a small increase in the burden of illness.
4. Husbands of women who develop breast cancer do not generally respond with increased illness seeking behaviour. Whether this “withdrawal” has any effect on the outcome of the breast cancer is unknown.
5. Within the husbands in the breast cancer group some did respond with increased help seeking behaviour. It was not possible to determine any differences from the husbands who did not respond this way. Whether the behaviour was recognised by the general practitioner is uncertain, but it may be important for practitioners to recognise the behaviour and to raise the issue of the husband’s response to his wife’s illness.
6. The increase in burden of illness in a family after a myocardial infarction was significant. Practitioners need to be aware of this potential and pro-actively intervene with the spouses. Whether such an intervention will have positive benefits for the patient in recovering from a myocardial infarction is unknown.
7. General practice medical records do not contain sufficiently detailed information for research purposes. They were not improved by computerisation. Practitioners wishing to use medical records for research or audit purposes will need to consider the limitations carefully.

8. This study confirmed the power of the bio-psychosocial paradigm as an explanation for responses to illness in a family, and to provide a structure for practitioners to consider the effect of illness.

This study has raised a question concerning Duke University Severity of Illness scale. An instrument that relies on patients reporting their illnesses or symptoms to practitioners will miss a proportion of the burden of illness. This limitation will reduce the sensitivity of the instrument.

A number of potential research proposals have arisen from this project, however three seem to be of high priority.

1. This study needs to be replicated by different researchers in different locations.
2. The modified family DUSOI needs to be explored further to characterise its strengths, limitations and its broader applicability.
3. Will an intervention shortly after the occurrence of an infarction, minimise the increase in a family's burden of illness.

This study has confirmed the supposition outlined in the introduction that mental illness in a family member leads to increased burden of illness in that family, but only if the illness is of sufficient severity and duration.

Chapter 8

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Appendix A

Psychosomatic and psychological conditions

The appendix sets out the conditions in this study that were classed as psychological or psychosomatic. The list represents only those conditions seen in this study and the classification is based on the author's experience in clinical medicine.

Condition	ICPC code
Arthralgia	A01
Unusual feeling in head	A29
Itchy finger	A29
Painful axilla	A29
Dyspepsia	D07
Diarrhoea	D11
Irritable bowel syndrome	D93
Dizzy spells	H82
Atypical chest pain	K01
Vasovagal syndrome	K99
Neck pain	L01
Neck discomfort	L01
Headache	N01
Migraine	N89
Tension headache	N95
Stressed	P01
Emotional distress	P01
Insomnia	P06
Eating disorder	P11
Enuresis	P12
Conduct disorder	P22

Adolescent acting out	P23
Panic attack	P29
Poor concentration	P29
Globus hystericus	P29
Anxiety	P74
Depression	P76
Dysmenorrhoea	X02
Impotence	Y07

Not all conditions in an ICPC code group were included in this list. For example neck pain and neck discomfort (L01) were included, but cervical spondylosis (L01) was not. Where a specific pathology could be identified the condition was not included in the psychological/psychosomatic group.

Appendix B

Description of patients in the counselling group

Appendix B sets out a brief summary of each patient treated in the Counselling group. All names have been changed to preserve anonymity. As mentioned previously (page 93) the diagnostic categories are not precise and do not meet the criteria set out in DSM-IV. The medical records do not contain enough information to enable the precise classification of the illness.

Case 1

At the time of presentation Patricia was a 43-year-old single parent who had been separated from her husband for 4 years. She presented with initial insomnia and easy to anger as the main symptoms. A secondary issue was the behaviour of her 19-year-old son. She has five children aged 14 to 21, and they were all living with her. She considered herself to be “neurotic” and also felt her son kept choosing girlfriends similar to herself.

Her marriage had a long history of difficulties with her husband being a highly social extrovert and she being an introverted loner. Some of her current difficulties were related to his desire to “work on” the marriage. She is adamant that the marriage would not work. She had not done anything to finalise the relationship in the four years since her husband left for another woman. He lived alone in a nearby suburb.

Diagnostic formulation: Adjustment disorder with anxious mood occurring in response to her ex-husband's attempt to “work on the marriage.”

Case 2

Diane was a 31 year old enrolled nurse who lived with her 34 year old husband and 3 daughters aged 6 to 10 years. Twelve months prior to the start of therapy she ran into her stepsister who was “high on drugs.” The stepsister warned her about her stepfather. This

led to memories of sexual and emotional abuse as a child. She confirmed the memories with another stepsister. Since remembering the events she had become depressed and angry. She often cried and felt dirty. She felt guilty about the events – “I must have done something to cause it.” She was very emotional at work.

Of major concern had been Diane’s husband. Because of his inability at age 19 to resuscitate his sister when she choked he has had major difficulties handling emotions. He found it impossible to talk with Diane about her problems. He responded to the issue of sexual abuse by developing severe, intractable dermatitis of his hands. (The Freudian significance was not lost on anyone other than the husband.)

Diagnostic formulation: Mixed anxiety and depression. (Possibly post-traumatic stress disorder)

Case 3

Kelly, at age 44 presented with difficulty in dealing with her anger. Over the 2 years prior to presentation her husband had left her on 7 occasions to live with a younger woman. On each occasion, including the last, she allowed him to return. She became extremely angry with him but would not express her anger for fear of chasing him away. She wanted help in controlling anger.

Diagnostic formulation: Adjustment disorder with agitation following her husbands return.

Case 4

James was a 16-year-old student who lived with his parents. For the 6 months prior to presentation he had found it difficult to study at home due to conflict with his parents. He is the youngest of 4 children and was the only child living at home. He felt his parents were more interested in their grandchildren than him. He felt they were distant but controlling. The problems had reached a point where he was late submitting an assignment and would fail year 12 English.

The other major issue had been his decision to commit to the church. His parents “accepted it” but disapproved. There were a number of minor issues including the suicide of a teenager who lived down the road.

Diagnostic formulation: Adjustment disorder secondary to changes in family situation

Case 5

Jenny was a 53-year-old woman married to her second husband. A daughter of her first marriage had accused Jenny’s current husband of sexually abusing her as a child. Her daughter had a long history of lying and was generally manipulative in her approach to people. After a lot of soul-searching Jenny decided to believe her husband and not her daughter.

Diagnostic formulation: Adjustment disorder secondary to accusation against husband.

Case 6

Joy was a 37 year old married woman with 3 children (7-12 years) who was sad, weepy, angry and suffered from headaches. These were attributed to the death of her stepfather and father-in-law, major marital difficulties and living away from mother.

Diagnostic formulation: Adjustment disorder with depressed mood.

Case 7

Violet was a 55 year old married woman with 2 adult children living at home. She complained of increasing conflict with husband who had a long-standing head injury. She recently developed a back injury that was not improving. Her husband was dependent but directive and her back injury had altered the relationship.

Diagnostic formulation: Adjustment disorder secondary to multiple events.

Case 8

Jean was a 30-year-old separated mother of three children under five. She has a past history of sexual abuse by her father and his suicide when charged over the abuse. Her difficulties at the time of presentation related to difficulties fighting her violent husband for custody of the children.

Diagnostic formulation: Adjustment disorder on a background of dysthymia.

Case 9

Marion, 58 years old and living with her husband, presented, in her words, as “the classic menopausal woman.” She was depressed and had lost control over her life. She described herself as always weeping and being a quitter. Symptoms had been present for three months and her premorbid personality had been good. She had sleep disturbance and had lost interest in her usual activities.

Diagnostic formulation: Depression

Case 10

Mary was 32-year-old woman living with 2 young children. She had recently separated from husband. The children fought a lot and she had difficulty controlling them.

Diagnostic formulation: Adjustment disorder.

Case 11

Josie was a 9-year-old girl with living with her parents and younger sister. Josie was bright, but strong willed and had a problem with acting out in groups and alienating all around her. She threw tantrums and seemed to go out of her way to upset her mother and other people with whom she interacted.

Diagnostic formulation: Conduct disorder.

Case 12

Corine was a 33 year old married woman whose husband had an affair. This caused a separation, and difficulties with her daughter. The daughter's riding instructor was "the other woman."

Diagnostic formulation: Adjustment disorder.

Case 13

Dorothea, aged 60, lived with her retired husband. Three months prior to presentation her husband suffered a back injury which was not responding to treatment. Her husband had taken to moping about the house, making Dorothea miserable. She was having trouble coping with the changes in her husband.

Diagnostic formulation: Adjustment disorder

Case 14

Helen, aged 45, married with two adult children, was in conflict with her mother and sister. This occurred on a background of ongoing disquiet over her mother's behaviour in relation to Helen's, now deceased, father. The conflict had started over a misunderstanding over a mother's day present two years prior to presentation. Helen was "down", weepy and could not see any future. She spent most of the day moping around home and had ceased socialising. She had insomnia and loss of appetite.

Diagnostic formulation: Depression

Case 15

Penny was 35 years old and lived with her partner. She presented for help with losing weight. During discussions significant problems within the relationship were revealed. The precipitant was the loss of her job and subsequent financial difficulties.

Diagnostic formulation: Adjustment disorder.

Case 16

Three weeks prior to presentation Patricia (37 years) had a blazing row with the mother of her partner. Since then she had been agitated and sleeping poorly. She had started getting angry at the machinery at work.

Diagnostic formulation: Adjustment disorder.

Case 17

Carla was a 40-year-old secretary whose life had been turned upside down by a person who had tried, in Carla's eyes, to join their family. This person had got between Carla and her parents and in the last few months Carla had felt angry, frustrated and anxious.

Diagnostic formulation: Adjustment disorder.

Case 18

Wilma (22 years) had felt depressed since her marriage three years previously. On her wedding day her mother announced that she was separating from Wilma's father. For the three years she had felt down and unable to enjoy many things. She could still have fun, but found herself considering separation or divorce.

Diagnostic formulation: Dysthymia.

Case 19

Raelene was a 34-year-old woman living with her husband and their two children. She had a long history of low mood (for most of her life) and is not able to enjoy life. She saw herself as an overcommitted perfectionist who went to pieces in face of her son's serious illness and husband's road accident.

Diagnostic formulation: Dysthymia (with subsequent adjustment disorder).

Case 20

Sally, aged 33, presented with a long list of irritations and stresses that had been present for about 3 years. She was having trouble coping and felt put upon by her own and her extended family. She had lost interest in sorting out problems. She had had little energy for the 3 years.

Diagnostic formulation: Dysthymia.

Appendix C

Diagnoses in psychiatric referral group

Diagnostic classification of patients in psychiatric referral group.

Diagnosis	Age	Sex	Medication used	Diagnosis made by
Mixed anxiety and depression	54	F	Yes	Psychiatrist
Anxiety	55	F	?	GP
Alcoholism	38	M	?	Psychiatrist
Panic attacks	49	F	Yes	Psychiatrist
No record	43	M	?	
Adjustment disorder with depressed mood	52	M	Yes	Psychiatrist
Obsessive-compulsive disorder	37	F	?	Psychiatrist
Obsessive-compulsive disorder	39	M	?	Psychiatrist
Depression	43	M	Yes	Psychiatrist
Personality disorder – immature	15	M	Yes	Psychiatrist
Behaviour problems	3	M	No	GP

Anxiety	48	M	No	GP
Attention deficit hyperactivity disorder (?)	7	M	No	GP
No record	42	F	?	
Adjustment disorder with agitation	53	F	Yes	Psychiatrist
Impotence	68	M	?	GP
Anxiety	39	M	?	GP
Behaviour disorder	10	M	No	GP
Depression	48	F	Yes	Psychiatrist
Depression	42	F	Yes	Psychiatrist

Appendix D

Inter-group comparisons

This appendix sets out the results of the inter-group comparisons. As set in the results section (see page 145) the following comparisons were undertaken.

1. Year prior of Groups 1 and 2
2. Year after of Groups 1 and 2.
3. Year prior of Groups 3 and 4.
4. Year after of Groups 3 and 4.
5. Year prior of Groups 1 and 2 with year after of Groups 3 and 4.
6. Year after of Groups 1 and 2 with year prior of Groups 3 and 4.

Because of the multiple comparisons the level of significance (α) was set at 0.004 (see page 145).

The Levene statistic indicated that the groups could be treated as having equal variances (Levene statistic = 1.864, $df_1 = 7$, $df_2 = 152$, $p = 0.079$).

Comparison	t	df	Sig (two tailed) p =
Year prior Gp1 & Gp2	-1.894	152	0.060
Year after Gp1 & Gp2	-0.628	152	0.531
Year prior Gp3 & Gp4	-0.406	152	0.685
Year after Gp3 & Gp4	-2.030	152	0.044
Year prior Gp1 & year after Gp3	0.103	152	0.918
Year prior Gp1 & year after Gp4	-1.972	152	0.056
Year prior Gp2 & year after Gp3	1.997	152	0.048
Year prior Gp2 & year after Gp4	-0.033	152	0.974
Year after Gp1 & year prior Gp3	-0.193	152	0.847
Year after Gp1 & year prior Gp4	0.213	152	0.831
Year after Gp2 & year prior Gp3	-0.821	152	0.413
Year after Gp2 & year prior Gp4	-0.415	152	0.679

Group 1 = Counselling group

Group 2 = Psychiatric referral group

Group 3 = Breast cancer group

Group 4 = Acute myocardial infarction group

Appendix E

Future research

There are virtually endless research projects that arise out of this study. The following list attempts to highlight what the author considers to be important areas of research.

Issues relating to DUSOI

1. Characterise the modified family DUSOI to determine its normal range, sensitivity and its dependence on
 - A. The age of family members;
 - B. The family structures, including single parent families;
 - C. Who in the family is “the patient”; and
 - D. What conditions are occurring in the family.
2. Are there more sensitive measure of burden of illness?
3. What is the effect of family dysfunction on the DUSOI?

Issues relating to counselling

1. Is counselling cost-effective when carried out by general practitioners?
2. Would a more sensitive measure of burden of illness in a family reveal any change?

Issues relating to psychiatric referral

1. Is it the act of referral or the treatment by the psychiatrist that makes the greatest impact on the family?
2. Would a group of depressed patients treated in general practice by antidepressants and counselling show a positive outcome?

Issues relating to breast cancer

1. The literature (164, 233, 244) suggests that patients with breast cancer are unhappy with support from their spouse. Does this affect the outcome of the breast cancer?
2. Does spousal behaviour have significant effects for the patient and/or the spouse?
3. Would an intervention to involve a spouse more productively lead to better outcomes for the patient with breast cancer?
4. In what way are husbands (or husband-wife dyads) where the husband shows an increased burden of illness, different from the husbands who do not show such a response?
5. Is the absence of an increase in the burden of illness specific to breast cancer or does it apply to all malignancies and/or other serious conditions?

Issues relating to acute myocardial infarction

1. Would an intervention at the time of the infarction minimise the increase in burden of illness?
2. Would an intervention that minimises the increase in the spouse's burden of illness improve the outcome of the patient?
3. The literature (173, 245) suggests that age has an inverse effect on the level of distress. An extension of the current methodology could be used to examine this further.
4. This study suggests that gender has an effect on the increase in burden of illness. An extension of this study could be used to compare outcomes for male and female patients suffering an AMI.

Appendix F

Refereed publications based on this research

Wilson, I., (2001) The impact of mental illness on family members.
Australian Family Physician, v. 30 (9), pp. 899-901.

NOTE:

This publication is included in the print copy
of the thesis held in the University of Adelaide Library.

Wilson, I., (2001) Helping families of patients with mental illness.
Australian Family Physician, v. 30 (12), pp. 1172-1174, 1159.

NOTE:

This publication is included in the print copy
of the thesis held in the University of Adelaide Library.