

VALUES AND LONG-TERM CARE

DECISION-MAKING FOR

FRAIL ELDERLY PEOPLE

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Thesis submitted for the degree of Doctor of Philosophy

January 2006

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Abstract

This project explored the values considered by elderly people, their younger relatives, and health professionals in decisions about residential long-term care, aiming to contribute to the literature on prospectively held values.

The mixed methods design utilised a medical record review of 60 frail elderly hospital patients, a stratified survey of 3,015 adults in the South Australian community, and interviews with 36 stakeholders (10 elderly people, 8 younger relatives, and 18 health professionals).

The medical record review confirmed that the hospital patients and their outcomes resembled those described internationally. It was used to develop a hypothetical vignette, used in the later studies.

Survey responses suggested that when considering a hypothetical long-term care decision, community members put the elderly person's physical health and safety first. Situational variables (the elderly person's autonomy, environmental adaptation, and caregiver burden) appeared secondary, albeit less so with increasing age of the respondent.

Thematic analysis of the interviews demonstrated that elderly stakeholders considering a hypothetical decision were more likely to mention autonomy values, and less likely to mention safety values, than were relatives or health professionals. However, elderly stakeholders were also more likely to suggest restrictive solutions, such as residential placement and proxy decision-making. This finding raised methodological issues concerning 'third person' vignettes, in that respondents might be

responding as proxy decision-makers, rather than as if the hypothetical decision applied to themselves.

The project confirmed that, in this context, prospectively held values resembled the retrospectively described values identified by McCullough, Wilson, Teasdale, Kolpakchi and Shelly (1993). Hence, the retrospective literature could be applied. The project supported the importance and complexity of psychosocial predisposing factors when applying the Andersen Behavioral Model (Andersen, 1995) to long-term care decisions. Additionally, the Ecological Theory of Aging (Nahemow, 2000) and the MacArthur Model of Successful Aging (Andrews, Clark, & Luszcz, 2002) were found to be relevant to long-term care decisions for individuals and populations.

It was concluded that both clinically, and at a policy level, discussions of long-term care could be more effective if they focussed on maintenance of elderly people's autonomy and control, rather than on their physical health and safety.

Dedication

To the memory of my parents

Margaret Grove Ogilvie and George Frederick Denson

Statement

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.

Acknowledgments

I would like to thank the many people without whom this project would not have been possible. In particular:

Associate Professor Helen Winefield, my primary supervisor, for her unfailing help, ideas, inspiration and encouragement throughout the project. Her kindness and her commitment to supervision have been exceptional.

Professor Ted Nettelbeck, co-supervisor, for his willingness to assist, and for his thoughtful comments.

Jacqueline Howard, research officer, for interview transcription, poster design, and much more.

Anne Stacey of the University of Adelaide Department of Public Health for kindly sharing her survey data on carers and her expertise concerning caregiver burden.

Colleagues who assisted with recruitment, study design, advice, and checking the data and thesis, in particular Professor Justin Beilby, Maree Farley, Margaret Hartstone, Margot Masters, Kathryn Moar, Barry Mortimer, Dr Marie O'Neill, Dr Robert Penhall, Heather Peters, and Rachel Roberts.

The study participants, for so generously sharing their time and thoughts.

The Royal Adelaide Hospital for its support of the interview project with an Allied Health Research Grant.

The Psychology Department of the University of Adelaide for funding participation in the 2002 Health Omnibus Survey, conducted by the Health Department and Harrison Health Research.

The staff of the Royal Adelaide Hospital and the University of Adelaide Departments of Psychology and Public Health for their help: especially Bob Willson, Emmae Ramsey and Justin Lokhorst for statistical advice, and Nick Paterakis for technical advice.

My friends, family and colleagues, for their encouragement and assistance.

Bruce Denson, my brother, for encouragement and computing support.

Greg Williams, my husband, for his good ideas and wonderful cooking, and for his full and unwavering support.

Chapter 1. Introduction to the research program

1.1 Overview

The goal of this program of research was to explore the values considered by elderly people, their younger relatives, and health professionals, in decisions about future residential long-term care for elderly people.

Research in this complex area is conducted by members of many disciplines and professions, and published in several quite separate areas, including the rehabilitation psychology, health care, health economics, professional practice and ethnography literatures. As a result there are gaps in the literature and this area lacks integration, theoretical underpinnings, and clear directions for research. Researchers, clinicians and policy-makers are often aware of research in their own areas, but may not always encounter potentially illuminating work published in other areas.

In this project, the research literature was critically and comprehensively reviewed. Theoretical models were applied and examined for relevance. The aim was to improve the theoretical understanding of long-term care decision-making, and to inform professional practice and policy-making, so that elderly people and their families could be provided with more useful assistance and information.

Specifically, the project examined whether (with regard to long-term care decisions) prospectively held values followed the same pattern as the retrospectively held values which had been identified in a study by McCullough et al. (1993). If so, elderly people considering long-term care decisions would be more likely to express values relating to autonomy, and less likely to express values relating to safety, than their younger relatives, and than health professionals involved in discharge planning.

Within the Andersen model of health service usage (Andersen, 1995), modified by Keyser, Desai, and Mutran (1999) and Bradley et al. (2002), these values were considered to be predisposing factors likely to influence whether or not individuals decided to utilise residential care services, all other things being equal.

The project applied a mixed methods research design (Creswell, 2003) to the task, utilising multiple sources of information, large samples, and both quantitative and qualitative methods. Research findings and methods located across a number of literatures were integrated, to design and interpret three studies which would shed light on residential care decision-making.

1.2 Values and decisions related to residential long-term care for elderly people

The study of values and decisions related to long-term care is one of many points where psychological research overlaps with ethnography, with public health research, and with the research of other health disciplines: in particular professions involved in the health care and rehabilitation of elderly people, such as medicine, nursing, social work and occupational therapy.

The decision to utilise residential long-term care is of potential interest to health professionals for several reasons. The residential care decision is recognised as a major stressor for an elderly person (Braithwaite, 1990; Dill, 1995; Minichiello, Alexander, & Jones, 1990) and also for relatives and caregivers (Gubrium, 1989; Pearson et al., 1998), with issues of control and choice having significant psychological, familial and social implications (Dill, 1995). It has been found that optimal psychological adjustment to residential care is more likely to occur if the elderly person has taken part in the decision to seek placement and/or in the selection of the residential facility (Minichiello

et al., 1990; Reinardy, 1992). However this occurs relatively rarely (Dill, 1995). Elderly people, particularly those who are very unwell and/or cognitively impaired, may have less involvement in the decision than family members and health professionals, and little opportunity to make decisions with which they are satisfied (R. A. Kane, 1995; Minichiello et al., 1990).

In many cases the move from home to residential care occurs via an admission to an acute care hospital or geriatric rehabilitation unit (Challiner, Carpenter, Potter, & Maxwell, 2003; Richards & Coast, 2003). Ideally, admission to a general hospital would be followed by the resolution of the acute medical issues that caused the admission. When this occurs the crisis in the individual's health and health care which resulted in admission (Sager, Franke et al., 1996) has, at least temporarily, been resolved. The patient is then discharged home, with stabilised health and/or coordinated access to relevant health and community services. Sometimes, however, an elderly person does not return to live at home, but instead transfers from acute care to long-term, or residential, care (Dill, 1995). In Australia residential care is classified as either "low level residential care" in hostel-type accommodation, or "high level residential care" in a nursing home (Duckett, 2004). Approval for federal government funding of a particular level of residential care is based on the outcome of assessment by a multidisciplinary Aged Care Assessment Team (ACAT), indicating that the elderly person's care requirements warrant the public funding of that level of care (Aged and Community Care Division of the Commonwealth Department of Health and Ageing, 2002; Duckett, 2004). Psychologists are not part of ACAT teams, but may contribute to the process. For example they may provide psychological treatment to elderly people and their families before and during the placement process, or perform psychological

assessment of underlying depression and /or cognitive impairment which may influence decision-making competency and/or the need for placement (Lichtenberg, MacNeill, Lysack, Bank, & Neufeld, 2003a; Morris & Kopelman, 1992).

The process of placement can present significant personal, professional and ethical dilemmas for psychologists and other health professionals (Dill, 1995; Feigin, Cohen, & Gilad, 1998; Healy, 1998), and in particular for those professionals, often social workers, involved in the formal planning and implementation of individuals' discharge from hospital (Clemens, 1995; Grimmer, 1997; Kadushin & Kulys, 1993).

Decisions about the timing of residential placement are rarely easy, and they become most complex and difficult for relatives, health professionals and society when issues of competence, proxy-decision-making and / or duty of care have been raised and the implications are not straightforward (Dill, 1995). These situations occur in the 'grey area' between clear competence and clear incompetence: when it is not clear that the decision can or should be left to the elderly person, and yet the elderly person is not unambiguously incompetent. In these situations in Australia, the hospital neuropsychologist, clinical psychologist or psychiatrist may be called on to undertake an interview and mental status testing and provide an opinion on the patient's competence to make decisions (Morris & Kopelman, 1992). In the first instance, this information will be provided to the patient, the family, the treatment team and the ACAT team, to aid in discharge planning. A formal report may also be required as evidence for consideration by the state Guardianship Board or equivalent tribunal, which may adjudicate concerning the individual's need for a guardian and proxy decision-maker (Darzins, Molloy, & Strang, 2000). As a result, psychologists and psychiatrists, like other health professionals in the treatment team, find that their client

is not, or not only, the individual patient but also (or alternatively) the family, the institution and/or the community: a situation fraught with potential for ethical dilemmas, and conflicts of interest (Arras, 1995; McCullough & Wilson, 1995b).

Attitudes and values concerning residential long-term care are also important to health administrators, who must plan, provide and budget for residential care facilities. The Andersen behavioural model of health service utilisation (see below) propounds that in health services generally, utilisation depends not only on a person's need for a health service, and on his or her ability to obtain it, but also on the predisposition to utilise such a service. It has been demonstrated that in the case of residential placement of the elderly, the attitudes of elderly individuals (Haken, Steverink, van den Heuvel, & Lindenberg, 2002) and their caregivers (Shyu & Lee, 2002) towards residential care predict the likelihood of its being utilised.

In this chapter, some theories relevant to ageing, long-term care and health service usage are introduced, followed by an overview of the literature on long-term care decisions, a discussion of research methods, and a description of each of the three studies which comprise this research project.

1.3 Theories which explain long-term care utilisation

1.3.1 The Andersen Behavioral Model of Health Service Utilisation

Attitudes to the move to a residential aged care facility have been classified as health beliefs, and thus as “predisposing” factors within the behavioural model of health service utilisation, originally proposed by Andersen, a medical sociologist, in 1968 and further developed by Andersen (1995) and others including Wolinsky, Callahan., Fitzgerald and Johnson (1992) and Gelberg, Andersen and Leake (2000). This is the

most widely used model of health service usage (Wolinsky, 1994) and it has increasingly been adopted and applied by health economists and by psychologists (Andersen, 1995). Originally designed to predict the use of acute care services, the model has been modified over the years by Andersen and others for predicting the use of a wider range of services, such as long-term care of elderly people (Bradley et al., 2002), and also for predicting health-related behaviours, for example oral hygiene (Andersen & Davidson, 1997).

The Andersen model asserts that, as well as being determined by broader societal factors and health system factors, usage of health services is affected by individual characteristics. In this model, the personal and environmental characteristics of individuals which influence and predict their level of service utilisation are classified into “predisposing”, “enabling”, and “need” factors. The three factors are seen as interacting in a recursive fashion, rather than operating in a particular sequence (Andersen, 1995; Andersen & Davidson, 1997).

The concept of predisposing factors has been used to explain the observation that some individuals are more likely to utilise health services than others are, given the same level of enabling factors (access to services, comprising family and community factors such as income, transport and geographic proximity) and the same level of need factors (as perceived by the individual in terms of symptoms, level of disability etc, and as measured by health professionals using symptoms and diagnoses).

Predisposing factors incorporate demographic factors, such as age, sex, marital status and past illnesses. They also include ‘social structure’ factors such as education, occupation, race, family size, religion, and residential mobility.

Thirdly, and most relevantly to this project, predisposing factors include “health beliefs”. In the Andersen model, health beliefs are defined as “attitudes, values and knowledge that people have about health and health services that might influence their subsequent perceptions of need and use of health services” (Andersen, 1995, pg.2). Health beliefs comprise values concerning health and illness, knowledge of disease, and attitudes toward health services.

The model has been extensively applied in studying the usage of health and long-term care services by elderly people, including the usage of residential aged care services (Bradley et al., 2002; Keysor et al., 1999; Rabiner, 1996). However, in a critical review of the literature on health service usage by the elderly, Wolinsky et al. (1994) observed that measurement of the three Andersen factors had suffered from serious limitations, including reliance on cross-sectional studies and failure to document predisposing factors in sufficient breadth and depth. Wolinsky et al. pointed out that in most studies of elderly people’s health service usage, health beliefs were either not studied at all, or were defined in terms of a single item only, for example sense of control or amount of worry concerning health (Wolinsky, 1994 p.473).

Subsequent studies have attempted to address this issue, particularly in the area of long-term care, for example Mitchell & Krout, (1998), Keysor et al. (1999), and Bradley et al. (2002).

Mitchell and Krout (1998) observed that need factors were particularly important in the prediction of usage of those health services (such as acute hospital care) where use did not appear discretionary. However, the prediction of the use of discretionary services, such as community care and home-delivered meals, required more information about predisposing and enabling factors.

Keysor and colleagues (1999) reviewed the literature on the residential placement decision, observing that there had been a focus on need factors and enabling factors. Few studies had investigated the relationship between elderly people's attitudes and residential placement, or looked at the complexity of the decision or the context within which it was made. They suggested a modification of the Andersen model. They drew a distinction between some cognitive variables (such as health beliefs) that might function as predisposing factors, and others which they described as "appraisal" factors – attitudes towards residential care and evaluation of present resources and context (including financial resources, family strain and the severity of the present situation). They proposed that this latter group of appraisal factors might intervene between the three Andersen groups of factors (predisposing, enabling and need factors) and the decision about service utilisation. Keysor et al. utilised a large study of elderly people and their caregivers to test this new model and concluded that the appraisal factors they had defined did play a significant role in decisions about location of care. In considering hypothetical future decisions about short- and long-term care, elderly people were strongly influenced by their individual appraisal of the situation; not only its severity and potential duration (need factors) but also its likely impact on themselves, their finances and their families.

Bradley et al. (2002) suggested that the concept of beliefs was too narrow to encompass the range of psychosocial factors operating when a long-term care decision was made. They suggested that if psychosocial variables were examined in more detail, and also if interactions between need, enabling and predisposing factors were considered, there was the potential for more satisfactory prediction and explanation of variations in long-term care usage, for example race/ethnicity differences. They

interviewed focus groups of elderly African-American people and elderly White people concerning their plans and views about long-term care. In addition to need and enabling factors, the major themes of the elderly people's discussions included a number of different psychosocial factors, such as attitudes, knowledge, social norms and perceived control. These appeared to operate slightly differently in the two ethnic groups. Bradley et al. concluded that psychosocial factors were an important component of the Andersen model as it applied to long-term care.

In summary, it appears that if the Andersen Model of Health Service usage is to be applied to usage of long-term services by elderly people, detailed research into predisposing and appraisal factors is essential.

1.3.2 The Ecological Theory of Aging

Another area of the literature with a bearing on this topic is environmental psychology which, with its focus on the relationship between the person and the environment, emerged in the 1960's as part of a multi-disciplinary approach to urban and ecological issues (Saegert & Winkel, 1990; Stokols, 1995). One theory which continues to be used in a practical way to examine the health and housing needs of elderly people is the Ecological Theory of Aging or ETA (Lawton & Nahemow, 1973). The theory was proposed by Lawton and Nahemow in the early 1970's, and developed through a series of studies by these and other authors (Nahemow, 2000). It has been used to examine a range of situations in which elderly people adapt to changes in their needs and in the environment (Nahemow, 2000), including the medical rehabilitation process (Lichtenberg, MacNeill, & Mast, 2000).

In this theory, an “adaptation model” is proposed. Individuals’ adaptation to the environment (their adaptation level) is predicted by their competence (high or low) and the amount of demand the environment exerts on them (environmental press). Individual competence is based on the extent to which individuals have the skills required to perform necessary tasks. The higher an individual’s competence, the broader their adaptive range, that is, the range of environmental press to which he or she can successfully adapt, either at an optimal level, or with a manageable degree of under-stimulation (“comfort zone”) or over-stimulation (“challenge zone”). Individuals are thought to seek their own level of environmental press. Within the individual’s adaptive range, extended periods in the challenge zone result in increased competence, but extended periods in the comfort zone result in decreased competence. Outside the adaptive range, behaviour and affect may be negatively affected. The less competent the individual, the less able he or she is to adapt, change or leave the environment, and the more crucial is the fit between the person and the environment. The ETA model emphasises that adaptation by an individual to an environment will not occur instantly, but over a period of time. The environment and the individual’s competence will also change over time, requiring ongoing adaptation. In that sense, time is the fourth dimension of the adaptation model (Nahemow, 2000).

In their review article on the contribution of Lawton and the ETA to their own work in planning environments for elderly people, Weisman, Chaudhury, & Moore (2000) observed that “environment” was not a simple concept and that it had not been easy to develop a taxonomy of the major dimensions of humans’ environments. The ETA acknowledges that the environment can be studied at multiple levels (physical, psychological, interpersonal, social, organizational and cultural). This has provided a

framework for the study of psychological concepts such as 'sense of place', and the related concept of 'place experience' which is built up from personal experiences and, reciprocally, serves as a cue for memories and a means of retaining self-identity, particularly in old age (Weisman et al., 2000)

These concepts, springing out of the ETA and related work in the social sciences, have provided useful insights into people's decisions about choosing, and changing, the environments within which they live. For example, in a study of elderly Australians Russell (1999) found that a major reason for elderly people's attachment to their homes was that they perceived home as the place most likely to support their independence and autonomy and (particularly in the case of female respondents) their personal identity. For these elderly people, independence was not based on physical independence; indeed the receipt of formal care services was irrelevant. Rather, living in one's own home was seen as independence, and living in an institution was seen as dependence. In a series of Australian studies Read (1996; 2000), an anthropologist, has identified neighbourhood and place as being important to individuals' identities, but under-acknowledged in recent white Australian history with its promotion of migration, dispossession, change and progress.

The ETA has limitations. In their critical review of environmental psychology, Saegert and Winkel (1990) observed that adaptation paradigms such as ETA, which focused on an organism's adaptation to the environment in order to cope with threats and meet basic biological needs, were limited in that they did not always describe the transactional or process aspects of relations between the person and the environment, or address the sociocultural context within which the person, the environment and the processes existed. However, Saegert and Winkel saw adaptation models as useful in that

they addressed important outcomes such as health, well being and the ability to fulfil goals.

1.3.3 The MacArthur Model of Successful Aging

The literature on placement decisions for the elderly, and the related literature on outcomes for elderly people after hospital admission, is found where two large bodies of research intersect: the literature on aging as a part of human development and the literature on health and health service usage.

Within the study of stages of human development, the importance of the study of human aging is increasingly being recognised because, with increased survival and decreasing birth rates, the proportion of elderly people in the community continues to rise. For example, people over 65 comprised 9% of the Australian population in 1976, and 12% in 1996. The percentage has been predicted to rise to 16% by 2016 (Luszcz, 1998). There are significant social, economic and health care implications (Access Economics, 2001), particularly as elderly people already make up the majority of individuals with health problems in developed countries (Grundy & Sloggett, 2003).

Longitudinal studies have identified differing trajectories of aging within the elderly population (Andrews, Clark & Luszcz, 2002). Attempts have been made to identify those elderly people with minimal functional limitations who demonstrate 'successful aging' (Rowe & Kahn, 1987), and to compare them with individuals with lower levels of functioning (Andrews et al., 2002; Berkman et al., 1993; Jorm et al., 1998). The MacArthur studies of aging in the U.S.A. (Berkman et al., 1993) demonstrated that if predetermined measures of physical and cognitive performance were used to classify elderly people into three groups (high, intermediate and low

functioning), the groups also differed on measures of social, psychological and physiological functioning. These studies have led to some productive research on the prediction of elderly people's health outcomes, based on the MacArthur model of successful aging.

For example, as part of their involvement in the Australian Longitudinal Study of Aging (ALSA) in Adelaide, South Australia, Andrews et al. (2002) applied the criteria developed in the MacArthur studies of successful aging (Berkman et al., 1993) to a stratified random sample of 1403 community dwelling elderly people. The sample was selected to provide equal-sized age and sex cohorts for each five years from ages 70 to 85, and one grouping for those aged over 85. Participants were divided into three subgroups according to predetermined levels of functioning, based on a combination of test performances: cognitive performance, mobility performance, and independence in activities of daily living (ADL). The three functional groups (high – 36% of participants, intermediate - 27% and low – 37%) were then compared in terms of other functional measures, and their mortality at eight years was also compared.

Andrews et al. found that functional grouping predicted mortality at eight years, and it was also strongly associated with other measures of physical activity, health, physical performance, cognitive performance, depression, morale and self-esteem. As well as being more likely to survive, participants with a high level of functioning (i.e. those who had met the criteria for successful aging), had a better quality of life, and were more likely to maintain or improve their levels of psychological functioning in the two years after baseline. Conversely, low level of functioning ('unsuccessful aging') was strongly associated with poor self-rated health, compromised mobility and ADL functioning, and diagnoses such as stroke and hip fracture.

Luszcz (1998) examined changes in the same ALSA participants' psychological functioning over time. One aim of her study was to test Salthouse's 1991 "limited impact" theory of cognitive decline in old age, which asserts that small decrements in group means are due to a large decrement in the scores of a small subgroup of individuals, with the cognitive function of the remainder of the group remaining essentially stable over time. Luszcz found some evidence for this. The study group, as a whole, displayed quite high and stable levels of cognitive and affective functioning. However within the group, her analyses revealed that the two older age-cohorts (aged 80-84 years and 85+ years) showed more decline in psychological functioning, (cognitive and affective measures) than did the two younger age-cohorts (70-74 years and 75-79 years). Luszcz suggested that this phenomenon was consistent with the 'limited impact' hypothesis that there was an increased rate of change near the end of life. The phenomenon was also thought consistent with the concept of terminal decline.

Population-based studies of the elderly, such as the ALSA and MacArthur studies, demonstrate that the population of elderly people includes individuals with a wide range of functional abilities, and that within this population some individuals have stable (or even improving) levels of function, while others decline.

It is likely, however, that clinical research on elderly people's health outcomes (conducted in health settings and published in the health and health service usage literature) captures a different subgroup of elderly people. By studying those who have been admitted to hospital and in some cases transferred to a medical rehabilitation facility, this subgroup is likely to contain higher proportion of individuals who – at least at the time they are being studied and perhaps for the rest of their lives – meet criteria for unsuccessful aging and/or for a low level of functioning. Hence the observation by

Lichtenberg, MacNeill, Lysack, Bank and Neufeld (2003a) that in population studies, elderly people who lived alone had higher levels of functioning than those who did not, whereas in clinical samples, living alone was a risk factor for poor health outcome.

Even within clinical samples of elderly people, there is variability in their level of functioning and rate of decline. In their study of 812 elderly patients undergoing geriatric rehabilitation (see Chapter 2 for more detail) Hanks and Lichtenberg (1996) were able to identify two subgroups. Their “young old” group of individuals had higher levels of comorbidity and alcohol abuse, and were cognitively impaired in comparison with age-peers. In contrast, their “old old” group had higher levels of ADL dependency, and were cognitively impaired in comparison with younger people but not in comparison with age-peers. Considered in terms of the successful aging model, the first group might represent people who were never likely to age successfully or to become the old old, because they had entered the developmental phase of old age with significant pre-existing health burdens. The second group could represent those who had been able to age successfully, or at least adequately, into their ninth decade, and whose poor current health reflected an acute illness or injury, or their recent entry to the terminal phase of life. Hence, the MacArthur model has application to the prediction of elderly individuals’ health care service usage and their long-term care planning and decision-making.

1.4 The research literature on residential long-term care decisions

The research literature on attitudes to usage of residential aged care facilities, and, more specifically, the residential placement decision, can be divided into two distinct bodies of literature with only a small overlap.

One major body of literature (discussed further in Chapter 6) is largely retrospective, studying elderly people or their relatives in the aftermath of a residential placement decision in which they have been involved. It focuses on process aspects: the timing of the placement decision, the way in which the decision was made and implemented, and its impact on participants. This research often employs a qualitative methodology. It is generally published in the nursing and social work literature and in journals focussing on ageing and health care. There is a smaller parallel literature concerning health professionals who, as part of their work, find themselves involved in placement decisions made by their clients and/or their employing agencies. This research, also largely qualitative in nature, is found in nursing and social work professional journals, and it too is discussed in Chapter 6.

The other major body of literature (reviewed in Chapter 4) is prospective in nature, and studies the attitudes of potential future participants, rather than current or recent participants. It is a smaller body of literature, surveying people who have not yet made a decision concerning long-term care, but who might be expected to do so in future: students, trainee health professionals, family caregivers, and people who are ill or elderly. The attitudes of the general public do not appear to have been extensively studied. The methodology in these studies is normally quantitative, with large groups being surveyed. The results have been analysed statistically to test specific hypotheses concerning respondents' attitudes and their likely, and actual, effects on subsequent health service usage. These studies are often conducted by health economists and/or published in the health services literature.

This project drew upon, and synthesised, the methodologies and findings of both of these literatures. The choice of methods is discussed further below.

1.5 Methodology

1.5.1 Schema of values, attitudes and beliefs

This project utilised the schema of values, attitudes and beliefs adopted by Forbes and Hoffart (1998) in their retrospective study, following on from McCullough et al. (1993), of values in older people's decision-making about long-term care. McCullough et al. (1993) had defined values as "standards by which human beings judge the worth or importance of themselves, other human beings and things" (p.325). Forbes and Hoffart (1998) provided additional definitions as follows. A belief was "a predisposition to action that contains a cognitive component and an evaluative component", whereas "attitudes are comprised of two or more underlying beliefs" (p.737). They stated that adults had relatively few values, but many attitudes and even more beliefs, adding that:

Once a value is internalised, it guides (consciously or unconsciously) action, decision-making, moral judgment, and maintaining or changing attitudes. A value is more global than are attitudes and transcendentally guides actions and judgments across situations beyond the immediate to more focussed end states of existence. (p.737).

1.5.2 Qualitative research methods in health care and psychology

In discussing the contribution of qualitative clinical research to health care, Miller and Crabtree (2000) highlighted the importance of acknowledging the experience and accounts of health care consumers and professionals. They described these accounts as a crucial, and often unused or missing, resource for the generation of research questions, the development of theory, and the interpretation of the outcomes of drug trials and

other quantitative studies. They noted that clinical researchers had a repertoire of research styles from which to select, including experimental, survey, documentary, field /qualitative, and action/ participatory methods. They suggested that in order to develop useful questions and obtain meaningful answers, effective research in the clinical setting would often employ a combination of methods.

Accordingly, a qualitative component to the research project was designed, however issues of validity and applicability of findings had to be addressed. Pope and Mays (1999) and Mays and Pope (2000) stated that qualitative methods were increasingly common in health research, but before the findings of any study could be applied to health care, it must be possible to evaluate the quality of the research. Whilst acknowledging the ongoing epistemological debate about the unique perspective and subjectivity of every research project, Mays and Pope asserted that it was possible to evaluate the validity and relevance of qualitative research projects. They suggested a number of methods for assessing qualitative studies: triangulation, respondent validation, clear exposition, reflexivity, attention to negative cases, and fair dealing. If research was designed, conducted, interpreted and reported in a systematic and self-conscious way, they claimed, it could contribute to the understanding of complex issues in health and health care (Mays & Pope, 2000; Pope & Mays, 1999).

Within psychological research, quantitative methods have long been well-established. However, the status of qualitative methodologies has varied over time (Hayes, 1997; Richardson, 1996). These methodologies have a long history within other social sciences, such as sociology and social anthropology (Richardson, 1996; Vidich & Lyman, 2000). In psychology, they were relatively better accepted in the 1920s and 1930s before the advent of behaviourism in American and British psychology (Hayes,

1997). Since the 1960's interest in the development and application of these methods has burgeoned in the social sciences (Richardson, 1996). This was reflected in the landmark publication of the first edition of the *Handbook of Qualitative Research* (Denzin and Lincoln, 1994). However, these methodologies remained largely unacknowledged within mainstream psychology until the 1990's. Since then, increasing numbers of psychologists have been interested in exploring and applying these methodologies (Elliott, Fischer, & Rennie, 1999; Hayes, 1997; Richardson, 1996).

Woolgar (1996) acknowledged the recent movement within psychology towards qualitative research, but cautioned against adopting qualitative research on the level of technique, while attempting to retain a framework for traditional or 'received' scientific method, or "representational realism". Woolgar observed that social constructivists had three main criticisms of the traditional view of scientific method. Firstly, that science itself was a historical, philosophical and social entity that continues to evolve, and not a changeless and objective institution. Secondly, that the practice of scientists was an active and constructive one, rather than a passive documentation of a changeless reality. Thirdly, that the attempt to represent events and objects in an objective and standardised way was futile. Events and objects could not be represented in an objective way or, in other words, they might be equally well represented in a number of different ways. Mays and Pope (2000) acknowledged this perspective of "extreme relativism" (p.50) but rejected it for applied health-related research, observing that research which did not offer any unequivocal information or recommendations would not be accepted in health settings. Furthermore, research that could not be understood or evaluated by researchers from other traditions would have limited acceptance.

Hayes (1997) examined the seven distinctions drawn by Hammersley (1992) between qualitative and quantitative approaches to ethnographic research. They were: the use of qualitative rather than quantitative data; the use of natural rather than artificial settings; a focus on meanings rather than behaviour; the rejection (or adoption) of natural science as a model; an inductive rather than a deductive approach; identifying cultural patterns rather than seeking scientific laws; and idealism rather than realism. Hayes reviewed these seven distinctions as they might apply to current psychological practice and concluded that the concept of a dichotomy, while attractive because of its simplicity, could not be applied to the range of current practices. Hayes concluded that a range of methodological possibilities existed and could be seen as existing on a continuum, based on “the degree of precision which our data expresses” (p.5).

A common concern for psychologists when considering qualitative research has been the extent to which the conclusions can be regarded as generalisable, reliable and valid. Miller and Crabtree (2000) provided a checklist for the evaluation of qualitative research. They suggested asking whether the method was appropriate for the question being asked, and whether the sampling was adequate and the information rich. They also required that the research process be iterative, that reflexivity should have been addressed, and that the interpretive process should be thorough and clearly described.

Flick (1998) suggested that, in qualitative research, reliability was based on the potential ability to check the data which had been obtained and the procedures which had been conducted. This required two forms of explication. Firstly, it must be possible to check where a participant’s statement ended and where the researcher’s interpretation began. Secondly the procedures by which the text was obtained and analysed – that is, the interview procedure and the method of textual analysis – must be made explicit.

Both forms of explication relied on clear documentation. Other approaches to the assessment of reliability, such as the repetition of studies with the aim of achieving similar results, were explicitly rejected.

Kvale (1996) summarised the discourse on generalisability, reliability and validity, observing that these three constructs had been seen as “the positivist trinity... employed by mainstream researchers to disqualify qualitative research” (p.230). In response, generalisability, reliability and validity had been dismissed by some qualitative researchers as irrelevant and oppressive. Other qualitative researchers, however, had reclaimed the discourse by using terms from everyday language, such as “trustworthiness, credibility, dependability and conformability” (Lincoln & Guba, 1985, cited in Kvale, 1996, p.231) or had seen validity as “an incitement to discourse” (Latehr, 1995, cited in Kvale, 1996, p.231). In conclusion, Kvale propounded:

A rather moderate post-modernism; although rejecting the notion of an objective universal truth, it accepts the possibility of specific local, personal and community forms of truth.... The understanding of verification starts in the lived world and daily language where issues of reliable observations, of generalization from one case to another, of valid arguments, are part of everyday social interaction. (p.231).

In a coherent attempt to address these issues in psychology, Elliott et al. (1999) described the aim of qualitative research as “to understand and represent the experiences and actions of people as they encounter, engage, and live through situations” (p.216). They presented a set of draft guidelines for the evaluation of qualitative research studies. Of their fourteen guidelines, they classified seven as common to qualitative and

quantitative methods alike. These were “Explicit scientific content and purpose; appropriate methods; respect for participants; specification of methods; appropriate discussion; clarity of presentation; and contribution to knowledge” (p.220). Another seven guidelines were thought to be specifically relevant to qualitative research. These were: “Owning one’s perspective; situating the sample; grounding in examples; providing credibility checks; coherence; accomplishing general vs specific research tasks; and resonating with readers” (p.220).

In summary, it appears that researchers in health and psychology have acknowledged the need, and developed the techniques, to utilise both quantitative and qualitative research methods. They are able to apply and evaluate them in a rigorous fashion, in the interest of obtaining rich and meaningful information. Accordingly, a “mixed methods” (Creswell, 2003; Goering & Streiner, 1996) research design was developed for this project.

1.5.3 Mixed methods research design

The mixed methods approach (Creswell, 2003; Goering & Streiner, 1996) involves the collection and analysis of both quantitative and qualitative data in a single study, with the aim of triangulating observations from multiple perspectives. This approach is thought to combine the methodologies and strengths, and avoid some of the limitations, of the separate quantitative and qualitative research traditions.

In the research program designed for and described in this thesis, after an exploratory review of elderly medical inpatients’ medical records, two investigations of values in long-term care decision-making were designed and conducted concurrently (Creswell, 2003). One was a survey of values in the general community with results

analysed quantitatively. The other was a qualitative thematic analysis of interviews with stakeholders (elderly people, their relatives and health professionals), nested within which was a quantitative analysis of stakeholders' practical suggestions. Findings were discussed separately in Chapters 5 and 7 respectively, and together in Chapter 8.

1.6 Plan of the research project

As mentioned above, the aim of this program of research was to explore the values considered by elderly people, their younger relatives, and health professionals, in decisions about residential long-term care. The following is an outline of the three empirical studies that were undertaken to fulfil this aim.

Initially (Chapters 2 and 3) the literature on the health outcomes of elderly medical patients was reviewed, followed by an exploratory study of the hospital medical records (casenotes or charts) of 60 elderly hospital inpatients who were facing a placement decision at the end of their hospital admission. The primary goal was to formulate a health, demographic and health service usage profile of elderly South Australian medical patients for whom long-term care decision-making appeared salient, and to compare this patient group with those described in the research literature elsewhere in the developed world. A subsidiary goal was to attempt to identify any predictors of patient outcomes (specifically, residential placement at the end of the admission, and 12-month survival) which could be obtained from the medical record during the index admission.

Next (Chapters 4 and 5) the literature on prospective attitudes to long-term care was reviewed, and a stratified community survey of 3,015 South Australian adults was undertaken. To ascertain their values and priorities in considering the residential

placement decision, respondents were asked to consider a brief hypothetical vignette based on the medical record study, and indicate (from a list of eight values or priorities) which three they felt were the most important. The survey was designed to obtain information about community members' prospective attitudes and values, and to serve as a triangulation point for validation of Study 3.

Concurrently with the community survey, 36 interviews with stakeholders were conducted, and the data were analysed using a qualitative method, research-based thematic analysis (Chapter 7). The thematic analysis was based on a review (Chapters 4 and 6) of the existing retrospective and prospective research on the values and priorities of people who had been involved in the process of transition to residential aged care, and the determinants of placement decisions. Prospective semi-structured interviews, based on a more detailed vignette, were conducted with 10 elderly people in poor health who were living in their own homes but who (according to the health profile established in Study 1) appeared likely to encounter a long-term care decision in the short to medium term. A parallel series of interviews was carried out with 8 relatives of such elderly people. Because direct comparisons between the views of consumers (elderly people and their relatives) and of health professionals were rarely identified in the review of the literature, a third series of interviews was conducted with 18 health professionals. Qualitative thematic analysis was used to describe the prospectively held priorities and values which influenced views of the long-term care decision-making in these three stakeholder groups. The goal was to document prospectively held values in stakeholders and compare them with the retrospectively held values described in the literature.

Finally (Chapter 8) the findings of the survey and interview studies were integrated. Their implications for theory, practice, policy and future research directions were discussed.

Chapter 2. Literature Review: Outcomes and discharge destinations of frail elderly hospital patients

2.1 Overview

In preparation for the descriptive study of elderly hospital patients' medical records and outcomes, a comprehensive critical review of the literature on the outcomes of frail elderly hospital patients was completed. There were two primary goals: to identify variables which in the literature were predictive of patient outcome, and to compare this group of frail elderly South Australian hospital patients with those described in the international literature.

2.2 Review of the literature

2.2.1 Criteria for inclusion

There is a considerable literature on frail or "at-risk" elderly hospital inpatients, and on planning their discharge from hospital and predicting their outcomes. Some of this literature concerns itself with the ethics and efficacy of the hospital discharge planning process, often from a social work perspective and with a primary focus on issues of process. Other studies, by health economists, attempt to describe and classify groups of such elderly patients according to their "case-mix" classification (their primary diagnosis and comorbidities) so that patients' outcomes can be costed and compared in the formal evaluation of health services. The largest body of research is found in the clinical literature, often in journals of medicine and specifically geriatrics, but also in journals of gerontology, and of other health professions such as psychology,

occupational therapy and nursing. It describes prediction of health outcomes of individual patients at the end of the period of acute care and post-acute medical rehabilitation. Motivated at least in part by the demands of managed-care health environments for cost-effective and evidence-based assessment and treatment, the focus of medical rehabilitation appears to be shifting “from process to outcome” (Lichtenberg & MacNeill, 2003, p.56). Accordingly, in the medical and rehabilitation literatures, there appears to have been an increased focus on the measurement and prediction of elderly medical patients’ outcomes.

Terms such as frail or at-risk are widely used but rarely specifically defined. Frailty has been defined in terms such as being dependent on others for daily care (Brody, Johnson, Reid, Carder, & Perrin, 2002, p.563) or as having impairment in more than one area of functioning (Lichtenberg, Murman, & Mellow, 2003b). Although these definitions may seem imprecise, they are effective. The degree of frailty, when defined in terms of functional dependence, has been found to predict a range of more specific and measurable outcomes such as mortality, acute hospital usage, and use of both high-level and low-level residential care facilities (Brody et al., 2002).

Functional dependence is in turn defined as the inability to perform one or more “activities of daily living” (ADL) without assistance. This term is found throughout the rehabilitation and occupational therapy literatures. Physical health is described as encompassing three hierarchical categories: general physical health or the absence of illness; the ability to perform activities of daily living (ADL); and the ability to perform independent activities of daily living (IADL) (Dunkle, Kart, & Lockery, 1994).

Each level of activity requires a higher level of functioning than the one that precedes it. General physical health is usually defined in one or more of five ways:

number of illnesses or conditions, days spent in bed, self-rated health, number of visits from a doctor, and number of hospital admissions. ADL are the most basic self-care activities. ADL measures usually include dressing, bathing, feeding oneself, toileting, mobility in bed, transferring into and out of a bed and a chair, and walking across the room or outside the home. IADL are more complex activities which provide greater independence; such as using the telephone, shopping, meal preparation, light and heavy housework, taking medications, using transport, and managing one's own finances (Dunkle et al., 1994).

In this review of the literature, the following reference databases were searched, for articles published between January 1990 up to and including September 2004: PsycInfo, PubMed, CINAHL, Australasian Medical Index, Health Business, Health Source Nursing, Sociological Abstracts, ISI Web of Science, Expanded Academic Index, Academic Search Elite, and ProQuest.

In their critical methodological review of outcome studies, Saravay, Steinberg, Weinschel, Pollack, & Alovic (1991) suggested that outcome studies should be prospective, and should effectively measure and control for potentially confounding variables such as illness severity, depression, and functional impairment, and social and economic factors including living arrangements and availability of caregivers. Studies should attempt to enroll homogenous groups of patients, and should cover the whole of an episode of illness, not just the hospital admission

Hence studies were selected for this review if they involved a systematic multivariate analysis of predictive and outcome variables, if they measured the health outcomes of elderly medical inpatients, and if the patients studied met a number of criteria.

Patients studied were to be aged 60 or older (in the majority of studies, patients were aged over 65 or 70), and admitted to a general medical unit or a geriatric medical unit (and not to a surgical unit or an intensive care facility). All or almost all of the elderly patient group studied were to have been living at home in the community, prior to the index admission, i.e. living in their own or a relative's home, or in sheltered accommodation (such as a retirement village) or low level care (hostel), and not living in a nursing home.

The presence of an acute and life-threatening and/or severely disabling illness (eg. severe dementia, advanced cancer, hemiplegia after stroke) needed to be either an exclusion criterion, or dealt with separately in the subsequent analyses, because the outcomes of such severe and/or specific illnesses and disabilities were beyond the scope of this study. Retrospective studies were included if they used systematic measures and multivariate analyses. No studies focussing on a large homogeneous group of elderly medical patients, assessed in a standardised fashion, could be found. Indeed this literature is notable for the diversity of diagnoses encountered and measures utilised (Campbell, Seymour, & Primrose, 2004), and for the extent to which a patient's major or presenting diagnosis tends to be accompanied by a number of other medical diagnoses known as comorbidities (Incalzi et al., 1997).

Some of the selected studies examined outcomes of elderly patients discharged directly from acute care (a hospital ward), whereas others followed up those who had been discharged from hospital via a medical rehabilitation unit (whether part of the hospital or free-standing), and a period of therapy and convalescence. Still other studies did not distinguish between the two pathways from acute care. In all studies the elderly people had been admitted to hospital with similar conditions, and had been managed by

similar medical or geriatric rehabilitation treatment teams. In practice, the choice of the pathway out of hospital often depends on what is available and affordable locally, and/or what is preferred by the patient, family and treating doctor, rather than on clear criteria. Hence, in selecting studies for this review, no distinction was drawn between these different routes out of hospital. Almost all of the included studies reported follow-up data obtained at 3, 6, 12 or 18 months after discharge from hospital. A few studies had discharge alive, or functional status at the end of the index admission, as their primary outcome measure.

Once these criteria had been applied, 31 peer-reviewed studies of the health outcomes of elderly medical inpatients were identified, along with one systematic review of the literature (Campbell et al., 2004). The studies are reviewed below, in order to develop a profile of the frail elderly medical in-patient as identified in the research literature, and to ascertain the recognised risk factors for poor outcome. Two major research groups were identified, and their publications are discussed in turn, followed by the other studies in chronological order, and the systematic review.

2.2.2 The Yale / Madison group: eight studies

Since 1993 a group of research associates including Inouye of the Yale University Medical School and Sager of the University of Madison-Wisconsin has published studies designed to analyse the outcomes of acutely ill elderly hospital patients, in order to reduce future patients' risk of functional decline. Margitc et al. (1993) published an initial description of the Hospital Outcomes Project for the Elderly (HOPE) study which aimed to pool data collected in separate but related studies across six large teaching hospitals in the USA, in 1989 and 1990. The over-arching goal was to combine

prospective and retrospective analyses in what was termed a “prospective pooled analysis” (Margitic et al., 1993, pg 259), and evaluate different strategies used to reduce risk of functional decline. Exclusion criteria for the HOPE study included severe cognitive impairment, inability to provide informed consent, institutionalisation prior to the index admission, terminal illness, and admission to intensive care during the hospital admission (Rudberg, Sager, & Zhang, 1996).

Dunham and Sager (1994) published a short-term outcome study using a subset of the HOPE data. They collected the one-month outcomes of 197 community-dwelling patients aged 70 and over (35% of the group were aged 70-74, 44.2% aged 75-84, and 20.8% aged 85 and over) who had been admitted to a community hospital in the Mid-West of the U.S.A. Their aim was to ascertain whether depression, assessed on admission using the Geriatric Depression Scale or GDS (Yesavage et al., 1983) was predictive of these patients’ medical outcomes one month after discharge. Medical outcome was assessed using the MOS 20-item Short-Form instrument (Stewart & Ware, 1992) which comprised three scales: Physical Functioning (limitations in various activities), Health Status (self-rated health status) and Mental Status (general mood and affect).

In addition, six activities of daily living (ADL) and seven instrumental activities of daily living (IADL) were selected for study. Patients were asked to report whether they were able to carry out each of these activities with assistance, or without assistance, or not at all. The six ADL were dressing, bathing, eating, toileting, transferring from bed to chair, and walking across the room. The seven IADL were using the telephone, shopping, using transport, meal preparation, housework, taking medications and managing one’s own finances.

Dunham and Sager found that 23.9% of their patient group exhibited symptoms of depression (defined as GDS score of 11 or more) on admission, but only 23.4% of these depressed patients had been prescribed antidepressants on discharge by their hospital doctors (who had not been made aware of the research findings for individual patients). Patients who were depressed were slightly (but not statistically significantly) more likely to be female and to be aged 75 or older.

Most patients reported that they had been independent in ADL prior to admission, with only 19.8% reporting more than one ADL with which they had needed assistance. IADL dependency was more prevalent: 70% of patients had required assistance with more than one IADL prior to admission, 42.6% had required assistance with two to four IADL, and 26.4% had required assistance with five or more IADL.

A series of univariate analyses followed by logistical regression revealed that self-reported pre-admission functional status and depression were significantly correlated in this group of acutely ill elderly patients. These two factors were also independently predictive of medical outcome on the MOS at 1 month. Dunham and Sager concluded that in order to improve medical outcomes, depression should be screened for and pre-admission level of function recorded, as a matter of routine.

Sager, Franke et al. (1996) published another outcome study based on the HOPE data in which elderly patients' functional outcomes at discharge from hospital, and three months after discharge, were compared with baseline level of functioning (two weeks before the admission). As in the Dunham and Sager (1994) analysis, six self-reported ADL and seven self-reported IADL were studied, for 1279 patients aged 70 or older (with a mean age of 79). Mental status was assessed on admission using an abbreviated Folstein mini mental status examination or MMSE (Folstein, Folstein, & McHugh,

1975). It was modified for acutely ill medical patients by the removal of the language tasks requiring motor activities (eg. 'write a sentence'). This modified version had been validated and found to be highly correlated with the original test.

At discharge from hospital 32% of the elderly patient group reported a decline in one or more ADL functions since the pre-admission baseline, 59% reported no change, and 10% reported an improvement. Of those patients who reported a decline, 40% reported a decline in three or more ADL. ADL decline was found to be predictive of death, and (among survivors) of re-hospitalisation and institutionalisation, in the three months following the index discharge.

Three months after discharge, 73 patients were unavailable for follow-up or had incomplete data, and 134 (11% of those still in the study) had died, leaving a study group of 1072. At this point, 19% reported a decline in ADL function since the pre-admission baseline, 70% reported no change, and 11% reported an improvement. Change in IADL function was also investigated: 40% reported a decline in one or more IADL since the pre-admission baseline, 38% reported no change, and 22% reported an improvement.

Logistical regression revealed that predictors of loss of independence in at least one ADL function during the index hospital admission were female gender, greater age, a longer hospital stay, a diagnosis of cancer, and lower baseline IADL scores. Loss of ADL function at three-month follow-up was predicted by greater age (85 years or older), lower baseline IADL scores, and a lower mental status score on admission. Decline in ADL function between discharge and follow-up was predicted by ADL decline during the index admission, and by re-hospitalisation after discharge. Loss of IADL function at the three-month point was more common than loss of ADL function,

and it was predicted by age (75-84), lower mental status score on admission, loss of ADL function during the index admission, and re-hospitalisation after discharge.

Sager, Franke et al. had expressed some reservations about the validity of self-report measures in this context, particularly because elderly patients during a hospital admission were not necessarily required or allowed to perform all ADL unassisted, and so they might not be aware of their current level of functioning. A preliminary analysis (Sager et al., 1992) had indicated some discrepancy between elderly hospital patients' self-report of their ADL functioning and the results of a formal assessment by an occupational therapist using the Functional Independence Measure (FIM). The FIM is widely used in rehabilitation settings (Granger, Hamilton, Keith, & et al., 1986) and measures two constructs: physical functioning and 'social cognition'; comprehension, expression, social interaction, problem solving and memory (Lysack, Neufeld, Mast, MacNeill, & Lichtenberg, 2003). Despite this possible discrepancy between self-report and formal assessment, Sager, Franke et al. observed, their findings were consistent with those of other studies. Also, self-reported decline in ADL functioning predicted more objectively measurable events such as death, re-hospitalisation, and admission to residential care.

Sager, Franke et al. (1996) concluded that their study had identified a vulnerable subgroup of elderly hospital patients at increased risk of developing new disability, which in turn was predictive of death, re-hospitalisation and institutionalisation. They noted that these patients were generally older, with lower cognitive functioning on admission and more reported difficulty with IADL, and that this patient profile was 'consistent with current concepts of frailty' (p. 650).

Subsets of the HOPE data were then used (Sager, Rudberg et al., 1996) to develop and validate an instrument (the Hospital Admission Risk Profile or HARP). This was based on data that would be readily available at the time of the patient's admission to hospital, and would allow clinicians to identify patients at risk of a decline in ADL function during the admission. Patients' HARP scores were based on their age, their scores on the abbreviated MMSE, and the number of IADL they reported having been able to perform without assistance two weeks before the index admission.

For a selected subgroup of patients (who were not admitted from residential care and did not require surgery, and who survived three months after admission), the HARP was found to be moderately predictive of risk of ADL decline. Some of the remaining variation in functional outcome was predicted and explained by length of the index hospital stay. For each HARP category, patients who had longer hospital stays also had worse functional outcomes. The authors observed that although the HARP measured relevant characteristics of the individual patient, length of stay might be a proxy for other variables which could also influence functional outcomes. These included the nature and severity of the acute medical illness, the de-conditioning and/or iatrogenic illness which can occur in long hospital admissions, and the process of treatment. They concluded that the HARP was a simple and practical indication of a patient's "underlying physiological reserves and, thus, the ability to withstand the stress associated with acute illness and hospitalization in a given patient" (Sager, Rudberg et al., 1996, p.256). The HARP would be most useful in identifying which patients were most likely to require formal rehabilitation and/or comprehensive discharge planning at the end of the admission.

Next, Rudberg, Sager and Zhang (1996) analysed a subset of the HOPE data, using logistic regression, in search of risk factors for nursing home use after the index admission. They found that 8% of their 1265 patients (all of whom had survived the hospital admission and had not been admitted to hospital from a nursing home) were discharged to a nursing home after the index admission. These patients were older and were more likely to be White and to have been living alone prior to admission. They had also had longer index hospital admissions. They had lower pre-admission ADL scores, and were more likely to have had a decline in ADL (but not more likely to have had a decline in IADL) during the period of measurement. They were more likely to die within three months after discharge (18% of the nursing home group died within this period, compared with 10.4% of the whole sample). Nevertheless those who were discharged to nursing homes and survived for three months did not all remain in nursing homes. By the end of three months 39% had left their nursing homes and only 43% remained there.

Rudberg, Sager and Zhang observed that those patients who had been discharged to nursing homes were the oldest and sickest of the group, but even they did not all require permanent nursing home care. Conversely some of the HOPE study patients who had initially been discharged home or into lower level care settings had died, or had been admitted to nursing homes, during the three months after discharge. This was thought to reflect the complex and fluid nature of transitions between home, hospital and residential care during this period in the life of a frail elderly person. The authors concluded that a functional decline in ADL was a marker for risk of nursing home admission. However decline in IADL was not a marker, perhaps, they thought, because

support with IADL could be provided in the patient's home by formal agencies or informal carers, and a residential care setting was not required.

Again using logistic regression, Inouye, Rushing, Foremen, Palmer, and Pompei (1998) analysed another subset of the HOPE data. This study aimed to ascertain the contribution of delirium on admission to four outcome measures at discharge and at three-month follow-up.

Inouye, Rushing et al. examined the outcomes of 727 elderly patients (with a mean age of 78.9, SD 6.9), of whom 60% were female, 68% were white, 41% had been living alone prior to the index admission, and only 4% had been admitted from a nursing home. They used their own Confusion Assessment Method (CAM) instrument (Inouye et al., 1990). The diagnostic criteria for delirium were inattention, acute onset, fluctuating course, and either disorganised thinking or an altered level of consciousness. The outcome measures were death, new nursing home placement, death or new nursing home placement, and decline in ADL.

Both on discharge and at three months, Inouye, Rushing et al. found a significant association between delirium on admission and new nursing home placement, death or new nursing home placement, and decline in ADL. This was independent of age, gender, dementia, illness severity, and baseline ADL and IADL scores. They did not find an association between delirium on admission and death alone, but noted that there had been a small number of deaths and a limited power, so that firm conclusions could not be drawn. They proposed that delirium on admission was not only a marker for poor prognosis, but an independent determinant of patient outcome.

Inouye, Peduzzi, et al. (1998) published a risk-adjustment study designed to utilise measures of cognition, depressive symptoms and IADL functioning, in order to predict

the 90-day and 2-year mortality of elderly hospitalised medical patients. Introducing their prospective cohort study, the investigators commented that functional status measures had been shown to be strong and valid predictors of patient outcome, more so than diagnoses or diagnosis-related groupings (DRGs) or other standard measures of medical burden. Despite this finding, functional measures were not usually incorporated in the 'burden of illness' indices used by government agencies, funding bodies and consumer groups when examining outcomes.

After reviewing previous studies, Inouye, Peduzzi et al. selected 10 variables related to patients' functional abilities for potential inclusion in their model. These fell into three categories: 'physical' (any ADL impairment, any IADL impairment, any mobility impairment), 'cognitive' (delirium at baseline, score of less than 20 on Folstein MMSE, score of 4 or more on the modified Blessed Dementia Scale (Uhlmann, Larson, & Buchner, 1987) derived from a family interview), and 'other' (vision impairment, hearing impairment, score of 7 or more on the shortened Geriatric Depression Scale (Sheikh & Yesavage, 1986)). The outcome measures were death at 90 days and death at 2 years. This information was ascertained from telephone interviews in the first instance, and confirmed using hospital records and state records.

Inouye, Peduzzi et al. used a development group of 207 participants aged 70 and over (mean age 79.0, SD 6.0, 59% being female, 91% being White, 43% being married, and 7% having been admitted from a nursing home). They undertook a series of analyses designed to reduce the number of variables, and to select those variables which were independent and predictive of outcome and which met a number of a priori criteria (including increased relative risk, prevalence in the sample, and clinical relevance). Backward elimination was used to select the final set of three variables (any IADL

impairment, MMSE score of less than 20, and short GDS score of 7 or more) which the investigators described as a 'functional axis', noting that there was one physical function variable, one cognitive function variable and one 'other' variable (depression). The predictive value of the functional axis was tested by dividing the patients in the development sample into three groups, members of which had been classified, on the basis of the three variables as being at low, medium or high risk of mortality, and comparing their mortality statistics at 90 days and two years. There was close matching of observed and predicted survival rates in the three groups, and the C statistic for the final model was 0.69.

Inouye, Peduzzi et al. tested and validated their risk stratification model on another group of 318 participants aged 70 and over: mean age 79.6 years, SD 6.0, with 54% being female, 91% being white, 49% being married, and 7% being admitted from a nursing home. They did not differ significantly from the development group on any of these variables. A χ^2 procedure indicated that the model was effective in differentiating between groups at low, medium and high risk of mortality ($p < .001$), and there was close matching of observed and predicted survival rates in the three groups.

Next, the investigators tested the contribution of their functional axis to the prediction of mortality, by combining it with each of five well-known 'burden of illness' indices and evaluating the improvement in predictive accuracy, at 90 days and at two years. The five selected 'burden of illness' indices were the Charlson Index (Charlson, Pompei, Ales, & MacKenzie, 1987), the APACHE II Index (Knaus, Draper, Wagner, & Zimmerman, 1985), the Disease Staging score (Fields, MacKenzie, Charlson, & Perry, 1986), APR-DRGs (Edwards, Honemann, Burley, & Navarro, 1994), and a nurse's severity rating modified from Charlson's procedure (Charlson et

al., 1986) in which on admission the patient's primary nurse was asked to rate illness severity as either high, or low-to-moderate. A series of χ^2 analyses revealed that in both the development cohort, and in the validation cohort, addition of the functional axis significantly improved the prediction of mortality at 90 days and two years, for each of the five selected 'burden of illness' indices. Moreover, the contribution of the functional axis was independent of the contribution of each of the main measures.

Inouye, Peduzzi et al. concluded that they had identified a valid predictive model, based on three measures from three distinct areas of patient functioning (any IADL impairment, a cognitive score, and a depression score). They suggested that as both function and "burden of illness" were independently predictive of mortality in elderly hospital patients, measures aimed at risk adjustment should include both domains.

Desai, Bogardus, Williams, Vitagliano, and Inouye (2002) used data from a subset of the HOPE study to develop a risk-adjustment index for elderly inpatients admitted to a hospital general medicine service. Their aim was to predict mortality within 12 months of the index hospital admission date, based on discharge diagnosis.

The development sample consisted of 524 patients aged 70 or over, admitted consecutively to the general medical service of a teaching hospital between 1989 and 1991. Patients had a mean age of 78.7 years (SD 6.1) and a mean MMSE score of 22.7 (SD 6.5). Most were White (91%) and female (56%). Although 33% were impaired in one or more ADL, only 7% had been living in a nursing home prior to the index admission. By the end of the 12-month follow-up period, 29% of the group had died, with 6% dying in hospital, 12% dying within a month of discharge, and 11% dying between 1 and 12 months of discharge.

The validation sample was a consecutive sample of 852 patients aged 70 or over, admitted to the same service between 1995 and 1998. Patients had a mean age of 79.7 years and a mean MMSE score of 23.5. Again, most were White (87%) and female (61%). Although 35% were impaired in one or more ADL, only 6% had been living in a nursing home prior to the index admission. By the end of the 12-month follow-up period, 23% of the group had died, with 2% dying in hospital, 7% dying within a month of discharge, and 14% dying between 1 and 12 months of discharge.

The risk index was based on summation for each patient of the presence or absence of each of 10 'high-risk' medical diagnoses, weighted respectively by 1 (pneumonia, diabetes mellitus with end-organ damage), 2 (congestive heart disease, cardiomyopathy, chronic obstructive pulmonary disease, chronic lung disease, major stroke with hemiplegia, chronic renal failure), 3 (cancer – localised solid tumour or metastasised), 5 (acute renal failure) or 6 (lymphoma, leukaemia). The list did not include dementia. Mean scores were 1.9 for the development cohort (range 0-14) and 2.0 for the validation cohort (range 0-16). The index was found to predict 12-month mortality effectively, with a C-statistic for logistic regression (continuous model) of 0.69, and more effectively than some other published methods such as APR-DRGs (Edwards et al., 1994) and the Deyo-adapted Charlson Medical Index or CMI (Charlson et al., 1987).

Desai et al. concluded that this index could be used to identify high-risk groups of patients who would benefit from early intervention or case-management, and to compare patient groups when treatment outcomes were being evaluated. It was acknowledged, however, that other medical conditions, such as malnutrition or

delirium, had a significant influence on patient outcome but were under-diagnosed in the hospital setting.

2.2.3 *The Michigan group: eight studies*

A group of Michigan rehabilitation academics (psychology, neuropsychology, occupational therapy and gerontology) based in Wayne State University (Lichtenberg) and Henry Ford Health System (MacNeill) has conducted a series of outcome studies. These aim to identify characteristics of elderly patients that can be measured during an admission for medical rehabilitation and are predictive of outcomes, particularly discharge destination and specifically patients' potential for returning home to live alone.

Their recent work has utilised the ecological theory of aging (Lawton & Nahemow, 1973) as a framework for examining adaptation to disability (specifically, rehabilitation outcomes). The theory (see Chapter 1) suggests that an individual's adaptation is determined by his or her competencies, by the level of environmental press (the demand placed on the individual by the physical and social environment), and by the interaction between individual competencies and the level of environmental press. The fit between competence and environmental press determines the individual's level of adaptation. As competencies decline, environmental press increases. Hence, the Michigan group has asserted that outcome research, which has tended to focus on characteristics (specifically competencies) of the individual patient, should also consider contextual variables.

Hanks and Lichtenberg (1996) compared levels of functioning and outcomes at discharge for four age cohorts of geriatric rehabilitation patients, respectively aged in

their 60's, 70's, 80's, and 90 and over. They used archival data from 812 consecutive patients aged 60 and over who had been admitted to a geriatric rehabilitation service (an in-patient rehabilitation program directly following a hospital admission) at a large teaching hospital.

Hanks and Lichtenberg noted that in previous research, for example outcome studies after stroke, age had not been considered to be a significant predictor of functional outcome. Functional score on admission had been viewed as a more useful predictor of eventual functional status. Using a number of χ^2 tests, analyses of variance (with Bonferroni corrections) and bivariate correlations, Hanks and Lichtenberg examined the relationship between age and various outcome measures. They hypothesised that within their group of rehabilitation patients, greater age would be found to be associated with greater medical burden, depression, and alcohol abuse, and with lower functional abilities and less independence in living status on discharge.

Their results confirmed a significant relationship between increased age and increased medical burden, decreased functional ability and decreased independence in living status on discharge. However increased age was not found to be associated with increased depression, and (when compared with age norms) alcohol abuse and cognitive impairment were relatively more common in the younger age cohorts than in the older age cohorts. Comorbid physical disease was also more common in the younger age cohorts.

Hanks and Lichtenberg found that their younger group of geriatric rehabilitation patients (aged in their 60's and 70's) had higher rates of comorbid disease than the older group, more cognitive impairment and alcohol abuse than their age-peers, and presumably reduced life expectancy. The older geriatric rehabilitation group (in their

80's and 90's) had a greater prevalence of cognitive impairment than the younger group (but no more so than their age-peers in the community), had similar rates of alcohol abuse to their age-peers in the community, and at discharge had lower levels of functional ability and independent living status than the younger group. Hanks and Lichtenberg acknowledged that longitudinal research would be needed to confirm the findings of the cross-sectional study. However, they suggested, it might be useful to consider rehabilitation patients in the geriatric age-range as two separate sub-populations with different clinical issues.

MacNeill and Lichtenberg (1997) conducted a retrospective study of 372 geriatric rehabilitation patients aged 60 or more, all of whom had been living alone prior to the index admission. At the end of the admission 39% had returned home to live alone, but 61% were discharged to residential care or the care of family members. MacNeill and Lichtenberg noted that “the primary goal of medical rehabilitation is physical independence with self-care tasks (ADL)” (MacNeill & Lichtenberg, 1997, p. 755) but that this goal might be problematic for older patients, due to the higher frequency of cognitive impairment, chronic illness, and medical complications. The authors observed that for elderly people who had been living alone, a return to independent living after medical rehabilitation required the ability to resume basic ADL, and some IADL such as cooking, financial management, and medication use. As well as requiring a range of physical skills, these activities also required motivation, cognitive skills, and an adequate level of general health and physical fitness.

Hierarchical logistic regression identified two significant predictors of being discharged home alone. The total FIM score on admission was the strongest predictor, followed by the score on the Mattis Dementia Rating Scale or DRS (Mattis, 1988). No

additional predictive contribution was made by demographic factors, diagnostic category or medical burden. Patients discharged home alone scored higher on the social cognition items (but not the motor items) of the FIM than did the other patients. As a group, those who were discharged home alone scored above the cut-off score of 125 on the DRS (mean score 126.9, SD 12.4), and hence appeared to have reasonable cognition, whereas those who were not discharged home had a mean score below the cut-off (mean score 118.3, SD 15.6).

MacNeill and Lichtenberg concluded that their results supported the importance of cognition in the rehabilitation of elderly patients, and the significance of cognitive status (and hence the usefulness of cognitive assessment) in the prediction of outcome. They acknowledged that other relevant factors in discharge planning, such as patient decision-making and environmental factors, had not been addressed in this study.

Asserting that the predictive value of depression and cognitive impairment had not been fully examined (despite their prevalence among medically ill older patients) Arfken, Lichtenberg and Tanner (1999) undertook a follow-up study of 667 consecutive patients aged 60 or older who had been admitted to a rehabilitation hospital, and calculated odds ratios for survival. Of these patients, 455 completed a set of three standardised measures: of cognition: – Mattis DRS (Mattis, 1988), depression - GDS (Yesavage et al., 1983), and disability - FIM (Granger et al., 1986). Mortality at 12 months was predicted by male sex, depression and cognitive impairment. This was independent of age, disabilities, and medical burden (Charlson Index (Charlson et al., 1987)), and there was no interaction between depression and cognitive impairment. Patients who had not completed the protocol in hospital were more likely to have died in the subsequent 12 months: 24% compared with 17%. Arfken et al. concluded that

depression and cognitive impairment independently predicted mortality in medically ill older people.

To validate the findings of MacNeill and Lichtenberg (1997), MacNeill, Lichtenberg, and LaBuda (2000) conducted a prospective study on another, similar, group of adults aged 60 or over who had been living alone prior to admission. They used a consecutive sample of 194 elderly patients admitted to the stroke and geriatric units of an urban rehabilitation hospital, of whom 85% were black, 72% were female, and 44% returned home to live alone. Logistic regression revealed that as in the previous study, cognition was “a significant predictor of return to living alone, above and beyond demographic characteristics, chronic medical illness, and self-care abilities” (MacNeill et al., 2000, p.361). The authors concluded that their results supported the inclusion of cognitive assessment in the discharge planning process for elderly patients. They emphasised the importance of accurate and empirically based assessment procedures, and the aggressive treatment of reversible causes of cognitive impairment, in older medical patients.

Next, Lichtenberg, MacNeill and Mast (2000) analysed 3 and 6 month follow-up data for the same patients. Using path analysis they found that three “personal competency variables” (cognition, medical burden and ADL functioning) were predictive of IADL functioning at 3 and 6 months. IADL functioning was in turn predictive of living arrangement at 3 and 6 months.

Lichtenberg, MacNeill, Lysack, Bank, and Neufeld (2003a) undertook another follow-up study of the same patients’ outcomes 6 months after their discharge from rehabilitation. They acknowledged that their research focused on personal characteristics (specifically competencies) of the individual patient, but that contextual

factors should also be considered. In terms of the ecological theory of ageing (Lawton & Nahemow, 1973) the current study examined only one part of the equation: the relationship between personal competencies and outcome.

Lichtenberg et al. (2003a) discussed the use of the use of “living alone” as an outcome measure, pointing out that despite the increasing number and proportion of elderly people who were living alone, studies of living alone lacked an underlying theoretical framework. There was some confusion about the meaning of living alone as an indicator of health status: “To date, living alone has either been characterized in the literature as an indicator of robust health or conversely as an indicator of extreme frailty” (p.37). Lichtenberg et al. suggested that this confusion might in part reflect the different samples of elderly people whose health was being studied. In population studies, those elderly people who lived alone had higher levels of functioning than those who did not. However, within clinical samples, living alone had been found to be a risk factor for poor health outcomes.

At the 6-month point, Lichtenberg et al. had data for 135 of their group of 194. Those who had died, become severely confused or been lost to follow-up had had, at baseline, lower levels of functioning and cognition and more medical burden. Otherwise they had resembled the main patient group, in terms of age, education, gender, race and depression.

Lichtenberg et al. hypothesised that there would be a linear relationship between functional competence and the timing of the return to living alone. To test this they divided their patients into four groups: those who were discharged home alone directly from the rehabilitation hospital (44%), those who resumed living alone within three months after discharge (30%), those who resumed living alone between three and six

months (10%), and those who had not resumed living alone six months after discharge (16%). When the baseline health and competency data for the four groups were compared using analyses of variance, there were only two significantly different groups. Those who returned to live alone within the first three months and those had been discharged straight home alone did not differ significantly in their baseline functional abilities, cognition, depression measured using the GDS (Lichtenberg, Marcopoulos, Steiner, & Tabscott, 1992; Yesavage et al., 1983), or medical burden, and these two groups were combined as the “early return” group. Similarly, those who returned home alone between three and six months did not differ on baseline functioning from those who had not returned home alone by the six-month point. These two groups were combined to form the “late return” group, which was found to have had lower baseline functioning than the early return group. Examination of eighteen-month follow-up data revealed that members of the late return group were also less likely than the early return group to be living alone at that point.

Logistic regression revealed that group membership (early return or late return) was significantly predicted by baseline FIM motor score and by medical burden, but not by depression. There was a trend ($\beta = -.03$, $p < .10$) for cognition to predict group membership. Lichtenberg et al. were able to use the resulting equation to predict group membership with 91% sensitivity, 70% specificity, 86% positive predictive power and 79% negative predictive power.

Lichtenberg et al. (2003a) concluded that their data supported the application of the Environmental Theory of Ageing (and specifically the use of personal competency variables to predict outcome) in the rehabilitation of elderly patients, and also the importance of the concept of frailty, defined as having impairment in more than one

area of functioning. They noted that components of frailty (such as cognition, functional abilities, and comorbid diagnoses) might be better predictors of outcome for this patient group than their major medical diagnoses (eg. hip fracture or stroke). Patients who were frail were less likely to return home alone, either at discharge from hospital or later. If they did return home alone, they were less likely to maintain this status over time. Lichtenberg et al. suggested that rehabilitation psychologists should advocate for interdisciplinary collaboration, and the integration of functional, cognitive and medical assessments, in discharge planning for elderly rehabilitation patients.

Lysack and others from the Michigan group (Lysack, MacNeill, & Lichtenberg, 2001; Lysack et al., 2003) published 6-month and 18-month follow-up data for 125 female patients, for whom they had complete data, from the same longitudinal project. Almost all of the group were Black. Lysack et al. found that the FIM motor score improved throughout the index admission and was predictive of living status at 6 months, at which point those who were living alone reported higher ADL and IADL competencies than did those who were not living alone. A logistic regression procedure revealed that at 18 months, living alone status was independently predicted by FIM motor score, cognition (Mattis DRS score), and medical burden. Once these variables had been considered, there was no predictive effect of depression (GDS score), age, race, education, or length of index admission.

Mean self-reported IADL scores for those who were living alone were considerably higher than for those who were not, raising the possibility that this was a significant mediating variable in determining living status. Path analysis demonstrated that FIM, cognition and medical burden all contributed to IADL scores at 18 months, and once IADL score at 18 months was entered into the equation, there was no

significant effect of the clinical variables. It was concluded that the relationship between the three significant clinical variables and living situation at 18 months was mediated by IADL functioning. Lysack et al. concluded that in addition to formal cognitive assessment by psychologists, formal assessment of IADL skills by occupational therapists could be useful in discharge planning and the prediction of patient outcome. They noted, however, that some elderly women with very low IADL scores were living alone at 18 months. They concluded that these individuals might have been receiving considerable assistance from formal and informal support services, and/or that they might have been at some risk of death or a change in living situation.

Lysack et al. (2003) acknowledged that they had not been able to measure environmental variables such as the level of support provided by the family and the community, and that their definition of living alone, as being the sole resident of the home, did not take these variables into account. They went on to acknowledge that, although as a group, elderly people have been found to prefer discharge home to discharge elsewhere, living alone might have different meanings for different people. It might have been a preferred choice for some, but an economic necessity for others. In the funding system operating in the USA, elderly people who are indigent and receiving welfare funding through the Medicare system (Kayser-Jones, 1990), or who have private insurance, are more likely to take up residential care than are elderly people who are uninsured and must pay for residential care themselves (Cox & Verdieck, 1994). Lysack et al. recommended that future research should explore the meaning of place for elderly people from various backgrounds, and the relationship between functional independence and people's strong feelings about living alone.

Using their original sample of 194 patients (MacNeill et al., 2000), Mast, Azar, MacNeill, and Lichtenberg (2004) attempted to identify baseline data which predicted re-hospitalisation in the 18 months after the index admission. They observed that geriatric rehabilitation facilities had undergone significant changes in the previous decade, with shorter admissions and a higher level of patient frailty, so that patients were being discharged “sicker and quicker” than in the past (Mast et al., 2004, p. 222). Predicting and preventing re-admissions had become more salient. The investigators contacted patients at 3, 6 and 18 months (at which points 157, 167, and 140 patients, respectively, were available for phone interview) and asked about hospital re-admission in the preceding 3 or (at the 18 month follow-up) 12 months. Re-hospitalisations were reported as follows: 25.5% of patients had been re-hospitalised between 0 and 3 months after discharge, 16.0% of patients had been re-hospitalised between 3 and 6 months after discharge, and 25.5% of patients had been re-hospitalised between 6 and 18 months after discharge.

Logistic regression was used to examine whether re-admission during each of these periods was predicted by one or more of the following clinical characteristics at baseline: ADL functioning - FIM score, cognitive functioning - Mattis DRS score, depression - GDS score below the cut-off score of 10, and/or medical burden - Charlson Index (Charlson et al., 1987). Re-admission was found to be predicted by baseline ADL limitations in the first 3 months, and by baseline depression in the period from 3 to 6 months. No baseline clinical characteristic predicted re-admission in the period from 6 to 12 months. Although there was a trend indicating that patients with higher medical burden might be more likely to be re-admitted during the period from 6 to 12 months, the effect was not statistically significant ($p=0.08$).

Mast et al. concluded that short-term prediction of re-admission was more feasible than long-term prediction. They also concluded that depression, not always considered as a potential predictor of patient outcome, deserved more attention in outcome studies, and in clinical discharge planning by rehabilitation psychologists and other members of multidisciplinary teams.

2.2.4 Fifteen studies by other investigators

Incalzi et al. (1992) undertook a prospective outcome study of 178 patients aged 70 and over, consecutively discharged from a teaching hospital in Rome. Their aim was to predict patients' death or disability in the following year, based on an assessment before discharge. Their measures were demographic (age, sex, living arrangement); medical (primary diagnosis, concomitant diagnoses, and number of medications used); and functional (cognition - Folstein MMSE score, with a cut-off point of 24; affective state - GDS score, with a cut-off point of 14; and ADL disability). Patients were classified as either fully independent in 6 basic ADL, dependent in 1 to 5 ADL, or dependent in all 6 ADL.

The mean age of patients in the study was 75.6 (SD 13.1), and 52% were female. Most were discharged home, either to live with a partner or relative (77.5%) or alone (7%). However Incalzi et al. observed that this low level of discharge to residential care reflected an under-supply of nursing home beds in Italy and so it did not imply a high level of function on discharge. Indeed, at discharge 20% of patients had required assistance with all 6 ADL, and another 36% had required assistance in 1 to 5 ADL. Depression was found in 22% of patients, and cognitive impairment in 11%.

The outcome measures were death within 12 months and, for survivors, ADL disability classification (re-assessed at 12 months) and self-reported (or proxy-reported if the patient was unable) health service usage during the 12 month period after discharge. Incalzi et al. found that at follow-up, 19% of the group had died and of the survivors, 4% were living in a nursing home and 3% were in a hospital. The ADL disability classification was unchanged for 42% of the original group, better for 23%, and worse (death or increased ADL dependence) in 35%. Logistic regression revealed that death within 12 months of discharge was predicted by baseline ADL dependence, by a diagnosis of cancer or cardiovascular disease, and by high medication use. Increased physical dependency or death was predicted by baseline ADL dependence, and by a diagnosis of cancer or cardiovascular disease. Among those who survived 12 months, increased physical dependency was predicted by the same variables, but less strongly.

Incalzi et al. concluded that their assessment provided a simple method for identification of elderly patients at risk of poor outcome, and that ADL function was a valid and important prognostic indicator, independent of medical diagnosis. It had not been possible to predict health service usage from baseline data, perhaps in part, Incalzi et al. concluded, because the relationship between need and health service usage in this sample was mediated by enabling factors such as the limited health services in the region (there were minimal secondary and tertiary geriatric services, and most of the post-discharge health care had been provided by general practitioners), and the availability of family members or others to help elderly people attend health services.

Some members of this research group proceeded to a study of the prognostic utility of comorbidities in predicting elderly hospital patients' likelihood of dying

during the index hospital admission (Incalzi et al., 1997). Pointing out that comorbidities were common in the elderly, they asserted that, rather than excluding patients with comorbidities from outcome studies and evaluation research, it was appropriate to measure comorbidities in a valid and reliable fashion and to study their impact on outcome. In this study they used retrospective data from 370 elderly people (aged between 70 and 90) consecutively admitted to the general medical and geriatric wards of a teaching hospital. The aim was to develop an index of comorbidity, establish whether an index based on the interaction between age and comorbidity had more prognostic value than an index of comorbidity alone, and to test whether the resultant indices were useful in prognosticating, more so than existing models based on specific indicators of health status (for example malnutrition).

Measures included age, sex, simplified pre-admission ADL score (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), MMSE score (Folstein et al., 1975), nutritional assessment (Incalzi, Landi, Cipriani, & et al., 1996), body mass index, and blood measures (haemoglobin concentration, serum albumin and lymphocyte count).

Comorbid conditions (including the diagnosis which had caused the admission), were recorded. Each condition was allocated a weight, based on a scoring system developed in-house through an analysis of the mortality rates of 500 previous elderly patients admitted to the same wards. The comorbidity index for each individual patient in this study was obtained by adding the weights of all his or her comorbidities. The age-comorbidity index was obtained by adding two points to the comorbidity index for patients aged 76-85, adding three points to the comorbidity index for patients aged 86-95, and adding four points to the comorbidity index for patients aged over 85. The outcome measure was death in hospital during the index admission.

Patients were found to have a mean age of 78.7 years (SD 5.9), a mean comorbidity index of 3.8 (SD 2.1) and a mean age-comorbidity index of 5.3 (SD 2.4), with 55% being female, 28.9% having been dependent for at least one ADL prior to the index admission, 21.0 having a MMSE score of less than 21, and 18.4% having a severely impaired nutritional status. The majority (341 patients) survived the index admission, but 29 individuals (7.8%) did not.

Using a logistic regression procedure Incalzi et al. (1997) found the independent predictors of death in hospital to be a clinical diagnosis of malnutrition, the age-comorbidity index, lymphocytopenia (a low level of white blood cells) and pre-admission dependency in at least one ADL. This group of predictors produced the best prediction of mortality. Using the same group but substituting the comorbidity index for the age-comorbidity index was slightly less effective. If neither index was used, the best predictors available (a clinical diagnosis of malnutrition, pre-admission dependency in at least one ADL, lymphocytopenia, and low albumin level) gave a goodness-of-fit coefficient of 0.492. The authors concluded that their study established a clear relationship between mortality and burden of disease in the heterogeneous geriatric population. They suggested that the age-comorbidity index could be used to stratify elderly patients in research trials and when evaluating and costing their care.

Francis and Kapoor (1992) reported on the utility of delirium (specifically, its occurrence at any time during the index admission) as a predictor of two-year outcome, using a consecutive sample of 229 elderly patients (aged 70 or older) admitted to the general medical service of a teaching hospital. The study was restricted to patients who had been living in the community before the index admission, had not required assistance with more than one ADL prior to admission, and did not have terminal

illness, severe dementia, or inability to communicate. Francis and Kapoor hypothesised that the occurrence of delirium at any point in the admission would be predictive of higher levels of mortality and morbidity, and of reduced ability to live independently (which they defined as living outside an institution and requiring support in no more than one of four basic ADL: bathing, eating, dressing and transfers). They assessed patients every 48 hours for delirium, using DSM-III-R criteria (American Psychiatric Association Committee on Nomenclature and Statistics, 1987), and found that 50 patients met criteria for delirium on at least one occasion during the index admission.

At two-year follow-up, information was available for 45 of the 50 patients who had had delirium (defined by the investigators as cases, with a mean age at admission of 78.9 years, SD 6.1), and for 160 of the 179 patients without delirium (defined by the investigators as controls, with a mean age at admission of 77.7 years, SD 5.6). On admission there had been no significant difference between cases and controls for age, gender, race, marital status or severity of illness. However, those who were delirium cases had had worse cognition in the 6 months prior to admission (as reported by caregivers), did not perform as well on the Folstein MMSE during their admission, and were more likely to have required ADL assistance at baseline.

At two-year follow-up, 39% of delirium cases and 23% of controls had died. Relative risk for mortality, estimated using the proportional-hazards model, was 1.82 (95% confidence interval 1.04-3.19). Exploratory analyses revealed that pre-admission cognitive impairment and ADL dependence were strong independent predictors of mortality, as was a diagnosis of cancer, and once these were entered into the model, delirium no longer had an effect. Long-term survival was not predicted by age, sex, race, marital status, other medical diagnoses or severity of illness.

Only 35% of cases, and 64% of controls, were living independently (as defined above). Relative risk for loss of independence, estimated using the proportional-hazards model, was 1.82 (95% confidence interval 1.31-2.53). Logistic regression revealed that the strongest predictors of independent living situation were age, marital status, cancer and delirium.

Francis and Kapoor were only able to conduct follow-up cognitive assessment (modified Folstein MMSE administered over the telephone) on 11 of their delirium cases and 81 of their controls, the attrition being due to death, residential placement, and inability to use the telephone. The individuals who underwent testing differed from the main follow-up sample in having higher baseline levels of cognitive functioning and less likelihood of a diagnosis of cancer. A repeated measures analysis, adjusting for age, sex and pre-admission cognitive level, indicated that delirium cases were significantly more likely ($p=.023$) to have had a decline in cognition (assessed using the MMSE) over 2 years than controls.

Francis and Kapoor concluded that although their sample was small and their measures limited (for example, their use of self-reported ADL dependence), they had been able to show that delirium in this study, although not an independent predictor of mortality, was an independent predictor of cognitive decline and of decline in the ability to live independently. As such, they concluded, delirium should be considered a marker for the need for comprehensive geriatric assessment, intervention and/ or monitoring of outcome.

In their study (Rock et al., 1996) of 250 randomly selected elderly patients aged 65 or over, admitted to a large teaching hospital in New York between January and May 1993, a social work group aimed to develop a method for predicting, early in the index

admission, which patients were likely to be classified as “alternate level of care” (ALC) patients. These were patients who, because of delays in their discharge planning, could not be discharged at the end of their acute illness. The measures, which were administered in an interview early in the admission, included age, gender, ethnic group, living arrangement, diagnostic category, Katz ADL Scale (Katz et al., 1963), an IADL measure (Lawton & Brody, 1969), and the Short Portable Mental Status Questionnaire or SPMSQ (Pfeiffer, 1975). Stepwise logistic regression revealed that lower ADL score and lower IADL score were both predictive of ALC status. ALC status was found to be highly correlated with actual length of stay in hospital (LOS). A second logistic regression procedure revealed that LOS was predicted by having a lower ADL score and by not living with a spouse.

Rock et al. (1996) concluded that in predicting patients’ needs at discharge, the impact of the illness on a patient’s functional status was more important than the exact nature of the illness. Hence the medical diagnosis, although necessary, was not sufficient, and functional status measures had administrative as well as clinical significance. It was concluded that ADL and IADL measures should be administered routinely in the emergency department, and that admission of members of this patient group to an acute geriatric inpatient unit for rehabilitation might improve outcome and reduce length of stay.

With the aim of developing a case-mix measure which could be administered to elderly patients on an admission to a geriatric medicine unit, and would predict length of stay, resource utilisation and patient outcome, Dunstan, Amar, Watt and Seymour (1996) undertook a pilot study (n=202) in Birmingham, UK followed by a validation study. They sought to devise and validate a measure which would be simple to

administer but, because it included a measure of function, would have more predictive value than complex case-mix measures which were based on administrative data alone and designed for the purpose of reimbursement, such as Diagnostic Related Groupings (DRGs), Health Related Groupings (HRGs), or Resource Utilization Groups (HUGs), (Soderlund, 1994).

Two domains were assessed, the first domain being presenting illness. This was classified as: acute but not potentially disabling (eg. acute chest infection); acute and potentially disabling (eg. stroke); exacerbation of an existing disability; or chronic disability. The second domain was functional status, based on a combination of the patient's scores on the Abbreviated Mental Test or AMT (Hodkinson, 1973) and the mobility item from the Barthel scale (Mahoney & Barthel, 1965). A potential third domain – previous support received – was abandoned, as it was found to overlap significantly with the functional status domain.

In the pilot study, associations between the two domains were tested using the Mann-Whitney test, and associations between the two domains and outcome categories (discharged home / discharged elsewhere / died in hospital / still in hospital after 90 days) were tested using a χ^2 analysis. Acute and non-disabling illness and a high level of function were both associated with discharge home, whereas immobility was associated with mortality, and the combination of confusion with mobility was associated with not being discharged home.

The results of this pilot study by Dunstan et al. (1996) suggested that a simple coding system could be used to predict outcome and resource utilisation. Patients scored zero for an acute but not potentially disabling illness, and one for any other illness. They scored 0 if they had scored 7 or more on the AMTS and had also scored 4 or more on

the Barthel mobility item (i.e. mobile without human aid), otherwise they scored 1. These two scores were summed to give the CMIX score which had potential values of 0, 1 or 2.

This coding system was applied to the validation group of 400 patients (aged 65 or over, gender and mean age not specified but more than half the group was aged 75-84) from the acute geriatric units of two UK hospitals - Birmingham (n = 200) and Rhymney Valley (n = 200). A series of univariate and multivariate analyses revealed that length of stay and discharge destination were both predicted by presenting illness, functional status and CMIX score, and that these simple predictor scores explained 20% of the variance. Age and sex did not contribute additionally to the accuracy of the prediction. Dunstan et al. acknowledged that, as suggested in the literature, there might be other factors predictive of outcome and resource consumption, such as continence, admission route, and particular medical conditions such as hemiplegia. Nevertheless they felt that the CMIX might have utility in comparing groups of patients for purposes such as audits.

The CMIX scoring system was subsequently tested in a similar patient group (all aged over 65, mean age 82 years, half of the group being aged 75-84) admitted to acute geriatric medicine beds in a hospital in Zaragoza in Spain (Perlado, Midon, & Mesa, 1999). Perlado et al. noted that in Spain, as in the UK, the audit tool for hospital length of stay was the DRG. They reported findings very similar to those of Dunstan et al., observing that once the illness and functional domains had been coded, age and sex were not additionally predictive of length of stay. They concluded that the CMIX was usable in a different health system, had promise as an audit tool, and was reasonably effective in predicting individual patients' outcomes.

Covinsky, Justice, Rosenthal, Palmer and Lande (1997) expressed similar concerns that in evaluating hospital mortality rates or resource use, case-mix was largely assessed on the basis of medical diagnoses and comorbidities, or on vital signs and the results of laboratory measures. It had been well established that measures of function (physical, emotional and cognitive) were useful in the prediction of prognosis and resource usage, and yet these measures were not being used to improve case-mix measures or the prediction of patient outcomes

Covinsky et al. analysed data from 823 elderly patients aged over 70, with a mean age of 80.7, admitted to the general medical service of a teaching hospital in Cleveland, Ohio. Of their patient group, 68% were female, 40% were African-American, 40% were living alone, 36% were married, and 5% had been admitted from a nursing home. Covinsky et al. divided patients into four quartiles based on their levels, on admission, of ADL independence (dependent in either none, one to three, four to five, or six of the following ADL: bathing, dressing, grooming, transferring, eating and toileting). They controlled for age, sex, and race, and for illness severity using the Acute Physiology Score (APS) from the APACHE II admission instrument (Knaus et al., 1985) and the Charlson Comorbidity Index (Charlson et al., 1987).

Logistic regression revealed that ADL functional status strongly and independently predicted mortality (in hospital and at one year) and nursing home use (within 90 days of discharge). Controlling for DRG cost weight as well as the variables above, a linear regression procedure revealed that ADL function also independently predicted hospital cost. ADL function predicted mortality better than either APS or Charlson scores, and when combined with either or both of these scores, ADL function significantly improved their predictive ability.

When covariates were examined, it was found that higher hospital mortality was also predicted by APS, Charlson score and female gender. Mortality at one year was also predicted by APS and Charlson score. Nursing home use within 90 days was also predicted by age. Hospital cost was also predicted by admission from a nursing home, white race, and APS score. In summary, Covinsky et al. found that their measure of ADL function could be used to classify elderly hospital patients into categories of risk for poor outcome and/or high resource usage. This remained the case even when standard illness measures were controlled for (a strength of this particular study). They also concluded that case-mix and other predictive systems would be improved by the inclusion of ADL measures. They suggested that ADL functioning was predictive of outcome because rather than measuring the illness itself or its direct impact on physiology, it was a measure of the impact of the illness on the individual as a whole, and on that person's ability to function.

Alarcon, Barcena, Gonzalez-Montalvo, Penalosa, and Salgado (1999) conducted a follow-up study of 353 elderly patients admitted to the geriatric ward of a Madrid teaching hospital (mean age 81.8 years, SD 7.2, range not stated). They attempted to identify which, if any, components of the geriatric assessment on admission might be predictive of length of the index admission, death during the index admission, or discharge from the index admission to residential care (for those patients who had been living in the community). They also used 6 month follow-up data to ascertain which components might be predictive of longer-term outcome, that is; death, re-admission to hospital, new admission to residential care, or attendance at the hospital emergency department, in the 6 months after discharge from the index admission.

Alarcon et al. recorded patient age, sex, referral source (mostly from the hospital emergency department), main diagnosis, comorbidities, and medications on admission. They assessed ADL using the Spanish version of the Barthel Index (Mahoney & Barthel, 1965) and the Red Cross Hospital Functional Disability Scale or RCF (Guillen & Garcia, 1972), which included pre-admission level of functioning as well as current level of functioning. They assessed cognitive functioning using the Spanish version of the Short Portable Mental Status Questionnaire (Pfeiffer, 1975), and the Red Cross Hospital Mental Disability Scale (Guillen & Garcia, 1972) which included pre-admission mental state as well as current mental state. Patients were asked the amount of their pension, and with regard to the two months prior to admission, where they had been living (some were already in residential care), whether they had lived alone, whether they had had home help, and whether they had needed help with personal care.

A series of logistic regression procedures was undertaken. This revealed that death during the index admission occurred in 10.5% of cases, and was predicted by severe pre-admission functional impairment (on RCF), moderate to severe functional impairment on admission (Barthel score), and polypharmacy on admission. A prolonged hospital stay was predicted only by severe functional disability on admission, and not by expected variables such as polypharmacy, main diagnosis, comorbidities, or impaired function prior to admission.

Death during the six months after the index admission was predicted by moderate to severe functional impairment on admission (Barthel score), and by polypharmacy, malnutrition and/or pressure sores on admission.

New admission to residential care on discharge from hospital was predicted by severe functional disability on admission (RCF) score. New admission to residential

care within 6 months after discharge from hospital was predicted by severe functional disability on admission (RCF) score and also by cognitive impairment on admission and by lower income.

Alarcon et al. observed that the power of their study had been limited by the small size of the sample. They acknowledged that in addition to the need and enabling factors they had been able to measure in their study, admission to residential care in Spain was also significantly influenced by poverty, by cognitive and functional impairment, by living alone and by having no children. Nevertheless, they concluded, their findings supported the utility of a comprehensive geriatric assessment on admission, as predictive of death, discharge destination and events in the 6 months after discharge. In particular, they had found that on admission, ADL dependence and some conditions common among elderly people (malnutrition, pressure sores and polypharmacy) were the strongest predictors of outcome.

As part of a large prospective study of falls after leaving hospital, Hansen, Mahoney and Palta (1999) selected a cohort of 312 elderly patients (aged 65 or over), who had had a medical (i.e. not surgical or psychiatric) admission to an area hospital in Wisconsin, USA. The mean age of patients was 80.7 years, with 97% being white and 39% being married. Exclusion criteria included metastatic cancer, recent stroke or myocardial infarction, dementia (if living alone), non-ambulatory status, and inability to communicate in English.

Hansen et al. observed that decisions about living situation were often made on the basis that full ADL independence was necessary for independent living. Dependence in even one ADL could imply the need for home services or a move to residential care.

Hence the aim of the study was to ascertain predictors of return to full ADL independence within one month of discharge.

The selected patients had all been independent with ADL prior to hospital admission, but were not fully independent on discharge, and had had formal support with ADL (provided by a home health agency) arranged for them on discharge. Data obtained included medical diagnosis, comorbidities, medications used, length of hospital stay, involvement of a physiotherapist and/or occupational therapist in hospital. Patients (and significant others if required) were interviewed within 5 days of discharge concerning their pre-admission and current levels of mobility and ADL independence. Objective assessments was also undertaken, including assessments of vision, grip strength, balance, Folstein MMSE, delirium (using the Confusion Assessment Method (Inouye et al., 1990)), and a timed “Up and Go” task in which patients were asked to rise from a chair (using the arms if need be), walk 20 feet (using an assistive device such as a walking frame if required) and seat themselves again. One month after discharge, the interview concerning ADL independence was repeated.

Univariate analyses revealed that patients who had not recovered full ADL independence at one month were more likely to have used an assistive device for indoors mobility before the admission and to have been dependent in two or more ADL at discharge. At the post-discharge assessment, they were more likely to have been impaired in cognition, balance, and timed Up and Go performance. It appeared that difficulties in any of these areas represented a significant risk for persisting ADL dependence at one month, but that absence of these risk factors did not imply a good recovery. Although patients with one or more of these risk factors had a high probability

of persisting ADL dependence, about half of the patients without these risk factors also had persisting ADL dependence.

Sequential analyses and logistic regression revealed that those patients who were least likely to recover ADL independence were those who had an MMSE score less than 24, and who had used an assistive device for indoors mobility before the hospital admission. For those who had an MMSE of 24 or greater, and who had not used an assistive device prior to admission, simple physical tests such as balance or timed 'Up and Go' were effective in predicting poor recovery of functional independence.

Hansen et al. concluded that recovery of ADL function after a hospital admission required an adequate level of functioning in the domains of cognition and mobility. They acknowledged that other individual and environmental factors (such as affect, nutrition, living alone or with others, and sensory and upper limb functioning) might also be important to regaining ADL independence, but they observed that the small size of their sample had reduced the power of the study to detect such effects.

Using a new assessment instrument which had been internationally validated, the Minimum Data Set for Post-Acute Care (MDS-PAC), Landi, Bernabei, Russo, Zuccala, Onder and Carosella (2002) studied 244 elderly people in the aftermath of acute illness. The patients were admitted consecutively to an intensive rehabilitation program within a teaching hospital in Rome. The aim of the study was to determine which aspects of patient medical and health status were predictors of functional gain during the rehabilitation program, using the MDS-PAC to record health status. The MDS-PAC included measures of cognition, communication, vision, mood, behaviour, social functioning, physical functioning (including ADL and IADL functioning), continence, nutrition, hydration, dental health, skin condition, disease diagnoses and medications.

The MDS-ADL scale had a correlation of 0.74 with the Barthel Scale, and involved rating the patient's performances between 0 (independent) and 7 (fully dependent) on each of 7 basic ADL: dressing, eating, toilet use, bathing mobility in bed, transfer, and locomotion. The MDS-CPS (Cognitive Performance Scale) had a correlation of 0.81 with the Folstein MMSE. Items included level of consciousness, memory, decision-making, feeding oneself and making oneself understood. Patients were classified as normal, moderately impaired or severely impaired.

Patients had a mean age of 76 years (SD 10), and a mean length of stay in the program of 45 days (SD 10). It was unclear whether all the patients had been community-dwelling prior to their acute illness, or whether some had been in supported accommodation or residential care. However, 39% had been living alone prior to the index admission. At the end of the rehabilitation program 28% were discharged home with formal home care services, 52% were discharged home without formal home care services, and 20% were discharged to a nursing home.

More than 50% of the patients were aged 75 or older, with cognitive impairment being more prevalent for those aged 85 or older: 17% of those aged 65 to 74, 16% of those aged 75 to 84, and 45% of those aged 85 and older. Prevalence of sensory impairment, urinary incontinence and pressure ulcer was also greater in the older age groups. Patients who were aged 85 or over and who had cognitive or sensory impairment were found to be the least likely to demonstrate improvement in ADL functioning during the rehabilitation program.

A multiple regression model was constructed, with an improvement of one or more points on the ADL scale as the dependent variable, and the potential predictors of improvement including: age, sex, comorbidity, cognitive function, delirium, depression,

pain, pressure ulcer, urinary incontinence and social support. In the multivariate model, only cognition remained as an independent predictor of poor rehabilitation outcome. Patients whose cognition had been rated as impaired were significantly less likely to improve in ADL functioning (odds ratio 0.36: 95% confidence interval 0.14-0.92).

Landi et al. observed that their results, which suggested that cognitive impairment predicted poor outcome in a physical rehabilitation program, were inconsistent with other studies which had shown that patients with mild to moderate dementia could benefit from physical rehabilitation programs, for example after hip fracture. However they acknowledged that the issue of rehabilitation for patients with dementia was controversial. They suggested that rehabilitation programs might need to design their interventions for people with dementia more specifically, for example by training patients within the familiar environment of home.

Introducing their outcome study of 233 elderly (aged 65 and over) Taiwanese medical patients and their family caregivers Shyu and Lee (2002) observed that the majority of such outcome studies had been conducted in the United States. Because of differences in ethnicity, health care systems, culture and social organisation, USA findings might not apply to Taiwanese patients. For example, only 9% of elderly Taiwanese people lived alone. Only 2% of their study sample had been living alone prior to the index admission, and only 8% had been resident in a nursing home, whereas 90% had been living with a family member. Shyu and Lee focussed on the determinants of the decision to utilise nursing home care, home care services, or no services at all, at the end of the index medical admission. They identified 63 elderly people who were to be discharged with home nursing care, and 42 who were to be discharged to a nursing

home, and compared them with 128 randomly-selected patients who were to be discharged home without nursing support.

Variables identified as possible predictors included patient age, gender, living situation prior to admission, length of index admission, number of tubes in place at discharge, ADL on the Chinese version of the Barthel Index, and level of consciousness at discharge.

Because most of their sample had been living with family members prior to admission, Shyu and Lee (2002) also developed a 'Caregiver's Need for Social Services' Scale to record variables salient to the caregiver which might predict service usage at discharge. This included the caregiver's preferences with regard to service use (nursing home, home nursing, or no service) as well as the caregiver's perceptions of the elderly person's health needs, and of his or her own needs and resources with regard to providing ongoing care.

The mean age of the elderly patients was 76.2 years (SD 7.49, range 65 to 100), with 45.1% being female, 58.8% being married, 40.8% being widowed, and only one individual being single. Levels of ADL dependency (assessed just before discharge) were high, with 61.8% being fully dependent and only 12.9% being totally independent. The mean age of caregivers was 52.3 years, (SD 14.1, range 22 to 89), with 55.4% being female, 30.5% being spouses, and almost all of the remainder being adult children, most often sons (34.8%) or daughters-in-law (20.2%).

Discriminant function analysis was undertaken, with the sample being randomly divided into an analysis sample and a validation sample. The analysis revealed that the most important predictors of nursing home use were caregiver preference and pre-

admission nursing home use. Nursing home use was not predicted by age, health status, ADL dependency or length of index admission.

The most important predictors of home nursing were higher levels of ADL dependence, more tubes remaining, and lower level of consciousness, at discharge. Other health variables did not predict use of these services.

Shyu and Lee (2002) concluded that further study of elderly Taiwanese patients' outcomes was indicated, in particular addressing the issue of elderly patients who lived alone. They also indicated that whereas home-based wound care and tube replacement was provided through the hospital system, personal care was not provided. Hence economic factors would have been a limit on patients' ability to obtain this type of care at home. Importantly, they concluded that because of the high levels of family caregiving and cohabitation found, ascertaining caregivers' preferences with regard to discharge planning and providing support to caregivers after discharge would be particularly important in Taiwan and perhaps in other Chinese populations.

In a prospective study of 2557 elderly patients (aged over 70) admitted to hospital for acute medical care, Sands et al. (2003) noted that since ADL functioning was predictive of outcome in elderly hospital patients, and because ADL function might decline during hospital admission, it would be useful to identify predictors of decline, or failure to recover, in ADL functioning.

Using a cognitive screening measure, the Short Portable Mental Status Questionnaire (Pfeiffer, 1975), at the time of admission, Sands et al. divided their patients into three groups. Twenty-eight percent had 'moderate to severe cognitive impairment' (five or more errors on the SPMSQ) whereas 14% had 'mild cognitive impairment' (three or four errors), and the remaining 58% had 'little or no cognitive

impairment' (fewer than three errors). Multivariate repeated-measures analyses of covariance revealed that cognitive status on admission predicted the extent of functional recovery during the admission, even when delirium was controlled for. Cognitive status was also predictive of being admitted to a nursing home for the first time within 90 days of discharge. Sands et al. concluded that brief cognitive screening on admission could be used to identify elderly medical patients who were at risk of failing to regain pre-admission levels of functioning.

In a prospective study Aditya, Sharma, Allen, and Vassallo (2003) aimed to identify predisposing factors for discharge to a nursing home. They enrolled 150 elderly community-dwelling people (mean age 80.8 years, SD 6.6, range not stated) who had been admitted to the rehabilitation ward of an English non-acute geriatric hospital. The admission followed an acute illness but this was broadly defined, including stroke and orthopaedic problems. At admission the investigators recorded demographic data and a patient history (including incontinence, chronic illnesses, medications and any history of falls) and assessed vision, hearing, lower limb function, and gait (using the 'Get-Up-and-Go' test (Matthias, Nayak, & Isaacs, 1986)). They also assessed patients for confusion, which they defined as a score of less than 7/10 on the Hodkinson Abbreviated Mental Test (Qureshi & Hodkinson, 1974), and for risk of falling, using the Downton fall risk score (Downton, 1993) which was based on observation of patients' falls, wandering and/or unsafe mobilisation during the index admission. The outcome measure was discharge to a nursing home at the end of the admission. Decisions about nursing home placement were made at a multidisciplinary case conference (whose members: a consultant physician, nurse, occupational therapist, physiotherapist and social worker, were blind to the results of the research assessment),

agreed to by the patient or relatives, and confirmed by a social services panel (also blind to the research assessment results).

Univariate analyses and multiple logistic regression analyses were used, and the following variables were found to be independent predictors of, and risk factors for, discharge to a nursing home; confusion, incontinence, falls in hospital, gait abnormalities, use of tranquillisers, impaired distant vision, and living alone. Risk of nursing home placement was found to increase proportionally with the number of these risk factors present for an individual patient.

Aditya et al. (2003) concluded that in addition to functional disability (already recognised as a risk factor for nursing home placement), these other specific risk factors required attention, and where possible intervention, during hospital admission. They noted the importance of falls in hospital as a prognostic indicator, and the problematic role of tranquillisers for patients who might also be confused, wandering and/or at risk of falls. They suggested that the risk of placement increased with the number of risk factors at least in part because it was difficult to arrange community care packages for more patients with more complex needs: i.e. because of the absence of an enabling factor (for community services), rather than the presence of a need for placement.

As part of an attempt to develop standardised performance indicators for geriatric rehabilitation units in NHS hospitals, Challiner et al. (2003) undertook a comparative outcome study of 516 consecutive, elderly patients admitted to the geriatric rehabilitation wards of two NHS hospitals. The mean age of the patients was 84.9 years (SD 6.5 years), with 62.6% being female, and 36.7% having been admitted from low level or high level residential care.

Just after admission, and again just prior to discharge, the following data were collected: information about the pre-admission living situation including formal and informal support received, Barthel Index (Mahoney & Barthel, 1965), and Abbreviated Mental Test (Hodkinson, 1972). Sections of the Minimum Data Set / Resident Assessment Instrument, designed for use in nursing homes in the USA and subsequently modified and validated for use in the UK (Challis, Stewart, Sturdy, & Worden, 2000) were also administered: specifically the MDS cognitive performance scale (CPS), short ADL scale, mood scale, and scores for pressure sores, continence and falls. The 72 patients (14 %) who died during the index admission were excluded from the analyses. The main outcome measure was the patient's discharge destination, either home, to residential care (low or high level), or to other destinations. Logistic regression procedures revealed that the risk of discharge to residential care was predicted by female gender, worse cognitive performance on admission or discharge (AMT or CPS), and worse ADL performance on admission or discharge (Barthel or short ADL scale). Age and hospital were not independently predictive of discharge destination. Challiner et al. concluded that their measures of function were predictive of discharge destination and could accordingly be included in case-mix calculations when hospitals were compared. They added that UK professional bodies had recommended the routine use of the Barthel and AMT to assess elderly hospital patients, but that this did not always occur. They suggested that the MDS assessment system offered briefer measures which were equally useful.

Aiming to promote evidence-based decision making concerning residential placement at the end of a hospital admission, Slade, Fear and Tennant (2004) conducted a prospective cohort study of 549 elderly patients (mean age 83.9 years, SD 6.2, range

70-101). The patient group comprised a random sample of patients aged over 70, admitted to three NHS geriatric wards in the north of England, and not in residential care or in nursing homes prior to the index admission.

Slade et al. focussed on a group of seven assessment scales, widely used and promoted in the UK: the Hodkinson Abbreviated Mental Test Score (Hodkinson, 1973), the Hospital Anxiety and Depression Scale – HADS (Zigmond & Snaith, 1983), the Barthel Index (Mahoney & Barthel, 1965), the Northwick Park Dependency Scale (Turner-Stokes et al., 1998), the EuroQol (EQ-5D) (Brooks, 1996), the 36-item Short-form Health Survey - SF-36 (Ware & Sherbourne, 1992), and the Nottingham Health Profile (Hunt, McEwen, & McKenna, 1985). They aimed to establish which, if any, of the seven scales, if administered on admission, was predictive of placement at the end of the admission. The seven selected health status measures were randomised into sets of three, using every possible combination, and each patient received one set of three measures. Another measure, the Caregiver Strain Index (Robinson, 1983) was completed for each of the 155 patients who had a caregiver. The outcome measure was discharge destination: home (which included sheltered accommodation), low-level residential care, or nursing home.

Most patients (85%) had been admitted from home, but only 53% had returned there by the end of the study, whereas 13% had died, and 11% were still awaiting placement. Nursing home placement had occurred in 12.6% of cases, and low level care placement in 9.7% of cases.

Following a series of non-parametric analyses of variance, multinomial logistic regression was used to assess the predictive ability of the selected scales and subscales. Four scales were found to predict nursing home placement: the Barthel Index, the

Northwick Park Dependency Scale, the Abbreviated Mental Test and the Caregiver Strain Index. Residential placement (in low-level care) was also predicted by the Abbreviated Mental Test. The generic health status scales (EuroQol, SF-36, Nottingham Health profile) did not predict discharge destination.

Other patient variables which were predictive of nursing home placement were pre-admission use of home care services, pre-admission use of social work services, and a pressure sore of Grade 1 or above. The fact that a patient or a family had expressed a wish concerning discharge destination was predictive of the patient's not returning home, even though the wish itself was usually for a return home or to sheltered accommodation.

Slade et al. concluded that the four scales they had identified could be useful in predicting outcome, and perhaps as indicators for intensive intervention aimed at preventing placement. However, additional variables, such as the pre-admission situation, caregiver strain, and pressure sores (which raised the possibility of immobility and/or poor nutrition at home), were also indicators of the need for placement. Given that the wishes of the patient and family, when expressed, were often not met, it was recommended that the discharge planning process should involve patients and families more.

2.2.5 Published review

With funding from a European Union grant for development of the ACME system (Dunstan et al., 1996) - see above - the literature on predictors of outcome for elderly medical patients was reviewed by members of the ACMEplus project in Aberdeen (Campbell et al., 2004). They undertook a systematic search strategy including Medline

(1966-2000), CINAHL (1982-2000), ISI Web of Science (1981-2000), and a hand search of the journal *Age and Ageing* (1974-2000). Campbell et al. identified 313 relevant publications. Of these, 14 were rated as 'Category 1' because they were studies of patients aged 60 or over, admitted to general medical facilities, who had been assessed with standard measures reflecting case-mix, and the studies themselves met predetermined methodological and statistical criteria. All were prospective cohort studies, using a range of different measures to assess a range of outcomes.

Because of the heterogeneous nature of the studies they had discovered, Campbell et al. did not attempt a meta-analysis or a synthesis of results. Instead they summarised the studies' findings in terms of statistically significant predictors of outcome, as follows. Length of hospital stay was predicted by functional status (ADL) score, cognitive score, poor nutrition, polypharmacy, diagnosis or presenting illness, illness severity score, comorbidity score, age and gender. Mortality was predicted by functional status (ADL) score, cognitive score, polypharmacy, diagnosis or presenting illness, illness severity score, comorbidity score, age and gender. Discharge destination was predicted by functional status (ADL) score, cognitive score, diagnosis or presenting illness, illness severity score and age. Readmission to hospital was predicted by functional status (ADL) score, polypharmacy, diagnosis or presenting illness, illness severity score, comorbidity score and age.

Campbell et al. observed that evaluation of hospitals' performance was normally based on variables available to administrators, such as length of stay, deaths in hospital, and re-admission rates. However these administrative variables were not strongly related to elderly medical patients' outcomes. Even medical diagnosis was not a reliable predictor of mortality. Illness severity (despite having been reported as predictive of

mortality) had only been included in two of the studies reviewed. Instead, Campbell et al. concluded, the consistent predictors of elderly patient outcome were physical function – which had been found to be a significant predictor of mortality in all studies reviewed, and also generally of length of stay – and cognitive status, which had generally been found to be predictive of mortality and length of hospital stay. Physical and cognitive status were also generally predictive of discharge destination (and here age was also a significant predictor). Re-admission rates had not been studied comprehensively, and no particularly important predictors of readmission had been identified.

Campbell et al. concluded that hospital administrators needed to be aware that for elderly medical patients it was not the routinely collected pieces of administrative data – such as gender, age, or diagnosis – which predicted outcome. Instead, the determining factors were the elderly patients' functional and cognitive status. Unless this information was routinely collected for elderly medical patients, treatment outcomes and hospitals' performances could not be accurately compared.

2.2.6 Summary

As Campbell et al. (2004) also observed, this is a complex area to review. The groups of patients and the methods used are heterogenous, and measures range from the reliable and objective, through patient self-report, to observation and clinical judgment. Nevertheless strong themes emerge, and there is a surprising degree of consistency across studies, health care systems, and communities.

To summarise this review (and see Appendices A to D for tables of specific references), mortality in this patient group during or following a hospital admission has

repeatedly been found to be independently predicted by baseline levels of ADL functioning and cognitive functioning. Mortality has also been found to be predicted by severe specific diagnoses (such as cancer or cardiac illness), and by age, gender and medical burden (illness severity and/or the extent of comorbidities). The presence of depression, impaired IADL functioning and /or polypharmacy has also been found to predict mortality. Death during the index admission is predicted by ADL functioning, age, comorbidity, malnutrition and low white blood cell count.

Discharge destination has also been found to be predicted by baseline levels of ADL functioning and cognitive functioning, as well as by diagnosis, medical burden, and the presence of delirium, impaired mobility, incontinence, falls, gait problems, visual impairment and/or use of tranquilliser medication. However, the presence of depression and/or impaired IADL functioning has not always been found to predict discharge destination, perhaps because these issues can potentially be addressed in the elderly person's own home and need not involve residential placement.

General medical or health outcome after discharge, measured using a generic measure like the MOS, has also been found to be predictable from functional factors: specifically depression and preadmission ADL and IADL functioning.

ADL functioning has been repeatedly established as a major predictor of the health outcomes of elderly medical inpatients. ADL decline in this patient group is predicted by age, female gender, ADL decline during the index admission and re-admission, and by the presence of delirium. Impairments in cognition and/or mobility are also predictive of ADL decline, which is not surprising that given that cognitive skills and mobility are important underpinnings of ADL functioning (MacNeill & Lichtenberg, 1997).

2.3 Conclusions: Prediction of patient outcomes

As this review of the existing literature demonstrates, the medical and administrative measures commonly recorded in hospital databases and relied on in formal evaluation studies (such as presenting diagnosis, illness severity, comorbidities, medical burden, length of stay, and medication usage) have some relevance to the outcomes of frail elderly medical inpatients. However, there are significant gaps in the literature, and in the clinical assessment of elderly people.

The major factors influencing outcome appear to be related to function: the elderly person's cognitive status and level of independence in ADL. These key abilities interact with each other, and with IADL independence, as well as with other basic capacities (mobility, vision, nutritional status, continence), enabling factors (caregiver and financial resources), and predisposing factors (patients' and caregivers' wishes) to determine an individual's outcome. It appears that an elderly patient's function - the ability to carry out ADL and IADL, underpinned by the mobility, cognition, and mood - is the best predictor of his or her health outcome and discharge destination.

Hence, effective prediction of outcomes requires multiple measures and interdisciplinary collaboration. The notion of a functional axis (Inouye, Peduzzi et al., 1998) appears a useful one, in that measures of independent functioning, cognition, and depression all contribute independently to the prediction of outcome. When combined with standard measures of medical burden, they provide a good indication of at-risk status.

In a simpler world, or in a simpler project, each individual risk factor would be highlighted and measured, an experimental intervention would be undertaken, and the outcome for that variable would be recorded for univariate analysis – either in an

individual or across a group. However this research area is not, nor can it be, an experimental setting in which investigators can measure risk factors, then stand back and measure outcomes. In clinical settings, the terms and events being considered are non-independent, as perceived risk influences hospital discharge planning which in turn may affect outcome (Richards & Coast, 2003).

To further complicate outcome research, an intervention to prevent one undesired outcome may mean that a different undesired outcome occurs. A hospital admission may prevent a death, but result in an individual with a reduced level of functioning being discharged back into the community. Hospital admission implies current illness and/or inability to cope at home, and can represent an opportunity for increased support and improved access to health-care. It offers the opportunity for evaluation by the multidisciplinary team, and referral to community support services. For individuals with cognitive impairment, particularly those with little social support, a hospital admission may result in the provision of increased home supports, or in institutional placement in a hostel or nursing home. However the presenting illness and the period of hospitalisation may also result in de-conditioning and reduced ADL independence.

Similarly, residential placement is a negative outcome in its own right (hence its use as a variable in patient outcome studies). However it can also be seen as a marker of perceived risk, and as an active intervention to reduce the probability of other negative outcomes (death, accidental injury, malnutrition, poor self-care). For a person with a low level of cognitive and/or ADL functioning, discharge to residential placement may lead to the loss of intangible assets or values such as autonomy, home and neighbourhood, and increased risk of grief and depression. At the same time it may be protective, in reducing the risk of death or further illness.

In this sense, interventions such as hospital admission and residential placement can be seen as self-fulfilling prophecies in which, because a particular undesirable outcome has been predicted or expected, a different kind of undesired outcome may occur or be imposed. Studies that include the prediction of residential care placement reveal that the risk factors for residential placement are similar to those for mortality, re-admission and ill health. Discharge from hospital to a residential care facility is both a marker for a perceived risk, and an attempt to reduce risk. It is not a perfect indicator of perceived risk, which, in the Australian system as in others, is necessary for residential placement but not sufficient. Residential placement may have been recommended by hospital staff, and access to a funded place may have been granted by an Aged Care Assessment Team (Aged and Community Care Division of the Commonwealth Department of Health and Ageing, 2002) or its equivalent, but it will not occur unless a place in a residential facility is physically available at the time of discharge, and unless the patient (or guardian) agrees to the move.

Nor does risk, or need, always determine the use of health services (whether they are acute hospital services, rehabilitation units or residential care facilities). The Andersen model of health service usage asserts that enabling factors and predisposing factors are also predictive of health service usage, and in population studies of the health of elderly people, it has been found that social and economic circumstances significantly influence health outcomes (Grundy & Sloggett, 2003). Similarly in this specific area of research, the outcomes of frail elderly medical patients, it has been found that when enabling factors (for example financial access to nursing care, whether institutional or at home) are examined, they are shown to be highly salient.

For example, in societies where elderly people normally live with family members, and /or where residential care facilities are scarce or unfunded, such as Italy (Alarcon et al., 1999) or Taiwan (Shyu & Lee, 2002) little relationship is found between elderly patients' level of functioning and their discharge destinations. The relationship between ADL function and discharge destination, established in studies in the Western world (and mostly in the USA and the more affluent European nations) is found to be a function of cultural and economic context as well as need. Some developed countries (such as Australia) provide universally funded residential long-term care for all who meet the criterion of need. Others, like the U.S.A., only fund residential care for the indigent elderly and others must insure for, or pay, the full costs. In such systems, enabling and predisposing factors will be highly salient. Similarly, where predisposing factors (patients' and families expectations, wishes or beliefs) have been recorded, they have found to be predictive of service usage (Shyu & Lee, 2002; Slade et al., 2004).

There are also indications that health outcome research for elderly medical patients needs to encompass cultural and environmental differences. For example, in Western cultures where most elderly people live either alone or with an elderly spouse, frailty – the need for ADL assistance – is highly predictive of health outcomes and salient to discharge destination (residential care /other). It has been found less salient in another culture, that of Taiwan, where it is culturally normal for elderly people to live with their adult children and a lower level of day-to-day independence is required. To the extent that a community such as Australia is culturally diverse, family and caregiver factors may be more salient to patient outcomes, and individual patient factors less salient, than in the mainstream Western culture described in some of the literature.

Similarly the Michigan group's application of the environmental theory of ageing (Lawton & Nahemow, 1973) to the rehabilitation setting suggests that in predicting an individual's outcome, not only individual abilities but also environmental demands must be considered. It is the fit between the two which will determine whether successful adaptation (in this case the resumption of the pre-admission lifestyle) can occur.

In the clinical literature, which focuses on discharge destination as a measure of patient outcome, need factors such as those mentioned above (measures of function and/or of medical burden) are considered in more detail than the enabling or predisposing factors suggested by the Andersen model. This may, at least in part, be because need factors are easier to measure and more available to health professionals working within hospitals. It may also be because health professionals have been trained to focus mainly on the medical and functional condition of the patients they treat.

In an interesting intersection of two separate literatures, it appears that the model of successful ageing (Andrews et al., 2002; Luszcz, 1998) may be relevant to the clinical setting. There is an indication that two different health trajectories may lead to the geriatric rehabilitation setting (Hanks & Lichtenberg, 1996). People who are chronically ill may live long enough to become elderly. With their pre-existing burdens of comorbidity and poor function, they may be more likely to age unsuccessfully and to require ongoing support. Alongside them, an older group – the previously well or “successful” elderly who have either become acutely ill, or entered the terminal phase of their lives - could be assessed in more detail to assess whether they have the potential to return to independent living. Here IADL abilities and cognitive functioning may well have predictive value.

To summarise this critical review, there are indications in the outcome literature that the Andersen model of health service usage does apply to frail elderly medical patients' outcomes, specifically their usage or residential care after discharge from hospital. All three factors (need, enabling and predisposing factors) have been found to be predictive of discharge destination, specifically the use of residential care. However, they are not always measured, in individual cases and in research groups. To be useful, research and clinical practice related to the residential placement of frail elderly people must include all three Andersen factors, should attempt to understand cultural differences and the interaction between individual competence and environmental pressures, and may usefully consider the notion of successful and unsuccessful ageing.

Chapter 3. The health status and outcomes of frail elderly hospital patients: a review of medical records.

3.1 Overview

A hospital medical record (chart or case-note) review was conducted in order to develop a profile of a frail elderly hospital patient with suspected cognitive impairment, about whom a residential placement decision was being made, and for whom the decision was not ‘cut-and-dried’ – someone for whom the decision could go either way: either discharge back home, or into residential care. The profile was to be the basis for a vignette about a hypothetical elderly person for use in the subsequent community survey (Chapters 4 and 5) and qualitative interview project (Chapters 6 and 7).

Subsidiary aims of this study were to explore whether this selected group of elderly patients resembled those described in the wider literature, and whether predictors of their outcome (specifically mortality within 12 months, and/or residential placement at the end of the hospital admission) could be identified within the hospital medical record during the index admission.

3.2 Aims of the study

A retrospective medical record review was planned, in order to obtain a demographic, health and hospital service usage profile of the typical frail elderly hospital patient with suspected cognitive impairment, for whom residential placement on discharge was being considered. The profile was based on a sample of frail elderly medical in-patients who had been living in the community prior to their admission to a medical ward at the Royal Adelaide Hospital (RAH).

The RAH is the largest teaching hospital in the Australian state of South Australia. It is situated in the centre of the state's capital city of Adelaide, serving a South Australian population of 1,474,253 and a metropolitan population of 1,079,112. Twelve percent of the population of South Australia is aged 65 years or over (1999 figures), a proportion which is expected to increase to 26% of the population by 2051 (Department of Human Services, 2003). The hospital has 615 acute care beds. As well as providing statewide specialist services, it operates as a local general hospital for city residents and for residents of the inner-city suburbs and the eastern suburbs of Adelaide.

The primary aim of the medical record review was to develop a hypothetical profile of a frail elderly hospital patient with suspected or known cognitive impairment about whom a residential placement decision was being considered. The profile was to be the basis for a vignette about a hypothetical elderly person for use in the subsequent community survey (Chapters 4 and 5) and qualitative interview project (Chapters 6 and 7). In order to elicit values and priorities concerning placement, the hypothetical elderly person needed to be someone for whom the decision would be not clear-cut and whose competence, and/or intended discharge destination might not be agreed on by the patient, the family and the staff: This was someone for whom the decision might go either way: either discharge back home, or into residential care.

A subsidiary aim of this study was to explore whether within this selected group of elderly patients, (all of whom had, by definition, been identified by their ward teams as being at risk of a poor health outcome if discharged home) it was possible to identify elements of the patient's profile in the hospital medical record which were available during the index admission and predictive of a poor outcome. Although the study was limited in being retrospective and reliant on medical record data, it aimed to determine

whether routinely collected information, available in the medical record, was predictive of risk.

3.3 Method

3.3.1 The sample

The study participants were a consecutive series of 60 elderly people (aged 65 or over) living in the community (either in a private home or in low level residential care, such as a hostel or boarding house) prior to the index admission, who had been referred for neuropsychological assessment of suspected cognitive impairment, during an admission to an acute medical or geriatric ward of the Royal Adelaide Hospital.

The study group comprised all the patients who met study criteria and who had been referred between 1 July 1993 and 31 December 1996. All were living in the Adelaide metropolitan area and were considered by their ward treatment teams to have cognitive impairment and high support needs: i.e. to be at some risk of poor function if they returned to live at home.

Exclusion criteria were already being in high level residential care (a nursing home), and those comorbidities which involved significant mortality or morbidity and were thus likely to dominate health outcome (eg psychotic illness, intellectual disability, severe head or spinal injury, end-stage terminal illness).

As discussed in Chapter 1, the residential placement decision becomes most complex and difficult for relatives, health professionals and society when the patient's competence has been questioned but the implications are not straightforward. Patients about whom the question of cognitive impairment had been raised, but who had not,

prior to their admission, had a definite diagnosis of dementia or other brain impairment, were selected for the study.

Referral for neuropsychological assessment was selected as a marker for at-risk elderly individuals with suspected cognitive impairment. It is one of a number of actions taken by a multidisciplinary health team when concern is felt about the health status, support needs, safety and quality of life of such individuals, and where there is potential uncertainty or conflict about the discharge disposition (Dill, 1995). Neuropsychological assessment is utilised to assist in the diagnosis of dementing disorders, to assess the severity of cognitive impairment, and to support applications for community support services. In the last resort, when a guardian must be appointed by the state to make proxy decisions concerning treatment, living arrangements and/or financial administration, neuropsychological assessment provides evidence about mental incapacity (Morris & Kopelman, 1992).

Where neuropsychological assessment services are scarce, as they are throughout the South Australian health system, referral of elderly medical inpatients is most likely to occur if cognitive impairment is suspected (but is not so severe as to be self-evident) and a patient and/or family has not agreed to the discharge plan. In such cases, issues of legal incompetence, guardianship and non-voluntary placement are at least being considered by the treatment team. Similarly in an ethnographic study within a North American teaching hospital Dill (1995) found that in no case was a referral made for assessment of mental status where staff thought that the patient was competent to make decisions and where the patient and family had agreed to the discharge plan. Thus referral for neuropsychological assessment can be seen as a marker of perceived risk, of

a possible intention to intervene, and of at least the potential for doubt or disagreement about the patient's competence and/or the discharge plan.

3.3.2 Procedure

With the permission of the RAH Research Ethics Committee, these 60 patients' complete RAH medical records (their written case-note files, or hospital charts) were reviewed. Current and recent volumes were available in the Medical Records Department, and older volumes were obtained from the hospital's archive or viewed on microfilm.

The RAH Research Ethics Committee determined that patient consent was not required for this archival research, and hence individual patients' competence (or otherwise) to consent was not an issue (American Psychological Association, 2001).

Details of the patients' health status and hospital usage (number of admissions and bed-days) were recorded in a non-identifiable fashion, to protect the patients' privacy.

3.3.3 Measures

3.3.3.1 Potential predictor variables

Patients were described in terms of 12 pieces of information, potentially predictive of outcome, which were routinely collected and reliably available in the RAH case notes covering the index admission, that is, the admission during which a referral for neuropsychological assessment was made.

The following demographic information was selected: patient age and gender. Health information was selected as follows: the number of comorbidities (medical diagnoses, excluding the presenting diagnosis for which the patient had been admitted);

and whether or not the patient was documented in the case notes as having a disability (one or more sensory and/or motor impairments affecting everyday function) a cognitive impairment (as assessed by a psychologist, neuropsychologist or medical practitioner, at RAH or elsewhere, and recorded in the RAH case notes), and/or a substance abuse problem (usually alcohol and/ or benzodiazepines).

Information about the patient's living environment prior to the index admission was selected as follows: whether the patient had been living alone, and whether he or she was documented as receiving formal support services (support in ADL or IADL from a health or community agency), and/or informal support services, (support in ADL or IADL from a relative, neighbour or friend who did not live with the patient).

Hospital service usage was recorded as follows: the number of admissions to the RAH as an inpatient ever (before, and not including, the index admission), the number of admissions to the RAH in the 12 months preceding the first day of the index admission, and the number of bed-days spent as an inpatient at the RAH in the 12 months preceding the first day of the index admission.

The literature review (Chapter 2) had suggested that systematic recording of additional health information (eg. screening for depression or delirium, more detailed functional and cognitive assessment, recording of delirium on admission or during the admission) might be beneficial in predicting risk. This information was not reliably available for all cases, nor had it always been measured or recorded in the same manner, so it could not be included in this retrospective study. Similarly, enabling factors for residential care or home support (such as income, assets, availability of family members to provide care, and the local availability of residential care places or funded home care

packages) although often mentioned in the medical record, were not systematically recorded, nor were predisposing factors such as patients' or caregivers' wishes.

3.3.3.2 *Outcome measures*

Poor outcome was defined in two ways: mortality (death registered either during the index admission or within the 12 months after discharge), and, for those who were discharged from hospital alive, residential placement at the end of the index admission.

In relation to perceptions of at-risk status, mortality was selected as an objective and available measure of a poor outcome after discharge. Residential placement was selected as an indicator of perceived risk after discharge (perceived by one or more of the key interest groups – the patient, the family and the treatment team), and as an undesired outcome. It was not as reliable a measure of risk or need as mortality. As mentioned in Chapter 2, the perceived need for placement is necessary, but not sufficient, for placement to occur (a place must be available and the patient or guardian must consent). In that sense use of long-term care is discretionary, and both predisposing and enabling factors may operate. Also, as described in Chapter 2, the living arrangements of frail elderly people can be changeable. Some are discharged home but placed in residential care shortly afterwards, when care arrangements break down, and/or acceptable residential place becomes available. Others are discharged from hospital into residential care but later return home, or to a relative's home at a later time.

It was thought that there might be a relationship between mortality risk and placement, and/or the documented receipt of formal or informal support services. However it was unclear whether, in this patient group, the receipt of ADL support or

placement was more likely to operate as a marker of actual or perceived risk, or as a protection against poor health outcomes. Hence hypotheses concerning the potential impact of documented support and placement on patient outcome were two-tailed.

3.3.4 Hypotheses

Hypothesis 1 Mortality is predicted by greater age.

Hypothesis 2 Mortality is predicted by male gender.

Hypothesis 3 Mortality is predicted by the number of comorbidities.

Hypothesis 4 Mortality is predicted by documented pre-admission disability.

Hypothesis 5 Mortality is predicted by documented pre-admission cognitive impairment.

Hypothesis 6 Mortality is predicted by documented pre-admission substance abuse.

Hypothesis 7 Mortality is predicted by living alone immediately before the index admission.

Hypothesis 8 Mortality is predicted by the number of RAH admissions ever.

Hypothesis 9 Mortality is predicted by the number of RAH admissions in the 12 months preceding the index admission.

Hypothesis 10 Mortality is predicted by the number of RAH bed-days (days spent as an inpatient in RAH) in the 12 months preceding the index admission.

Hypothesis 11 Mortality is predicted by pre-admission receipt of formal support services. For this patient group it was not clear whether this would be a positive or a negative relationship, hence this was a two-tailed hypothesis.

Hypothesis 12 Mortality is predicted by pre-admission receipt of informal support services. For this patient group it was not clear whether this would be a positive or a negative relationship, hence this was a two-tailed hypothesis.

Hypothesis 13 For patients who are discharged alive, placement is predicted by greater age.

Hypothesis 14 For patients who are discharged alive, placement is predicted by male gender.

Hypothesis 15 For patients who are discharged alive, placement is predicted by the number of comorbidities.

Hypothesis 16 For patients who are discharged alive, placement is predicted by documented pre-admission disability.

Hypothesis 17 For patients who are discharged alive, placement is predicted by documented pre-admission cognitive impairment.

Hypothesis 18 For patients who are discharged alive, placement is predicted by documented pre-admission substance abuse.

Hypothesis 19 For patients who are discharged alive, placement is predicted by living alone immediately before the index admission.

Hypothesis 20 For patients who are discharged alive, placement is predicted by the number of RAH admissions ever.

Hypothesis 21 For patients who are discharged alive, placement is predicted by the number of RAH admissions in the 12 months preceding the index admission.

Hypothesis 22 For patients who are discharged alive, placement is predicted by the number of RAH bed-days (days spent as an inpatient in RAH) in the 12 months preceding the index admission.

Hypothesis 23 For patients who are discharged alive, placement is predicted by pre-admission receipt of formal support services. For this patient group it was not clear whether this would be a positive or a negative relationship, hence this was a two-tailed hypothesis.

Hypothesis 24 For patients who are discharged alive, placement is predicted by pre-admission receipt of informal support services. For this patient group it was not clear whether this would be a positive or a negative relationship, hence this was a two-tailed hypothesis.

Hypothesis 25 For patients who are discharged alive, mortality in the 12 months afterwards is predicted by documented placement.

3.4 Results

3.4.1 Data management

An α level of .05 was used for all statistical tests. The data were analysed using SPSS for Windows Version 12.0.

The distribution of the five continuous variables was examined using the SPSS EXPLORE procedure. This revealed that only patient age was normally distributed. For the other four variables, the distributions varied significantly from normality. Examination of outlier values for the five continuous variables revealed that there were six outliers, that is, individuals who had an extreme score on one of the continuous variable. Two patients (a woman aged 93, and a man aged 68 with Korsakoff syndrome) had had a very high number of admissions ever (23 or more). Three women (aged 72,

75 and 75), all with significant histories of depression, had had a very high number of bed-days in the past year (54 or more). One woman aged 78 had a very high number of comorbidities (11). Although each of these patients had a score on one of the five variables which deviated significantly from the norm, none had extreme scores on more than one variable. They were retained within the sample.

3.4.2 Patient profile

In age, the 60 patients ranged from 65 (the study's lower cut-off point) to 93 years, with a mean of 75.8 years (*SD* 7.06 years). Forty-three (71.7%) were female and seventeen (28.3%) were male. Sixty-five percent were living alone, 21.7% with friends or family, and 13.4% lived in a hostel or boarding house. None of this group was living in a nursing home before the index admission. Forty percent were documented as receiving formal support with ADL or IADL (district nurse visits, Meals on Wheels, home help, etc) at the time of the index admission, and 53% were known to have some informal ADL or IADL support (from family, friends, or neighbours not living with them).

In addition to the presenting diagnosis there were, on average, five comorbidities: for example hypertension, chronic cardiac disease or diabetes. There was known sensory and/or motor disability in 27 cases, and known substance abuse (usually alcohol, and less often benzodiazepines, or both) in 17 cases.

The mean number of previous admissions to RAH (ever) was 4.57 (*SD* 5.67), with the median number of admissions being 3. For 19 of the patients (31.7%) this was their first admission to the RAH. For the other 31 patients (68.3%) the number of previous admissions ranged from 1 to 28, with a mean of 6.68 (*SD* 5.74), and a median of 5.

Table 1 Demographic, health and hospital service usage information for patients who did and did not survive for 12 months, Part 1: 7 categorical variables.

NUMBER OF RESPONDENTS (% OF GROUP)	SURVIVORS N=51	NON- SURVIVORS N=9	WHOLE SAMPLE N=60
Female	36 (70.6%)	7 (77.8%)	43 (71.7%)
Sensory or motor disability documented	20 (39.2%)	7 (77.8%)	27 (45.0%)
Cognitive impairment documented	27 (52.9%)	5 (55.6%)	32 (53.3%)
Substance abuse documented	13 (25.5%)	4 (44.4%)	17 (28.3%)
Living alone before admission	33 (64.7%)	6 (66.7%)	39 (65.0%)
Receiving formal supports before admission	17 (33.3%)	7 (77.8%)	24 (40.0%)
Receiving informal supports before admission	25 (49.0%)	7 (77.8%)	32 (53.3%)

Table 2 Demographic, health and hospital service usage information for patients who did and did not survive for 12 months, Part 2: 5 continuous variables.

MEANS (STANDARD DEVIATIONS)	SURVIVORS N=51	NON- SURVIVORS N=9	WHOLE SAMPLE N=60
Age (years)	74.51 (6.34)	82.89 (6.99)	75.77 (7.06)
Number of comorbidities	4.47 (2.50)	4.67 (1.87)	4.50 (2.40)
Number of RAH admissions (ever) before the index admission	3.73 (5.11)	9.33 (6.60)	4.57 (5.67)
Number of RAH admissions in the year before the index admission	0.92 (1.15)	1.78 (1.30)	1.05 (1.20)
Number of RAH bed-days in the year before the index admission	14.78 (34.46)	22.3 (15.92)	15.9 (32.4)

The mean number of admissions to RAH in the 12 months preceding the date of the index admission was 1.05 (*SD* 1.2), with the median number of admissions being 1, and the mode 0.

Three patients had died during (i.e. at the end of) the index admission, and six died in the year after the index discharge. Fifty-one were alive one year after the index discharge. The demographic, health, environmental and pre-admission hospital service usage data of the 51 survivors and 9 non-survivors were tabulated and compared (see Tables 1 and 2).

Of the 57 patients who were discharged alive from hospital, 23 (40.4%) were documented as having been placed in residential care on discharge. Another 27 were recorded as being discharged home (to their own or a relative's home, or to sheltered accommodation such as a hostel). For the remaining 7, the nature of the discharge destination was not clear.

The demographic, health, environmental and pre-admission hospital service usage data of the 23 patients who were known to have been placed ("documented placement") and the 34 who were not known to have been placed were also tabulated and compared (see Tables 4 and 5).

3.4.3 Age: its relationship to other patient variables

As a preliminary analysis, the relationship between age and the other 12 patient variables was examined, to check whether any was so highly related to age that it could be considered redundant.

For the bivariate relationships between patient age and each of the other four continuous variables of interest: Pearson's *r* was calculated using the SPSS

CORRELATION procedure, as follows: number of comorbidities ($r = +.05$, $p = .34$), number of RAH admissions ever ($r = +.10$, $p = .22$), number of RAH admission in the past year ($r = +.18$, $p = .08$), and number of RAH bed-days in the past year ($r = +.11$, $p = .21$).

In summary, age was not found to be strongly or significantly related to any of these other continuous patient variables. The only significant relationships found within this group were between the number of RAH admissions in the previous year and the number of comorbidities ($r = .23$, $p = .04$), and, not surprisingly, between the number of RAH admissions in the previous year and the number of RAH admissions ever ($r = .4$, $p = .001$).

Similarly, the bivariate relationships between patient age and each of the seven categorical variables of interest were examined, using SPSS CROSSTABS and $2 \times 2 \chi^2$ procedures. For this purpose the patients were divided into two age cohorts. As mentioned in Chapter 2, Hanks and Lichtenberg (1996) had found that their group of elderly medical rehabilitation patients could be divided into two subgroups. Their “young old” group of patients aged 60-79, had high levels of comorbidity, cognitive impairment (compared to age-peers) and substance abuse. Their “old old” group, of patients aged 80 or more, demonstrated no more cognitive impairment or substance abuse than their healthy age-peers, but did demonstrate more cognitive impairment than the young old group (Hanks & Lichtenberg, 1996). Accordingly, patients in the present study were divided into a young old group aged 65-79 years ($n=40$: 15 men, 25 women) and an old old group aged 80-93 years ($n=20$: 2 men, 18 women).

For the relationship between age cohort and gender, the χ^2 value was 4.97 ($df = 1$, $N = 60$). This gave $p = .02$ for the one-sided hypothesis that the ‘old old’ cohort would

have a higher proportion of women than the ‘young old’ cohort. The value of Cramer’s V was 0.12 showing that within this patient group the relationship between age cohort and gender was small (explaining 8% of the variance).

None of the other categorical patient variables was found to be significantly related to age cohort within this patient group. Neither documented disability (χ^2 value = 2.72, $df = 1$, $N = 60$, $p = .08$), documented cognitive impairment (χ^2 value = 0.13, $df = 1$, $N = 60$, $p = .46$), living alone (χ^2 value = 0, $df = 1$, $N = 60$, $p = .62$), documented formal support (χ^2 value = 0.31, $df = 1$, $N = 60$, $p = .39$), nor documented informal support (χ^2 value = 0.54, $df = 1$, $N = 60$, $p = .33$), was found to be more prevalent (as predicted) in the ‘old old’ age cohort age-group than in the ‘young old’ age cohort. Nor was substance abuse (χ^2 value = 1.03, $df = 1$, $N = 60$, $p = .24$), which had been predicted to be less prevalent in the old old age cohort than in the young old age cohort, found to be significantly related to age cohort

In summary, age was related to gender, in that women were more significantly over-represented in the old old age cohort than in the young old age cohort. It was not related to any of the other 11 patient variables. The subgroups observed by Hanks and Lichtenberg (1996) were not evident within this group, perhaps because it was more highly selected.

3.4.4 Prediction of mortality within 12 months

Independent samples t tests were used to examine the bivariate relationships between survival for 12 months and each of the five continuous variables of interest: age, number of comorbidities, number of RAH admissions ever, number of RAH admission in the past year, and number of RAH bed-days in the past year (see results

below). Using the SPSS t test procedure, the scores of those who had survived 12 months ($n=51$) were compared with those who had not ($n=9$). Levene's test for equality of variances revealed that, for each of these five variables, variances did not differ significantly between the outcome groups.

Using SPSS CROSSTABS, 2×2 χ^2 procedures were used to examine the bivariate relationships between survival for 12 months and each of the seven categorical variables of interest, for the group of 60 patients.

3.4.4.1 Hypothesis 1: Mortality is predicted by greater age.

Patients who had survived 12 months after discharge ($M = 74.5$ years, $SD = 6.3$) were, on average, younger than those who had died ($M = 82.9$ years, $SD = 7.0$). The mean difference in age between groups was 8.38 years, which is a large effect size ($d = 1.29$). An independent t test was performed ($t(58) = 3.6$, $p < .01$, one-tailed). Hypothesis 13 was supported. Within this sample, age predicted risk of death.

3.4.4.2 Hypothesis 2: Mortality is predicted by male gender.

For the relationship between male gender and mortality, the χ^2 value was 0.19 ($df = 1$, $N = 60$). Since one cell had an expected frequency of less than 5, the appropriate statistical test was Fisher's exact probability. Hypothesis 2 was not supported ($p = 0.5$).

3.4.4.3 Hypothesis 3: Mortality is predicted by the number of comorbidities.

Patients who had survived 12 months after discharge, had, on average, slightly fewer comorbidities ($M = 4.5$, $SD = 2.5$) than those who had died ($M = 4.7$, $SD = 1.9$). An independent t test was performed ($t(58) = 0.22$, $p = .41$, one-tailed). Hypothesis 3 was not supported.

3.4.4.4 Hypothesis 4: Mortality is predicted by documented pre-admission disability

For the relationship between having a documented disability and survival, the χ^2 value was 4.6, ($df = 1$, $N = 60$). Hypothesis 4 was supported (Fisher's exact probability test, $p=.04$, one-tailed). The value of Cramer's V was 0.28 showing that within this group, the presence of a documented disability explained 7.8% of the variation in survival.

3.4.4.5 Hypothesis 5: Mortality is predicted by documented pre-admission cognitive impairment.

For the relationship between having a documented cognitive impairment and survival, the χ^2 value was 0.02, ($df = 1$, $N = 60$). Hypothesis 5 was not supported (Fisher's exact probability test, $p = .59$).

3.4.4.6 Hypothesis 6: Mortality is predicted by documented pre-admission substance abuse.

For the relationship between documented substance abuse and survival, the χ^2 value was 1.35, ($df = 1$, $N = 60$). Hypothesis 6 was not supported (Fisher's exact probability test, $p = .22$).

3.4.4.7 Hypothesis 7: Mortality is predicted by living alone immediately before the index admission.

For the relationship between living alone at the time of the index admission and survival for 12 months after discharge, the χ^2 value was 0.01, ($df = 1$, $n = 60$). Hypothesis 7 was not supported (Fisher's exact probability test, $p = .61$).

3.4.4.8 Hypothesis 8: Mortality is predicted by the number of RAH admissions ever

Patients who had survived 12 months after discharge, had, on average, had fewer RAH admissions before the index admission ($M = 3.7$, $SD = 5.1$) than those who had died ($M = 9.3$, $SD = 6.6$). The mean between-groups difference was 5.61 admissions, which is a large effect size ($d = .96$). An independent t test was performed ($t(58) = 2.9$, $p < .01$, one-tailed). Hypothesis 8 was supported. It was concluded that within this patient group, number of previous RAH admissions (ever) predicted mortality.

3.4.4.9 Hypothesis 9: Mortality is predicted by the number of RAH admissions in the 12 months preceding the index admission.

Patients who had survived 12 months after discharge, had, on average, slightly fewer admissions in the 12 months before the index admission ($M = 0.92$, $SD = 1.1$) than those who had died ($M = 1.78$, $SD = 1.3$). The mean between-groups difference was 0.86, which is a medium to large effect size ($d = .70$).

An independent t test was performed ($t(58) = 2.02$, $p = .02$, one-tailed). Hypothesis 9 was supported. It was concluded that within this patient group, the number of admissions in the 12 months before the index admission predicted mortality.

3.4.4.10 Hypothesis 10: Mortality is predicted by the number of RAH bed-days in the 12 months preceding the index admission.

Patients who had survived 12 months after discharge, had, on average, had fewer bed-days in RAH in the 12 months before the index admission ($M = 14.78$, $SD = 34.46$)

than those who had died ($M = 22.3$, $SD = 15.92$). An independent t test was performed ($t(58) = 0.64$, $p = .26$, one-tailed). Hypothesis 10 was not supported.

3.4.4.11 Hypothesis 11: Mortality is predicted by documented pre-admission receipt of formal support services.

For the relationship between documented receipt of formal support and 12-month survival, the χ^2 value was 6.30, $df = 1$, $N = 60$. Hypothesis 11 was supported (Fisher's exact probability, $p = .02$, two-tailed). Patients who died within 12 months of discharge were more likely to have been receiving formal support before the index admission than were those who survived (Table 1). The value of Cramer's V was 0.32 showing that within this group, the documented receipt of formal support explained 10.2% of the variation in survival.

3.4.4.12 Hypothesis 12: Mortality is predicted by documented pre-admission receipt of informal support services.

For the relationship between documented receipt of informal support and 12-month survival, the 2×2 χ^2 value was 2.54, $df = 1$, $N = 60$. Hypothesis 12 was not supported (Fisher's exact probability, $p = .15$, two-tailed).

3.4.4.13 Predictor variables and mortality: Summary of bivariate analyses

In summary, independent t test analyses suggested that within this at-risk elderly group, three of the continuous variables - age, number of previous RAH admissions ever and number of RAH admissions in the year before the index admission - were related to, and predictive of, 12-month survival. No such relationship was found

between 12-month survival and the number of comorbidities, or the number of RAH bed-days in the year before the index admission.

The 2x2 χ^2 analyses suggested that within this at-risk elderly group, two of the categorical variables, that is documented disability and documented receipt of formal support services prior to admission, were related to, and predictive of, 12-month survival. No such relationship was found between 12-month survival and patients' gender, living alone, documented cognitive impairment, documented substance abuse, or the documented receipt of informal support services prior to admission.

3.4.4.14 Predictor variables and mortality: Multivariate analysis

As the outcome was binary and discrete (death registered within 12 months after the end of the index admission, or survival for 12 months), a logistic regression procedure was selected, using SPSS BINARY LOGISTIC REGRESSION. This procedure requires at least 5, and preferably 15 or 20, cases per predictor variable (Dancey & Reidy, 2002; Gardner, 2001; Tabachnick & Fidell, 1996, 2001).

Table 3 Logistic Regression Analysis of 12-month survival as a function of five variables derived from the medical record.

VARIABLES	B	S.E.	WALD	DF	SIG.	EXP(B) ODDS RATIO
Age (years)	-.32	.14	5.36	1	.02	.73
Documented disability	- 2.38	1.31	3.28	1	.07	.09
Documented receipt of formal support	-.14	1.11	0.02	1	.90	.87
Number of RAH admissions ever	-.31	.13	5.50	1	.02	.73.
Number of RAH admissions in previous year	-.38	.15	0.56	1	.45	.68
Constant	30.69	12.29	6.34	1	.01	2.79E+13

The 5 variables which had individually been found to be predictive of risk of death were entered into the analysis as predictors. These were: age, documented disability, receipt of formal support services prior to index admission, number of previous RAH admissions ever, and number of RAH admissions in the year before index admission.

A test of the full model with all five predictors against a constant-only model was statistically reliable ($\chi^2 = 25.18$, $df = 5$, $N = 60$, $p < .01$, Nagelkerke $R^2 = .60$), indicating that the predictors, as a set, reliably distinguished between survivors and non-survivors, and accounted for 60% of the variance in outcome. Predictive success was unimpressive, however. Although the outcome of 93.3% of patients was correctly predicted, it was found that 100% of survivors, but only 55.6% of non-survivors, were correctly predicted.

Table 3 shows regression coefficients, Wald statistics, degrees of freedom and significance for each of the five predictors. According to the Wald criterion only age and number of RAH admissions (ever) reliably predicted 12-month mortality. The odds ratios (both 0.73) showed little change in the likelihood of survival based on a one-unit change in age or number of RAH admissions ever.

3.4.5 Prediction of placement at the end of the admission

For the 57 patients who had survived to be discharged from hospital alive, the relationship between documented placement at the end of the admission and 12 demographic, health and hospital service usage variables was examined, with the goal

of establishing whether one or more of these variables could be used to predict placement at the end of the admission.

Independent samples t tests were used to examine the bivariate relationships between documented placement and each of the five continuous variables of interest: age, number of comorbidities, number of RAH admissions ever, number of RAH admission in the past year, and number of RAH bed-days in the past year (see results below). Using the SPSS t test procedure, the score of those who had been placed 12 months ($n=23$) were compared with those who were not documented as having been placed ($n=37$). Levene's test for equality of variances revealed that for each of the five variables, variances did not differ significantly between the outcome groups.

Using SPSS CROSSTABS, 2×2 χ^2 procedures were used to examine the bivariate relationships between documented placement and each of the 8 categorical variables of interest.

3.4.5.1 Hypothesis 13: For patients who are discharged alive, placement is predicted by greater age.

Patients for whom residential placement was documented on discharge were, on average, older ($M = 77.35$ years, $SD = 7.30$) than those who were also discharged alive but who were not recorded as having been placed on discharge ($M = 73.97$ years, $SD = 6.18$). An independent t test was performed ($t(55) = 1.88$, $p = .03$, one-tailed). Hypothesis 13 was supported. The mean difference in age between groups was 6.74 years, which is a medium effect size ($d = 0.5$).

3.4.5.2 Hypothesis 14: For patients who are discharged alive, placement is predicted by male gender.

For the relationship between gender and documented placement, the χ^2 value was 0.77, $df = 1$, $N = 57$, $p = 0.29$, one-tailed. Hypothesis 14 was not supported.

3.4.5.3 Hypothesis 15: For patients who are discharged alive, placement is predicted by the number of comorbidities.

Patients for whom residential placement was documented on discharge, had, on average, slightly fewer comorbidities ($M = 4.43$, $SD = 2.41$) than those who were also discharged alive but who were not recorded as having been placed on discharge ($M = 4.44$, $SD = 2.41$). An independent t test was performed ($t(55) = -0.01$, $p = .50$, one-tailed). Hypothesis 15 was not supported.

Table 4 Demographic, health and hospital service usage information for patients who were, and were not, documented as having been placed at discharge, Part 1: 7 categorical variables.

NUMBER OF PATIENTS (%)	PLACED N=23	NOT PLACED N=34	WHOLE GROUP N=57
Female	18 (78.3%)	23 (67.6%)	43 (71.9%)
Sensory or motor disability documented	14 (60.9%)	12 (35.3%)	26 (45.6%)
Cognitive impairment documented	13 (56.5%)	18 (52.9%)	31 (54.4%)

Substance abuse documented	9 (39.1%)	7 (20.6%)	16 (28.1%)
Living alone before admission	14 (60.9%)	24 (70.6%)	38 (66.7%)
Receiving formal supports before admission	13 (56.5%)	10 (29.4%)	23 (40.4%)
Receiving informal supports before admission	12 (52.2%)	19 (55.9%)	31 (54.4%)

Table 5 Demographic, health and hospital service usage information for patients who were, and were not, documented as having been placed at discharge, Part 2: 5 continuous variables.

MEANS (STANDARD DEVIATIONS)	PLACED N=23	NOT PLACED N=34	WHOLE GROUP N=57
Age (years)	77.35 (7.30)	73.97 (6.18)	75.33 (6.80)
Number of comorbidities	4.43 (2.41)	4.44 (2.41)	4.44 (2.39)
Number of RAH admissions (ever) before the index admission	4.83 (6.55)	3.62 (3.99)	4.11 (5.16)
Number of RAH admissions in the year before the index admission	0.96 (1.11)	1.00 (1.15)	0.98 (1.13)
Number of RAH bed-days in the year before index admission	14.70 (27.70)	15.88 (36.35)	15.40 (32.87)

3.4.5.4 Hypothesis 16: For patients who are discharged alive, placement is predicted by documented pre-admission disability.

For the relationship between having a documented sensory and/or motor disability and documented placement, the χ^2 value was 3.62 ($df = 1, N = 57, p = .03$, one-tailed). Hypothesis 16 was supported. The value of Cramer's V was 0.25 showing that within this group, the presence of a documented disability explained 6% of the variation in documented placement.

3.4.5.5 Hypothesis 17: For patients who are discharged alive, placement is predicted by documented pre-admission cognitive impairment.

For the relationship between having a documented cognitive impairment and documented placement, the χ^2 value was 0.07 ($df = 1, N = 57, p = .40$, one-tailed). Hypothesis 17 was not supported

3.4.5.6 Hypothesis 18: For patients who are discharged alive, placement is predicted by documented pre-admission substance abuse.

For the relationship between documented pre-admission substance abuse and placement, the χ^2 value was 2.34 ($df = 1, N = 57, p = .06$, one-tailed). Hypothesis 18 was not supported.

3.4.5.7 Hypothesis 19: For patients who are discharged alive, placement is predicted by living alone immediately before the index admission.

For the relationship between living alone at the time of the index admission and documented placement, the χ^2 value was 0.01 ($df = 1, N = 57, p = .22$, one-tailed). Hypothesis 19 was not supported.

3.4.5.8 Hypothesis 20: For patients who are discharged alive, placement is predicted by the number of RAH admissions ever.

Patients for whom residential placement was documented on discharge, had, on average, had slightly more RAH admissions before the index admission ($M = 4.83, SD = 6.55$) than those who were also discharged alive but who were not recorded as having been placed on discharge ($M = 3.62, SD = 4.0$). An independent t test was performed ($t(58) = 0.87, p = .20$, one-tailed). Hypothesis 20 was not supported.

3.4.5.9 Hypothesis 21: For patients who are discharged alive, placement is predicted by the number of RAH admissions in the 12 months preceding the index admission.

Patients for whom residential placement was documented on discharge, had had, on average, slightly fewer admissions in the 12 months before the index admission ($M = 0.96, SD = 1.1$) than those who were also discharged alive but who were not recorded as having been placed on discharge ($M = 1.0, SD = 1.5$). An independent t test was performed ($t(55) = -0.142, p = .44$, one-tailed). Hypothesis 21 was not supported.

3.4.5.10 Hypothesis 22: For patients who are discharged alive, placement is predicted by the number of RAH bed-days in the 12 months preceding the index admission.

Patients for whom residential placement was documented on discharge, had, on average, had not more (as predicted), but slightly fewer bed-days in RAH in the 12 months before the index admission ($M = 14.70$, $SD = 27.70$), than those who were also discharged alive but who were not recorded as having been placed on discharge ($M = 15.88$, $SD = 36.35$). An independent t test was performed ($t(55) = -0.13$, $p = .45$, one-tailed hypothesis). Hypothesis 22 was not supported.

3.4.5.11 Hypothesis 23: For patients who are discharged alive, placement is predicted by pre-admission receipt (or non-receipt) of formal support services

For the relationship between having documented formal support and documented placement, the χ^2 value was 4.19, ($df = 1$, $N = 57$, $p = .04$, two-tailed). Hypothesis 23 was supported. Patients who were documented as having been placed were more likely to have been receiving formal support before the index admission than were those who were not documented as having been placed (see Table 4). The value of Cramer's V was 0.27 showing that within this group, the documented receipt of documented formal support prior to admission explained 7.3% of the variation in documented placement.

3.4.5.12 Hypothesis 24: For patients who are discharged alive, placement is predicted by pre-admission receipt (or non-receipt) of informal support services.

For the relationship between documented receipt of informal support and placement, the χ^2 value was 2.54 ($df = 1$, $N = 57$, $p = 0.78$, two-tailed). Hypothesis 24 was not supported.

3.4.5.13 Predictor variables and placement: Summary of bivariate analyses

In summary, the results of the bivariate analyses suggested that within this at-risk elderly group, three variables - age, documented disability and documented receipt of formal support services prior to admission - might be related to, and predictive of, documented placement. No such relationship was found between documented placement and gender, number of comorbidities, living alone, documented cognitive impairment, documented substance abuse, or the documented receipt of informal support services prior to admission, number of previous RAH admissions ever and number of RAH admissions in the year before the index admission or number of RAH bed-days in the year before the index admission.

Table 6 Logistic regression analysis of documented placement as a function of 3 variables derived from the medical record.

VARIABLES	B	S.E.	WALD	DF	SIG.	EXP(B) ODDS RATIO
Age (years)	-.58	-.54	1.61	1	.21	.94
Documented disability	-.68	.60	1.27	1	.26	.51
Documented receipt of formal support	-.92	.59	2.38	1	.12	.40
Constant	5.47	3.49	2.56	1	.11	236.18

3.4.5.14 Predictor variables and placement: Multivariate analysis

As the outcome was binary and discrete (placement at the end of admission documented, or not documented), a logistic regression procedure was selected, using SPSS BINARY LOGISTIC REGRESSION. The three variables which had individually been found to be predictive of documented placement were entered into the analysis as predictors. These were: age, documented disability, and receipt of formal support services prior to index admission. A test of the full model with all three predictors against a constant-only model was found to be statistically reliable ($\chi^2 = 8.04$, $df = 4$, $N = 57$, $p = .045$). However Nagelkerke R^2 was 0.178, indicating that the predictors, as a set, did not reliably distinguish between those who were and were not documented as

having been placed, and they accounted for only 18% of the variance in outcome. Predictive success was similarly unimpressive. Discharge destination was correctly predicted in only 71.9% of cases: 52.2% of those who were placed, and 85.3% of those who were not placed.

Table 6 shows regression coefficients, Wald statistics, degrees of freedom and significance for each of the three predictors. According to the Wald criterion none of the three reliably predicted placement.

3.4.6 Placement and survival

For those 57 patients who had been discharged alive, the relationship between documented placement at the end of the index admission and 12-month survival was examined. It was unclear whether the placement was more likely to operate as a marker of perceived risk, or as a protection against poor health outcome. Hence the direction of any relationship between placement and mortality had not been specified (two-tailed hypothesis).

In the event, 6 (26.1%) of the 23 individuals who had been placed died within 12 months, while none of the 37 individuals who had not been placed died. The 2 x 2 χ^2 value was found to be 9.91, ($df = 1$, $N = 57$). Since two cells had an expected frequency of less than 5, the appropriate statistical test was Fisher's exact probability. This gave $p < .01$ for the two-sided hypothesis that documented placement at the end of the admission might be related to 12-month survival. The value of Cramer's V was .417: i.e. the presence of documented placement at the end of the admission explained 17.4% of the variation in survival. This analysis suggested that within this group, documented

placement at the end of the admission might be related to 12-month survival, and a marker of higher risk of death within 12 months after discharge.

3.4.6 Summary of results

3.4.6.1 Patient profile

To summarise, the typical at-risk elderly patient with suspected cognitive impairment, and facing a problematic discharge with residential care as a possibility, was likely to be female, aged in her mid-70's, and having five comorbidities in addition to the presenting diagnosis. She was likely to have been living alone prior to the index admission.

Sensory and /or motor disability was documented for about half the group, as was cognitive impairment, but substance abuse was documented for less than half.

Prior to the index admission, informal support with ADL or IADL was being received by about half of the sample, while formal support was being received by forty percent.

While within the group age was found to be significantly related to gender, it did not appear significantly related to other patient variables and so they were not redundant.

3.4.6.2 Prediction of risk and outcome

Hypothesis 1 was supported. In this patient group, mortality was predicted by greater age.

Hypothesis 2 was not supported. Mortality was not predicted by male gender.

Hypothesis 3 was not supported. Mortality was not predicted by the number of comorbidities.

Hypothesis 4 was supported. Mortality was predicted by documented pre-admission disability.

Hypothesis 5 was not supported. Mortality was not predicted by documented pre-admission cognitive impairment.

Hypothesis 6 was not supported. Mortality was not predicted by documented pre-admission substance abuse.

Hypothesis 7 was not supported. Mortality was not predicted by living alone immediately before the index admission.

Hypothesis 8 was supported. Mortality was predicted by the number of RAH admissions ever.

Hypothesis 9 was supported. Mortality was predicted by the number of RAH admissions in the 12 months preceding the index admission.

Hypothesis 10 was supported. Mortality was predicted by the number of RAH bed-days (days spent as an inpatient in RAH) in the 12 months preceding the index admission.

Hypothesis 11 was supported. Mortality was predicted by having received formal support services prior to admission.

Hypothesis 12 was not supported. Mortality was not predicted by having received informal support services prior to admission.

Hypothesis 13 was supported. For patients who were discharged alive, placement was predicted by greater age.

Hypothesis 14 was not supported. For patients who were discharged alive, placement was not predicted by male gender.

Hypothesis 15 was not supported. For patients who were discharged alive, placement was not predicted by the number of comorbidities.

Hypothesis 16 was supported. For patients who are discharged alive, placement is predicted by documented pre-admission disability.

Hypothesis 17 was not supported. For patients who were discharged alive, placement was not predicted by documented pre-admission cognitive impairment.

Hypothesis 18 was not supported. For patients who were discharged alive, placement is not predicted by documented pre-admission substance abuse.

Hypothesis 19 was not supported. For patients who are discharged alive, placement was not predicted by living alone immediately before the index admission.

Hypothesis 20 was not supported. For patients who were discharged alive, placement was not predicted by the number of RAH admissions ever.

Hypothesis 21 was not supported. For patients who were discharged alive, placement was not predicted by the number of RAH admissions in the 12 months preceding the index admission.

Hypothesis 22 was not supported. For patients who were discharged alive, placement was not predicted by the number of RAH bed-days (days spent as an inpatient in RAH) in the 12 months preceding the index admission.

Hypothesis 23 was supported. For patients who were discharged alive, placement was predicted by having received formal support services prior to admission.

Hypothesis 24 was not supported. For patients who were discharged alive, placement was not predicted by having received informal support services prior to admission.

Hypothesis 25 was supported. For patients who were discharged alive, mortality in the 12 months afterwards was predicted by documented placement.

The multivariate analyses revealed that only age and number of RAH admissions (ever) reliably predicted survival, and none of the predictor variables reliably predicted placement.

3.5 Discussion.

3.5.1 Patient profile

This profile, derived from 60 elderly South Australian medical inpatients, resembled the patients studied in the outcome literature (reviewed in Chapter 2). This suggested that this patient group resembled those being studied at other centres and that the profile could be used to develop a vignette about a hypothetical frail elderly medical patient for whom discharge planning and long-term care decision-making would be problematic.

3.5.2 Prediction of risk and outcome

It was acknowledged from the outset that within a group of hospital patients who were all elderly and ill, and perceived by their treatment team as being at high risk of poor outcome, it might be difficult to extract reliable predictors of relative risk. It was

only possible to develop a validly predictive regression equation for mortality, and not for placement at the end of the admission.

The results of the literature review (Chapter 2) suggest that other variables with significant predictive power were not being measured. A more effective range of measures of patient need might have included the systematic recording of pre-admission ADL functioning, depression, and cognition in all elderly medical patients. As Campbell et al. (2004) had concluded, patients' functional abilities were the most important determinants of their outcomes and hence: "Outcomes cannot be accurately compared between hospitals caring for older patients unless these factors are taken into consideration, even though they are not readily available from routine data" (pg. 114).

Measurement and recording of enabling and predisposing factors (for the patient and the family/caregiver) and need variables (family/caregiver) might also have contributed to more effective prediction, even though they are not always found to be major determinants of the placement decision. As Cox and Verdieck (1994) found in their study of hospital discharge destinations of elderly people with diagnosed dementia, by the end of the patient's hospital admission, predisposing factors and caregivers' need factors (as expressed early in the hospital admission) appeared to have been over-ridden by patient need factors and the presence or absence of enabling factors.

Nevertheless it did appear that the RAH medical record for this patient group contained information which was predictive of outcome, and which could usefully be considered when comparing individual patients or groups.

Significant relationships were found between patient mortality (during, or within 12 months after, the index admission) and age, documented disability (sensory and/or motor), receipt of formal services prior to the index admission, and the number of RAH

admissions (ever, and in the year before the index admission). This suggested that, as in the studies reviewed in Chapter 1, three different domains - patient age, patient ADL independence (represented in this study by disability and the receipt of formal supports) and medical burden (represented in this study by the number of RAH admissions) - could all contribute to the prediction of patient survival.

Significant relationships were found between placement at the end of the admission and age, documented disability (sensory and/or motor), receipt of formal services prior to the index admission, and the number of RAH admissions (ever, and in the year before the index admission). Here it appeared that two different domains: - patient age and patient ADL independence (represented in this study by disability and the receipt of formal supports) - were predictive of placement. Medical burden (represented in this study by the number of RAH admissions) was not. Possibly, again, this is because all patients studied were being considered for placement (i.e. had serious levels of medical burden) and it was not medical need which determined whether or not they were placed at the end of the admission.

The fact that placement was implemented to reduce the risk of a poor health outcome, but was found to be related to higher, rather than lower, levels of mortality, is an interesting one. One possible explanation is that placement is a marker of perceived risk – i.e., awareness of life-threatening issues may make people who know they are ill, or whose families and treatment teams know they are ill, more likely to accept the suggestion of residential placement. However it is not impossible that entry into residential care could itself increase risk of death, perhaps via its psychological impact, and this and other explanations for this finding should be explored.

In summary, the medical record review produced a detailed profile of the ‘typical’ frail elderly medical patient, for whom placement had been suggested, and for whom the decision was not clear-cut: because of concerns about competency, or consent, or consensus. The patient profile, and the subsequent attempt at studying outcomes and predictors, revealed that the patients reviewed resembled those studies elsewhere: age and ADL independence were related to placement and mortality, and hospital usage (medical need) was also related to subsequent mortality.

The fact that 40% of the group were documented as having been placed suggested that this was indeed a group for which the residential placement decision could go either way. Similarly the number of deaths in the subsequent 12 months confirmed that this was, indeed, a group of frail and “at-risk” patients, but that only some, and not all, of the patients within this group were actually approaching the end of their lives. Hence the hypothetical profile would be valid for use in the two studies that were to follow.

Chapter 4. Prospective attitudes to long-term care and residential placement:

A review of the literature

4.1 Overview

This chapter reviews the literature on prospective attitudes to, and priorities concerning, the residential placement of elderly people, in preparation for the design of a community survey.

4.2 Review of the literature

Considerable research efforts (see literature review in Chapter 6) have been expended in ascertaining the subsequent attitudes of people who have been involved in residential placement decisions.

Less attention seems to have been focussed on the prospective views of those who are not yet required to make such a decision but who may need to do so in future: members of the general community. Yet almost all people have the potential for involvement in such a decision in future – most obviously, in that they may require and/or refuse residential placement themselves, but also as potential relatives or caregivers. Additionally, some are, or will become, health professionals and employees in aged care services. Everyone is an actual or potential taxpayer and voter, with some interest in, and influence on, decisions relating to the provision and allocation of long-term care services.

Database searches up to and including September 2003 (PsycInfo, PubMed, Australasian Medical Index, Health Business, Health Source Nursing, Sociological Abstracts, ISI Web of Science, Expanded Academic Index, Academic Search Elite,

ProQuest) revealed that the people most likely to have been surveyed on their attitudes and opinions concerning residential aged care facilities were those who were middle-aged (Holden, McBride, & Perozek, 1997; Robison & Moen, 2000; Spitze & Ward, 2000), or elderly (Biedenharn & Normoyle, 1991; Keysor et al., 1999; McAuley & Blieszner, 1985; McCormick et al., 2002; McCormick et al., 1996; Rabiner, 1996; Schoenberg & Coward, 1997; Sudha & Mutran, 1999; Woenne-Green, 1995) or very ill (Mattimore et al., 1997), and the family caregivers of elderly people (Chiu, Shyu, Liu, Wang, & Chang, 2001; Gubrium, 1989; Hagen, 2001; Sudha & Mutran, 1999; Wallhagen & Strawbridge, 1995).

This is understandable. Attitudes to placement are examples of health beliefs, one of the predisposing factors in the Anderson model of health service utilisation (Andersen, 1995; Keysor et al., 1999; Rabiner, 1996). Attitudes to residential aged care are often surveyed with a view to developing a more accurate model of future utilisation of different types of care (Rabiner, 1996). There is confirmatory evidence that attitudes to placement do predict future nursing home usage (Haken et al., 2002; Mui & Burnette, 1994; Rabiner & Hipskind, 1997). Hence, the attitudes of people who are ageing or ill, and of their caregivers, are seen as most immediately relevant to health service usage and to service planning.

Students' attitudes to residential care facilities have also been studied, specifically the attitudes of those enrolled in courses related to health and aged care (French & Mosher-Ashley, 2000). Again, there are implications in terms of workforce planning, training and retention.

However, surveys of the views of the general community concerning the determinants of the residential aged care or placement decision, appear to be rare or non-existent. None was identified.

Surveys of prospective attitudes, among different groups, to residential aged care and the placement decision are reviewed below. The review has been divided into the following categories: school students, university students, the middle-aged, caregivers, people who were in poor health, and elderly people.

4.2.1 High school students

As part of a larger study of adjustment among Laotian refugees in the USA, 60 Laotian refugee high school students and a matched sample of 60 American students attending the same high school in Tennessee were surveyed concerning their attitudes toward caring for aging parents (Aday & Kano, 1997). Students in both groups expressed a willingness to provide personal care to aging parents, but Laotian students were more likely to be positive about sharing their future home with an aging parent (87%) than were American students (43%). Laotian students were more likely than American students to explain their willingness to provide care in terms of cultural values. American students were more likely to explain their willingness to provide care in terms of personal affection.

4.2.2 University students

In their survey of the attitudes of college students towards residential care facilities, French and Mosher-Ashley (2000) arranged for each of 131 undergraduate

students, enrolled in a 'Psychology of Aging' course at a state college, to visit and interview a cognitively alert elderly person in long-term care. Each student then completed a questionnaire which, among other items, asked about the student's experiences of caring for elderly relatives, their grandparents' health, their impressions of the elderly person and the facility they had visited, and whether or not they themselves would be open to living in an aged care facility (of the same type as the one they had visited) later in life. The mean age of students was 24.8 years for females (S.D. 9.5, range 18-71 years, n=109) and 23.3 for males (S.D. 5.2, range 19 to 43 years, n=22).

Forty percent of these students reported that their lives had been affected by meeting the needs (physical or emotional) of an elderly relative, and 23% reported having at least one living grandparent who was in poor health. The study examined the impact of these two factors on expressed willingness to live in an aged care facility later. Students whose lives had been affected by caring for an elderly person were found to express significantly more willingness to live in an aged care facility themselves, with 63% of this group expressing willingness ("yes, but with reservations" or "very much so"), compared with only 49% of the remainder of the sample. Having a grandparent in poor health was not a significant predictor of expressed willingness, nor was the interaction between meeting needs and poor health.

Prior experience of, knowledge about, or interest in, residential care facilities did not appear to affect the students' attitudes. Respondents were asked whether they had ever been hospitalised themselves, or placed in a residential care facility for a long illness. Attitudes of the respondents who had had such an experience (12%) did not differ significantly from those of the remainder of the group. Similarly, the attitudes of

those who had visited an aged care facility prior to the study (92%), or had been employed in one (37%), or who were enrolled in a gerontology studies program (21%), or considering enrolling in a gerontology studies program (26% of those not currently enrolled in one), were not significantly different from the attitudes of the remainder of the group.

Willingness to live in an aged care facility later in life appeared to be independent of age and gender. Interestingly, however, the major field of study was found to be a significant predictor of willingness. Students majoring in health care professions (such as nursing, social work, occupational therapy and psychology) were significantly less likely than other students (majoring in fields such as biology, education, sociology, economics, arts, or other) to express willingness: 51% as against 62%.

4.2.3 People in mid-life

Three surveys of people in mid-life, while not all directly examining attitudes to nursing home placement, revealed health beliefs about long-term care and residence which had implications for service usage.

As part of the 1992 first wave of the USA Health and Retirement Study, Holden, et al. (1997) surveyed a nationally representative sample of 733 adults aged between 51 and 61, concerning their expectation of receiving long-term care in a nursing home, later in life. They found that respondents' expectations of nursing home usage were a close match for actual probability of usage, which was 37% (as determined using a sample of older people who had been followed up until their deaths). As a group, respondents estimated their probability of usage as 40%. There was no obvious gender difference. Non-married people in midlife appeared to rate their likelihood of receiving

nursing home care slightly higher (43%) than did married people (39%), but the statistical significance of this discrepancy was not reported. It appeared to be more evident among men (53% and 39% respectively) than among women (40% and 39%). Men and women appeared to base their estimations on different information. Men rated themselves as more likely to use a nursing home if they were not currently married, and if they had a medical condition likely to produce disability. Women did not appear to base their expectations on their current marital status, or their current health status, perhaps because they thought that their use of residential long-term care in future was more likely to reflect future conditions, such as dementia or widowhood. Those women who had fewer children, and/or whose own parents had used a nursing home, rated themselves as more likely to use a nursing home in future. Holden et al. concluded that people in midlife had realistic expectations about future nursing home use, and that they formed these expectations in a rational fashion, consistent with probable determinants of their future usage of nursing homes.

Spitze and Ward (2000) interviewed 1200 people aged 40 years and above in New York State, asking about their expectations for personal care if they were to be ill for more than a week, and who they thought would provide it. The mean age of respondents was 68, and only a third of them had living parents. A hierarchy of expectation was found, with self or spouse the most commonly mentioned option, followed by other household members (if available), nearby children (especially daughters), then other relatives, and finally non-relatives (friends, neighbours and formal sources of care).

Using data from the Cornell Retirement and Well-Being Study (1994-5 and 1996-7), Robison and Moen (2000) analysed the interview responses of 762 people in late midlife (aged 50-72 years) who were either working or retired. Respondents were asked

about their housing expectations; whether they were likely or unlikely to take up a range of options, including never moving, staying where they were but with home modifications and/or a reverse mortgage, moving to a retirement community, taking out long-term care insurance, moving into a relative's home or into a separate unit on a relative's property, or sharing their homes with unrelated people. The researchers decided to exclude the option of nursing home care from the study because of potential confusion between short-term and long-term care, and also because in their view people did not see nursing home care as an option for consideration, but rather as a last resort.

Robison and Moen found that as a group these late mid-life respondents were uncertain about whether they would be staying in their own homes, but they did not expect to become much more dependent on others as they aged. There was some consideration of purchasing long-term care insurance (34%), moving to a retirement community (23%) or obtaining a reverse mortgage (18%). Respondents saw themselves as less likely to move in with a relative (12%), share their homes with unrelated people (9%), or move into a dwelling on a relative's property (7%). The majority of respondents expected to "age in place" (Robison & Moen, 2000, p.518). This expectation increased with age. Compared with the younger members of the sample who were aged 50-59 years, respondents aged 60-72 were almost twice as likely to indicate that they did not expect to move. The expectation of staying in one's own home was more common among those who lived in non-metropolitan areas, those who were less educated, those who had lived in their current neighbourhood for more than 17 years, those who were volunteers, and those who indicated fewer depressive symptoms. Interestingly, measures of respondents' own or their spouses' past or current physical health did not predict expectations about moving house in future. However, the authors

noted, this was a relatively young group with current or recent employment. They suggested that health might become more salient to residential planning for people in their 70's and 80's.

In summary Robison and Moen concluded that their respondents expected to age in place and did not intend to rely on the care of family members, thus increasing their potential future reliance on formal long-term care services provided in their own homes.

4.2.4 Family caregivers

In 1981 a randomised and weighted survey of elderly people living at home in Adelaide (920 respondents) and Melbourne (1200 respondents) and their family caregivers, was conducted by the Australian Council on the Ageing and the Australian Department of Community Services (1985). The responses of the caregivers are reviewed here, and the responses of the elderly people are reviewed later in the chapter. It was found that almost 10% of elderly respondents had a handicap such that they required assistance from relatives with one or more domestic tasks. Family caregivers were most often female (65.5% of spouse caregivers and 84.6% of non-spouse caregivers) and 41% were aged over 60 themselves (80% of spouse caregivers and 20.4% of non-spouse caregivers). After a number of set questions concerning the type of care provided and difficulties encountered, the final question was open-ended and asked for general comments. Most of the caregiver respondents who had expressed concern that the elderly person's health would worsen also indicated that the old person would have to move and that nursing home placement would need to be considered once the demand for care became too high. The general opinion seemed to be that at a

certain stage it was no longer appropriate for elderly people to live alone and the need for special accommodation became inevitable: whether in a nursing home or in more independent shared accommodation.

As part of a North American field study of the experience of Alzheimer's Disease (AD), Gubrium (1989) used participant observation and focussed interviews to study two support groups for caregivers of people with Alzheimer's disease, over a three-year period. Gubrium focused on caregivers' considerations of "the domestic meaning of institutionalisation" (p.89), describing this as a major theme in a family's placement decision. Gubrium observed that this was a time in the life of a family at which a household ceased to be the care recipient's home, and an aged care facility must become a home. Gubrium suggested that in the literature and public discourse to date, there had been a focus on the practical aspects of nursing home care, and on the interaction between patient impairment and caregiver stress, but a neglect of the evaluative component of the placement decision. There had also been an assumption, expressed in the public discourse, that a dementia patient's move to residential care was a developmental and normative one, given the inevitable progression of the disease. In the ongoing consideration of residential placement, Gubrium suggested, as well as more objective factors, caregivers were weighing up the costs and benefits of care in the home versus care in the institution, and the impact of each on home life (for the elderly person and also for the rest of the family).

Gubrium examined the material in terms of two questions: "What is a good nursing home?" and "When is a house no longer a home?" and found that discussion of the first question could be divided into two categories or themes; (i) whether a facility

would provide a homelike environment or merely house someone, and (ii) whether the patient would be cared for as a family member or as a stranger.

Discussion relating to the second question, “When is a house no longer a home?” was analysed in terms of three themes. The first theme was the role of “support” or involvement by the extended family with the household that was providing care, and the extent to which this involvement by family might be more supportive of ongoing care in the home, or alternatively might generate debate leading to active consideration of institutional placement. The second theme concerned the point at which the demands of caring for the patient were such that the home was no longer homelike, either for the patient or the caregiver. Gubrium suggested that the commonly used phrase “It’s time” could be seen as a partial response to the question posed, reflecting the caregiver’s or family’s evaluation of the quality of the home environment and of the care that it was possible to provide. The third theme was that of “denial”; a term used within the support groups studied, and also within the public and research discourse, as a label for caregivers who appeared to be resisting the inevitability of residential placement.

Gubrium concluded that, in order to understand the residential placement decision and its determinants, it was essential to consider, not merely the measurable characteristics of home and residential care options, of available support, of caregiver stress, and of their interaction, but also to understand the meanings of “home” and of “institutionalisation” in this context, and the ongoing evaluative and interpretive process undertaken by caregivers when making the decision and determining its timing.

In their study of African American and White elderly people and their caregivers, Sudha and Mutran (1999) were critical of the Andersen model of health service usage. They asserted that even in its revised version (Andersen, 1995) the model was static and

too simple, and thus it underplayed the impact of social and cultural factors such as ethnicity, power and values. They proposed a more dynamic version of the model in which attitudes to long-term care would be seen as health beliefs that derived from, and were reciprocally influenced by, social and demographic factors (including predisposing and need factors) rather than existing in parallel to them. Sudha and Mutran noted that, despite greater disability, African American people were significantly less likely than White Americans to use nursing home care (Belgrave, Wykle, & Choi, 1993). This had been attributed to social and financial barriers to access, and/or to a preference among African Americans for families to take care of their own members. Sudha and Mutran hypothesised that attitudes to residential care and to family care might differ between these ethnic groups. They observed that with regard to long-term care decisions, ethnicity and attitude were often studied separately and their possible interaction had not been studied in detail. Their study was designed to separately measure and analyse attitudes to family care and to rest homes, and to compare both across ethnic groups.

Sudha and Mutran interviewed 492 family caregivers, recruited through a parallel 1994 study of 537 randomly selected elderly people aged 65 and over which is reviewed below (Keysor et al., 1999). The elderly participants were required to have one or more self-reported limitations in activities of daily living (ADL) but be cognitively able to undertake a telephone interview. They were recruited, via state Medicare records, from 10 counties in North Carolina, USA, which had been selected using demographic criteria to ensure a mix of ethnic groups and available care services. The mean age of the elderly respondents was 75 years (range 66 to 98), with 71% being female, 63% being urban, 47% being White, and 36% being married. More than half of the elderly sample had three or more comorbidities, and described their health as being fair or poor.

Two-thirds of the caregivers studied were caregivers of the elderly respondents taking part in the survey, the remainder being caregivers of elderly people who had also been approached to take part in the survey but who had refused or been unable to. The caregiver group comprised 265 African American and 227 White people. Members of other ethnic groups were excluded from the study. The mean age of caregiver respondents was 56 years (range 24 to 90), with 70% being female, and 61% being urban.

The attitudes regarding rest homes held by all respondents, both the elderly group and the caregiver group, were evaluated by asking participants to agree or disagree with a series of statements concerning rest homes and family care. Rest homes were a common long-term residential aged care option in that region, providing low level care (Keysor et al., 1999). Need variables were obtained by asking about the elderly person's self-perceived health and any limitations in their ability to perform basic ADL and instrumental activities of daily living (IADL). Enabling variables were sampled by asking about current sources of care for the elderly person (family, friends, church or paid help). The predisposing variables measured were age, gender, race, years of education, economic disadvantage, marital status, number of offspring and number of other relatives (for elderly respondents) or siblings (for caregivers).

Additionally, caregivers were asked about their own perceived health, and their prior experience of rest homes. Several "burden of care indicators" were collected: perceived need for assistance in care, actual assistance received, and the strength of feeling that care provision was having a negative impact, both on the caregiver's own life and on his or her family relationships.

Initial factor analysis revealed three underlying attitudinal constructs, which were the same for the African American group and the White group. These were a belief that family care at home was preferable to residential aged care, a negative attitude towards rest homes as locations for long-term care, and a single item expressing level of willingness to place someone in a rest home (asked of caregivers) or to live in a rest home oneself (asked of elderly respondents). Structural equation modelling revealed that African Americans were more likely than Whites to express a preference for family care. This was so for elderly respondents and also for caregivers.

Among the group of elderly respondents, family care was preferred more strongly by men, and by those with worse self-perceived health, lower education and lower income. Among the caregivers, family care was preferred more strongly by men, and by those with lower education, those who had less experience of rest homes, those who reported less stress and hardship in the caregiver role, and those who had been providing care for a shorter time. There was a weak negative relationship between being married and preference for family care, however this was not found to be statistically significant ($p = -.09$). The researchers commented that some of the caregivers were spouse caregivers and were married to the elderly care recipients, whereas other caregivers were the married offspring of the care recipients. The researchers attributed the possible negative relationship between the variables to the responses of this latter group of respondents.

With regard to dislike for rest homes, although African American respondents expressed a stronger preference for family care than did White respondents, they also expressed less dislike for rest homes than did White respondents.

Apart from ethnicity, few other variables significantly predicted dislike of rest homes. In the group of elderly respondents, those who were not receiving help from friends or family expressed more dislike of rest homes. Among the caregivers, those who were younger and more economically disadvantaged expressed more dislike of rest homes.

With regard to elderly respondents' potential willingness to be placed in a rest home, this was most strongly predicted by their attitudes. Both preference for family care and dislike for rest homes were positively related to unwillingness to be placed. Ethnicity was the next strongest predictor, with African American elderly respondents being less willing to enter a rest home. Married people were also less willing to do so.

With regard to caregivers' potential willingness to place the care recipient in a rest home, this too was most strongly predicted by attitudes. Both preference for family care and dislike for rest homes were related to unwillingness to place the care recipient. Willingness to place the care recipient was greater among men and among younger caregivers. More marginal effects were found as follows; more willingness to place the care recipient was expressed by those caregivers who had fewer siblings, by those who felt more stress and hardship, and by those who felt that their family lives were being negatively affected by care giving. Caregivers whose care recipients were more dependent in terms of ADL and IADL also expressed more potential willingness to place them.

Sudha and Mutran concluded that their results supported their proposed model. In both the elderly care recipient group and the caregiver group, preference for family care and dislike of rest homes predicted willingness to consider rest homes. Although the constructs underlying attitude formation in both ethnic groups appeared similar, there

were ethnic differences in the attitudes expressed. African American respondents preferred family care more, and disliked rest homes less, than did Whites. However although elderly African American care recipients indicated more unwillingness to consider placement than did their white counter-parts, African American and White caregivers showed no ethnic difference in their willingness to consider placement. Sudha and Mutran concluded from this complex and interactive pattern of responses that, alongside, and interacting with, other factors such as need and structural barriers, attitudes played a significant part in determining willingness to use services. It was also concluded that the relative under-utilisation of residential aged care by elderly African American people might reflect both dislike of residential care and preference for family care, and that these variables needed to be examined separately.

Wallhagen and Strawbridge (1995) conducted a quantitative and qualitative North American study of 100 individuals (mean age 50 years, range 29 to 70, 83% female) who were the adult caregivers of aging parents, focussing on the caregivers' views of how they themselves wished or expected to be cared for in later years. Most of the caregiver participants were white (88%), married (67%) and employed (69%). They were providing an average of 22 hours per week of care. Of the care recipients (mean age 80 years, range 59 to 97), 74% were mothers, 18% were fathers, and 11% were parents-in-law. Their most common major health problems were dementia and/or mental illness (46%). Of the care recipient group, 56% lived with the caregiver.

When asked "*Do you feel that adults should be willing to take care of their parents or in-laws when they become old and frail?*" the majority (76%) of the adult caregivers surveyed responded positively. However, when asked "*What if anything has caring for (care-receiver) taught you about how you might want to be taken care of if*

you were in a similar situation?" 46% indicated that they did not want family care for themselves in future. Those who did indicate willingness to receive family care expressed a number of reservations. Only 12% expressed a wish to be cared for in the same way, while 16% expressed a desire to set limits on the care received so as not to be a burden to their children, and 9% were unsure that the same type of family care would be available to them.

Reluctance to receive family care in future was not significantly related to the quality of the relationship with the elderly parent presently being cared for. Reluctance was, however, positively associated with all other caregiving variables measured: conflict with relatives, considering nursing home placement, burden, tasks performed, poor mental health, and years of care provision (even when age was controlled for). Reluctance to receive family care was also positively (if less strongly) associated with the caregiver's age.

In a qualitative study of family caregivers, Hagen (2001) commented that much research on the placement decision had been retrospective. Hagen prospectively interviewed five family caregivers (two wives, two daughters, and a son), recruited through the geriatric outreach program of a large urban Canadian hospital. All five were living with, and were primary caregivers for, individuals aged over 65 years with dementia. All caregivers had been identified as considering nursing home placement of the care recipient, but none had yet made an application for placement. Their responses were analysed in terms of themes or variables, of which six emerged. Those who described themselves as more able to make the placement decision generally described themselves as higher on three variables: independence in their relationship with the care recipient, perceiving more support from others, and having more sense of existential

self, i.e. having an identity apart from that of caregiver. They were less likely to describe themselves in terms of another three variables: guilt, fear of loneliness, and negative attitude to nursing homes. Hagen observed that these variables resembled those found elsewhere in the existing literature and concluded that the placement decision process was a complex one, to which many factors of caregivers' own lives were relevant, making the decision easier for some caregivers than for others. Hagen also noted that, as in the bereavement literature, a stronger sense of self and of independence seemed likely to help with adjustment to a change or loss of role.

In their telephone survey of 278 family members who were primary caregivers of dementia patients in the Taiwanese cities of Taipei and Kaohsiung, Chiu et al. (2001) asked whether caregivers would be willing to place the care recipient in a nursing home later on, if the dementia progressed. Willingness to place the elderly person in a nursing home in future was predicted by the current mental status of the care recipient. Caregivers were more likely to express future willingness to place elderly relatives with severe mental impairment, than to place elderly relatives who currently had only mild mental impairment. Additionally, for caregivers in Taipei (the more highly urbanised of the two cities studied), the availability of care-giving assistance from other family members was a relevant factor of their willingness to consider placement. Primary caregivers who had no assistance expressed more willingness to consider placement of the elderly person in future.

4.2.5 The ill

Between 1989 and 1994 Mattimore et al. (1997) conducted a survey of 3262 seriously ill adults in hospital. The mean age of participants was 61.8 years, with a

standard deviation of 14.6 years. Their poor health status suggested a high level of ‘need’ according to the Andersen model. Despite this, only 26% of respondents indicated willingness to enter a nursing home, with 7% of respondents indicated that they were “very willing” and 19% “somewhat willing”. In contrast, 11% were “somewhat unwilling”, 26% were “very unwilling” and 30% indicated that they “would rather die”. Six percent responded that they did not know.

4.2.6 Elderly people

Through the 1979 Statewide Survey of Older Virginians, McAuley and Blieszner (1985) surveyed 1240 North Americans aged over 60 who were cognitively intact and living in their own homes, alone or with their spouses. Using five separate questionnaire items they asked respondents whether “*if (they) became sick or disabled for a long time*” they would consider each of five long-term care (LTC) arrangements: adult day care, moving to a relative’s home, care from relative in one’s own home, paid in-home care, and nursing home care. Respondents most often indicated willingness to consider receiving care in their own homes, whether from a paid carer (70%) or a relative (66%). Adult day care was the next most frequently selected option (32%), followed by nursing home care (28%) and moving to the home of a relative (15%). Most respondents selected at least one option which involved being cared for in their own home (93%), and at least one option involving care from a non-relative (87%).

The factors associated with each choice were examined using a series of stepwise logistical regression analyses. Respondents who indicated a willingness to consider receiving LTC in a nursing home were more likely to be unmarried, to be non-white, to

have higher incomes, and to indicate that they did not have someone who would care for them for an extended period. Those who would consider moving to the home of a relative were more likely to be male, to be unmarried, to have a low income, and to believe that they had someone who would care for them for an extended period.

People who nominated paid care in their own home among the LTC options they would consider were more likely to be white, to have emotional problems, and to have a confidant. Those who indicated willingness to consider care in their own home from a relative were more likely to be male, to be married, to have low incomes, and to believe that they had someone who would care for them for an extended period. Those who nominated adult day care among their options were more likely to be non-whites, to be younger, to have better perceived health, and to have more emotional problems.

McAuley and Blieszner found that their study supported the widespread assumption that elderly people preferred to receive care in their own homes if possible. They noted the interplay of social and psychological factors including gender role, race, marital status, mental health, and the availability of practical and emotional support, which clearly influenced elderly people's preferences with regard to use of services. They also concluded that, as a group, elderly people were realistic about their care options, reluctant to move to the homes of relatives, and willing to consider a mix of formal and informal care.

As mentioned above, in 1981 a randomised and weighted survey of elderly people, aged over 60 years and living at home (920 respondents in Adelaide and 1200 respondents in Melbourne), and their family caregivers, was conducted by the Australian Council on the Ageing and the Australian Department of Community Services (1985). Elderly respondents were asked about their demographic details, health

status, health service needs and usage, housing, care needs, social contacts, work and retirement, and life satisfaction

The researchers observed that previous Census data had indicated a high level of residential mobility in the Australian community, with 45% of the population having changed address in a five-year period. This had been less evident in the older age group, with only 20% having changed address in a five-year period. As part of the housing section of the survey, respondents were asked whether they would like to move in the next five years, and whether they might wish to move when they became very much older. The majority of respondents (66%) indicated a preference for staying where they were, whereas 18% indicated a wish to move in the next five years and 16% indicated that they might wish to move when they were much older.

There was a significant age difference in the pattern of responses. Respondents aged 75 years and older were significantly less likely to indicate an actual or potential willingness to move (27%), when compared with those aged 60 to 64 (43%). The researchers commented that this might reflect older respondents having moved house already, or feeling less able to manage moving, but that it might also reflect an attachment to one's home, which increased with age and led to increasing reluctance to move.

Willingness to move was also associated, but less strongly, with gender, marital status and living arrangements. Men were more likely than women were to say that they would not move (70% as against 63%). Married men (71%) were more likely than single men (65%) to say that they would not move. Those who lived alone were more likely to indicate a willingness to move (38%) than were those who lived in other types of household (33%). Level of handicap exerted only a marginal influence; those who

reported a moderate or severe level of handicap being slightly less willing to move than other respondents (31% as against 34%).

Attitudes to the neighbourhood were explored further. It was found that 88.2% of respondents expressed liking for at least some aspect of their neighbourhood, while 33.6% expressed dislike for at least some aspect of their neighbourhood. The total amount of like and dislike did not vary significantly across the age-groups in this elderly sample, although younger respondents were likely to express both more reasons for liking and more reasons for disliking their neighbourhood. However, across the sample, the older respondents, and in particular those aged over 75, were more likely than younger respondents to give reasons for liking their neighbourhood in terms of having lived there a long time, liking their neighbours, and being near relatives and friends. They were less likely than younger respondents to report liking their neighbourhood because of its facilities or the general environment. Reasons for disliking the neighbourhood did not vary with age. It appeared that with age, preference for one's neighbourhood was increasingly experienced in terms of it being a familiar place, and providing proximity to relatives, friends, and neighbours.

In the late 1980's Biedenharn and Normoyle (1991) surveyed 250 North Americans aged over 60 years and living in the states of Indiana and Illinois, concerning their fear of entering a nursing home, and their perceived likelihood of doing so. Participants were recruited through a range of elderly citizens' groups, nutrition sites and retirement facilities. None was living in an institution. Most were white (98%), female (78%), had children living locally (62%), and had had at least some college education (56%). Two thirds were not married.

Biedenharn and Normoyle found that 16% of respondents reported being extremely fearful that they might someday have to enter a nursing home, 60% reported being somewhat or quite fearful, and 24% expressed no fear at all. Presented in turn with three different hypothetical circumstances; either being unable to live alone, being unable to survive otherwise, or entering a nursing home in order to avoid being a burden on one's family, respondents were asked to rate how likely they would be to entering a nursing home. Depending on the circumstances, they rated their likelihood of entering a nursing home as between 32% and 50%.

Fear of entering a nursing home was reported as higher by those respondents who believed that the cost would be prohibitive, those who reported that approaching relatives for help would be difficult, and those who believed that most families were unwilling to provide care. Fear was also more pronounced in those who felt that quality of life in a nursing home, and in particular the standard of care, would be poor; specifically, those who felt that the care would be problematic, and that it would be difficult for nursing home residents to maintain dignity, control over their lives, and an interest in worldly events.

Entering a nursing home was seen as at least a possibility, under one or more of the three hypothetical conditions, by 92% of respondents. Perceived likelihood of entering care was greater among those who assessed nursing home residents' quality of life as being poor. In attempting to interpret this somewhat paradoxical finding, the researchers commented that respondents possibly believed that people who were so disabled as to have to enter a nursing home against their inclination would not have the physical or mental capacity to enjoy life there. Perceived likelihood of nursing home

entry was also, and more predictably, related to feeling that it would be difficult to approach relatives for care.

Biedenharn and Normoyle also found that among respondents who had recently visited a nursing home, those for whom the experience had been positive had more positive attitudes to the quality of life of nursing home residents, and to families' willingness to assist elderly people.

In 1995 McCormick et al. (2002) surveyed 1244 Japanese Americans and 1354 Caucasian Americans, all aged over 65 years and living in the state of Washington, USA. When participants were presented with the hypothetical future situation in which they had dementia, 53% of the elderly Japanese Americans and 38% of the elderly Caucasian Americans said that they intended to use a nursing home, whereas 39% of the elderly Japanese Americans and 42% of the elderly Caucasian Americans intended to be cared for at home, by paid carers or family members. In each group, people who were married were less likely to indicate a future intention to use nursing home care. In explaining the higher intention by elderly Japanese Americans to use nursing home care, it was thought relevant that as a group they had a longer life expectancy than Caucasian Americans, and that there was a Japanese nursing home in the area where the survey was conducted.

Woenne-Green (1995) coordinated an indigenous and non-indigenous project team exploring the attitudes of central Australian indigenous elderly people, their relatives, and service providers, to the provision of long-term care and residential aged care services. Using an action research methodology, the project team surveyed members of the Ngaanyatjarra, Pitjantjatjara Yankunytjatjara indigenous communities in South Australia, Western Australia and the Northern Territory. Interviews (one-to-

one and in small and larger groups) were conducted by teams, each comprising an indigenous local person and a non-indigenous person.

It was noted that the average life expectancy of Aboriginal people (57 years for men and 62 years for women) was significantly less than that of non-indigenous people (Woenne-Green, 1995). Demographic information on the communities studied revealed that of their 4,827 members, only 749 (16%) were aged over 45. For the purposes of the study, Woenne-Green defined an elderly person as a senior person who was considered by others to be at risk: a definition that included “those persons who, regardless of age, were not able (or soon would not be able) to function independently of some form of assistance, either medical or from other sources of support” (Woenne-Green, 1995, p.16). The Docker River Community had operated a small pilot residential care facility in the past. However at the time of the study, apart from the provision of meals and some informal assistance with daily activities, no communities provided formal services to the aged or to younger people with disabilities. Some community members had had the experience of placing elderly relatives in hospitals or aged care facilities in towns. The project team interviewed approximately 400 indigenous people from 15 communities, including approximately 65 senior men and women, and their adult offspring. In addition they interviewed 30 medical staff, and visited a residential meeting of 80 senior members of the communities.

Analysing the interview data, Woenne-Green identified and described a shared understanding of the traditional model of care for the elderly, which was portrayed by respondents as still being the ideal, and as an obligation for the younger generation and particularly for women, but now rarely achieved. This model involved placing a high value on elderly people; putting their needs first; never leaving them alone; providing

them with the proper food; making special arrangements for their comfort; and the provision of hands-on care by a number of people. Older people would live as a small group (for example elderly siblings, or the parents and/or parents-in-law of a couple) and be cared for by a number of family members. This arrangement provided company for the elderly people and shared support for the caregivers. Another theme which emerged was the importance of dying on one's own country (one's tribal and totemic homelands).

Although endorsing the traditional model of care, respondents commented that current housing arrangements made it difficult to achieve, and that younger people might be reluctant to move to the older people's homelands for this purpose. There might also be reluctance to abandon a dwelling place after a death, as custom required. Nevertheless, a strong belief was expressed by elderly people and their relatives, that relocation into residential care was such a disruption of the natural course of events that it would lead to death, either immediately, or sooner than would otherwise have been the case. Separation from family and country should not be considered.

Rabiner (1996) used data from the USA National Long-term Care Survey to test hypotheses concerning the effect of attitudes to nursing home care on subsequent care utilisation, and also the effect of previous nursing home utilisation on current attitudes. The NLTC survey was a longitudinal study of a sample of people aged over 65, living in the community, who were enrolled in the Medicare system and had limitations in their activities. The study focussed on respondents' health status, attitudes and health service usage. Respondents were selected and their responses analysed using a weighted sample, and the sample was found to be representative of the community-dwelling elderly with functional limitations in the USA in 1982. Data from the 1989 wave of the

NTLC survey had become available in the public domain by the time the study was conducted, but unfortunately all items concerning attitudes to nursing home usage had been excluded from that wave. Rabiner used data from the 1982 and 1984 surveys instead.

The 1982 baseline sample had comprised 6,393 individuals. Rabiner's sample comprised 4,182 of the original respondents; those who were still alive and living in the community in 1984, and who had been able to complete their own questionnaires on both occasions (rather than having their questionnaires completed by proxy respondents). Individuals who were resident in nursing homes at the time of the second survey were excluded from Rabiner's analysis. While this might appear paradoxical, Rabiner justified the decision on the basis that residents' attitudes to nursing homes might have been modified by their subsequent psychological adjustment to placement, and/or that they might have been more reluctant than others to be frank about their attitudes to nursing homes, for fear of negative consequences.

The mean age of respondents was 76 years (range 65 to 108). Most respondents were female (two-thirds), White (86.6%), and not married (55%). They had an average of 2.3 children, and of more than two face-to-face contacts with relatives each week. There was a moderate level of disability, with an average of 1.02 limitations in activities of daily living (ADL) and 3.62 limitations in instrumental activities of daily living (IADL). Cognitive functioning was reasonable (an average of 6.67 on a scale from 1 to 10). Self-reported health ranged from poor (21% of the sample) to fair (34%), good (32%) and excellent (13%). At baseline 6% had prior experience of being in nursing home.

In Rabiner's study, attitudes to nursing homes were studied on the basis of responses to three questionnaire items; whether; "*In nursing homes, there is lots to do to keep people busy*", "*In a nursing home, people can count on help 24 hours a day*", and "*It's best to stay out of nursing homes as long as you can*". At baseline 70% of respondents reported that there was lots to do in a nursing home, and 99% reported that it was best to stay out of nursing homes as long as possible.

Applying the Andersen model, Rabiner found that four predisposing factors were predictive of nursing home usage between 1982 and 1984. Respondents who were older, who were not married, and who had indicated that there was lots to do in a nursing home were more likely to have used nursing home services, and to have done so for more months, during that period. Respondents who were White were more likely to have used nursing home services, but not to have had longer stays. Only two enabling factors were significant. Respondents in the 'North Central' and West regions of the USA were more likely to have used nursing home services (and for longer), as were people who had fewer children. Three need factors were significant; those who had more ADL or IADL limitations, and those reporting lower level of health, were more likely to have used nursing homes, and for longer periods.

At follow-up, attitudes as indicated by responses to the three questionnaire items were examined for their relationship to predisposing, enabling and need factors. Respondents who indicated that "*In a nursing home, people can count on help 24 hours a day*" were likely to be older, to be in better health, to have more children, to live on a farm, not to live in a city, and to live in some census regions rather than others. There was no relationship between responses to this item and prior nursing home experience.

Respondents who indicated that “*It’s best to stay out of nursing homes as long as you can*” were more likely to be older, be married, have more children, to live in cities or the suburbs of large cities, to live in some census regions rather than others., to be in good health, to have fewer ADL limitations, and to have decreased cognitive functioning. There was no relationship between responses to this item and prior nursing home experience.

Respondents who indicated that “*In nursing homes, there is lots to do to keep people busy*”, were more likely to be female, to be less educated, to live on farms, not to live in cities and to live in some census regions rather than others. There was no relationship between responses to this item and prior nursing home experience.

Rabiner concluded that having a favourable attitude towards nursing homes had a significant positive effect on subsequent service usage. However previous experience of nursing homes did not have a significant impact on respondents’ attitudes. Rabiner recommended that service planners should be mindful of geographic variations in attitudes, and that attitudes to nursing homes should be studied in more detail. Rabiner also suggested that nursing home placement decisions should be studied in more detail, particularly the impact of key decision-makers (the patient, family members, physicians and nursing home personnel) on the incidence of nursing home usage and on length of stay.

Reviewing the research to date, Schoenberg and Coward (1997) observed that a number of personal and contextual factors impacted on nursing home usage in the USA. African-Americans were less likely than the average American to enter a nursing home, and rural people were more likely than urban people to do so. Although there were enabling factors at work (rural people had access to relatively fewer community care

services, and relatively more nursing home beds, than did urban Americans) Schoenberg and Coward proposed that predisposing factors might also be operating. They therefore decided to interview elderly urban and rural African-Americans, to compare their attitudes to future nursing home placement. On the basis that women who were not married were more likely than others to enter nursing homes, and that they made up the majority of nursing home residents, the researchers elected to interview only women who were not currently married. They interviewed a convenience sample of 50 urban and 48 rural women, recruited through church and community groups. The urban respondents all lived in one large city in northeastern Florida, and the rural respondents lived in, or outside, nine small towns, also in northeastern Florida. Participants were aged between 65 and 94 years, with a mean age of 75 years (SD 8). A 111-item questionnaire covering predisposing and need factors (health status, family structure, health beliefs, etc) was followed by five questions covering respondent's own experience of nursing homes. Finally two open-ended questions: "*What do you think it would be like to move into a nursing home?*" and "*When is it "OK" for an older person to go into a nursing home?*" were asked and responses to these were analysed using formal content analysis.

In response to the first open-ended question, 56% of respondents expressed negative evaluations of nursing homes, and these fell into four categories; "Nursing homes are a big adjustment" (10% of sample), "Nursing homes are bad places to live" (10%), "Nursing homes are places to die" (3%) and "An undifferentiated resistance to entering a nursing home" (33%). Positive responses were grouped into three general themes: "Nursing homes can be beneficial if one's physical condition demands them" (17%), "Nursing homes are a good option if the care is good" (5%), and "An

undifferentiated appreciation for or positive perspective on nursing homes” (11%). Perceptions of nursing homes that depended on family circumstances were expressed by 13% of the sample. These perceptions were summarised as “Nursing homes are a good option if others cannot care for you” (several respondents), “Nursing homes are unacceptable because others have an obligation to care for you” (a very few individuals), and “Nursing homes are preferable to over-burdening one’s family” (3%).

In responses to the second open-ended question, respondents identified the combination of mental and physical incapacity with family inability to provide care, as indicative of the condition which it would be reasonable to enter a nursing home.

Elderly women living in a rural area expressed more positive attitudes to nursing homes than did their urban counterparts, perhaps, as the researchers commented, because there were fewer available alternatives such as community care. Familiarity may also have been a factor. Almost all of the rural respondents, but fewer than half of the urban respondents, had visited a nursing home. Also, given the nature of rural and urban communities, the researchers commented, rural respondents were more likely to be acquainted with the staff and residents of the local nursing homes they might envisage entering, than were urban respondents.

Schoenberg and Coward concluded that, among these elderly African-American women, in both urban and rural settings, there was a “surprisingly high level of acceptance of nursing homes” (Schoenberg & Coward, 1997, p.12). They attributed this to the possibility that respondents were discussing a hypothetical option rather than making a real choice. They also concluded that perception of family supports played a crucial role in attitudes to nursing homes. These elderly women often expressed attitudes to placement as being conditional on family circumstances, and they also

defined the criterion for acceptability of nursing home placement as the combination of severe disability with inability of the family to provide care.

Keysor and colleagues (1999) proposed and tested a modification of the Andersen model in which “appraisal” factors might intervene between the three Andersen groups of factors (predisposing, enabling and need factors) and the decision about service utilisation (see Chapter 1). They interviewed 537 randomly selected people aged 65 years and over, identified as having one or more self-reported limitations in ADL but cognitively able to undertake a telephone interview. Participants were recruited, via state Medicare records, from 10 counties in North Carolina, USA, which had been selected using demographic criteria to ensure a mix of ethnic groups and available care services. The mean age of the respondents 76 years (range 65 to 99 years), with 73% being female, 47% being White, and 36% being married. More than half of the sample had three or more comorbidities, and described their health as being fair or poor.

Respondents were presented with two hypothetical situations in which they had had a stroke and required 24-hour care. One situation involved partial dependency for a month, and the other involved complete dependency for the foreseeable future. For each scenario, appraisal variables were determined by asking respondents to evaluate home care in terms of financial manageability, strain on family relationships, and level of stress to themselves. Respondents were also asked whether in that situation they would prefer to go to a rest home (the term having been selected for this sample because it implied long-term residential care). This was defined as the outcome variable reflecting preferred service usage. Respondents’ attitudes to rest homes were evaluated by asking them to agree or disagree with a series of statements concerning rest homes. Need variables were obtained by asking respondents about their ADL and IADL limitations.

Enabling variables were sampled by asking whether the elderly person lived alone or with a caregiver – this was defined as a marker for family resources. Predisposing variables were age, gender, race, years of education, household income, and marital status.

In the short-term disability and home care scenario, anticipated financial difficulty was found to be associated with low income, worse perceived health, more than three comorbidities, and living alone. Family strain was associated with worse perceived health, and with low income. Personal stress was not significantly associated with any variable.

In the long-term disability and home care scenario, anticipated financial difficulty was associated with worse perceived health, and with living alone. Family strain was associated with worse perceived health. Personal stress was associated with higher education, higher income, and being white rather than African-American.

Preferred location of care (own home versus rest home) was predicted by marital status, attitude towards long-term care facilities, financial difficulties, family strain, personal stress, severity of situation, and an interaction between financial difficulty and severity of situation. Home care was more strongly preferred in the less severe of the two hypothetical scenarios. Home care was more strongly preferred by married people, those respondents with more negative attitudes to long-term care, and by those who predicted home care as likely to involve less financial difficulty, family strain or personal stress.

Keysor et al. concluded that the appraisal factors they had defined played a significant role in the decision about location of care, to the extent that once they had been included in the model, only one demographic factor – marital status - remained

significant. In considering short and long-term care decisions, elderly people were strongly influenced by their individual appraisal of the situation; not only its severity (a 'need' factor) but also its likely impact on themselves, their finances and their families.

As mentioned earlier in the chapter, using the same sample as a basis for recruitment, Sudha and Mutran (1999) had compared attitudes of African-American and white elderly people, and of African-American and white family caregivers. Their findings are summarised in Section 4.2.4.

4.3 Conclusions

This review of the literature on prospective attitudes to residential aged care leads to a number of conclusions, and some suggestions for further research.

- People appraised their own future likelihood of entering residential care in terms of their present and future health status, their marital status (especially for men) and the number of their children (more so for women). Attitudes to residential care varied between ethnic groups and genders, but not always simply or predictably.
- Respondents who expressed more willingness (or less unwillingness) to move into residential care were those who were younger, who lived alone, who lived in the country, who expressed more preference for family care, who disliked rest homes less, and who had experienced care-giver burden themselves.
- Family caregivers indicated more potential willingness to place their family members when mental impairment was greater, when care needs were higher, when care had been provided for longer periods, and when there was more burden on the caregiver and family. There was some indication that placement could be seen as

developmental and normal at a certain time, and beyond this time not making the decision was seen as “denial”. However this idea appeared to conflict with another view, expressed by all ethnic groups studied, that family care was preferable to institutional care.

- The concept of “home” is very salient to this area of study, and it is probably at least as influential as the image of the nursing home. With each decade of life, those elderly people who were still ageing in their own homes and in their own communities appeared less interested in moving in order to receive care. They also appeared more attached to their homes in terms of their familiarity, and of their proximity to relatives, friends and neighbours. These were aspects of life, and of quality of life, which a residential aged care facility could rarely provide.
- It was apparent from the literature review that simple research questions were likely to receive simple answers. As a single factor, “willingness” to move was low and “fear” was high. Very few people wanted to move into a residential aged care facility, and very few people wanted to place an elderly relative in care. However when more complex questions were posed, they evoked more complex responses. Almost everyone appeared to accept that there were situational variables that made the residential care decision – which was psychologically and culturally difficult – inevitable at some point.
- In terms of evaluating predisposition, the research question then became, not whether or to what extent residential long-term care was an acceptable option, but what factors could over-ride its initial unacceptability. Elderly people and their family caregivers appeared to share the view that these factors included the level of health care needs, the needs of the caregiver and of other family members, the

mental state of the elderly person, financial pressures, and the wish not to be a burden. It was apparent that when studying attitudes and health beliefs concerning residential care facilities, it was also important to ask about attitudes to home, to residential stability or mobility, and to family care (including issues of personal and financial strain).

- It needed to be acknowledged, as it was by some but not all of the researchers in this area, that in every prospective study the research questions are to some extent hypothetical. Even the people who were elderly or ill were being asked what they would do in a hypothetical situation, rather than what they were doing, or had done, in a real situation. Nevertheless it appeared that even consideration of a hypothetical placement decision was a complex matter, with caregivers and care recipients clearly weighing up the pros and cons of the status quo at home and of the potential move.
- It also appeared that prospective studies had not comprehensively explored the views of all those who were, or would be, involved in the residential care decision. There had been a number of surveys and studies of those for whom consideration of residential placement appeared imminent (family caregivers, those in mid-life, the elderly and the ill). There had been less recognition that everyone in the community was potentially involved in a range of ways; as electors, as taxpayers, as family members, as health professionals, as employees and planners in the aged care industry, and, in future, as potential family caregivers and residential care recipients. Given that long-term services need to be planned before they can be delivered, and that predisposition has an influence on usage, it appeared that prospective views of the community at large should be studied but this had not been undertaken.

A number of gaps in the literature were identified. Most importantly, no community-based survey of prospective attitudes to long-term care was found in the literature searched. Also, many of the studies which examined prospective views in stakeholders were limited either in the number of people interviewed, or in the detail and complexity of the information obtained. Large studies tended to ask few, and closed, questions about long-term care options. Accordingly the information obtained lacked detail and predictive value. Studies which asked detailed questions often utilised a small number of participants, and responses were described but not critically analysed or triangulated against other data. It was not always clear how far the findings of these studies could be generalised.

As a result of this prospective literature review (augmented by the findings of the retrospective literature review in Chapter 6), a number of areas requiring research had been identified and the second and third studies within this project were designed.

A study of prospective values concerning long-term care and residential placement decisions, within the general community, was planned. Chapter 5 describes a survey designed to ascertain the prospective attitudes and priorities of adults in the South Australian community, when considering the determinants of the residential care placement decision for an elderly person with dementia. In parallel with the quantitative survey study, an interview study (Chapter 7) was also designed and conducted, using a relatively large number of stakeholders, and applying research-based qualitative thematic analysis to the interview responses.

Chapter 5. Prospective values concerning residential placement: a stratified random survey of South Australian adults

5.1 Overview

A stratified random survey was undertaken in the South Australian community, designed to ascertain the prospective attitudes and priorities of adults, when considering a potential residential care placement decision concerning a frail elderly person.

5.2 Aims of the study

The study aimed to survey the attitudes of the South Australian population aged 15 years and over, and in doing so, to ask a question complex enough to enable some delineation of the community's health beliefs in the area of residential placement of frail elderly people. The community survey was designed to serve as a triangulation point for validation of the qualitative study. It provided a check on the extent to which the priorities reported by stakeholders (elderly people likely to be involved in residential placement decisions, their relatives and the health professionals who worked with them) might be shared by the South Australian community.

The specific area of inquiry was the nature of the priorities or values which community members might see as over-riding the unacceptability of residential long-term care for an elderly person, and justifying the consideration of placement. The literature review (Chapter 4) showed that these priorities and values had usually been studied retrospectively, and/or among stakeholders such as elderly people or their family caregivers, but that prospectively held community values had not been studied in any detail.

Age and gender differences in attitudes or priorities were a particular focus. The review of the prospective literature (Chapter 4) concerning stakeholders had revealed significant age-differences in attitudes to placement and its determinants. The review of the qualitative and retrospective literature (see Chapter 6, and in particular the discussion of McCullough et al., 1993) had also raised the possibility of age-differences as a significant issue. It appeared that with regard to the timing of the placement decision, elderly people might be more likely than younger people to place a higher priority on values related to autonomy (McCullough et al., 1993; Woenne-Green, 1995) and a lower priority on physical health and safety. This might conflict with their younger relatives' values, and also with health professionals' focus on duty of care and on patients' physical health and safety (Healy, 1998). The literature review in Chapter 4 had revealed gender differences in the way in which hypothetical and future situations were considered. Also it was apparent in the caregiver literature that women were more likely than men to undertake, and to be expected to undertake, unpaid care of family members (C. A. Lee, 1999; National Alliance for Caregiving & American Association of Retired Persons, 2004).

Another focus was the values or priorities expressed by caregivers. It appeared from the prospective literature (Chapter 4) that caregivers considered the mental status of the elderly person and the amount of burden experienced by family caregivers to be salient to the residential placement decision. It had also been suggested in the qualitative retrospective literature (see Chapter 6) that family caregivers of older people might experience a conflict between two sets of priorities or values: physical safety and autonomy (Dellasega & Mastrian, 1995; McCullough et al., 1993). On that basis it was hypothesised that with regard to priorities based on concepts of safety or autonomy,

people who were caregivers might show a different pattern of priorities from other respondents. It did not appear reasonable to hypothesise directionality of responses.

The hypothetical elderly person described in this study was based on the profile extracted from the casenote review (Chapters 2 and 3). However, the survey conditions required that the description be very succinct: no more than one sentence. It was decided to encapsulate a range of issues by describing the hypothetical elderly person as having confusion and underlying dementia. Dementia combines several features that are relevant to frail elderly people more generally, being a degenerative health condition with implications for ADL and cognitive functioning.

In the survey described here, South Australian adults were asked to consider a hypothetical situation in which an elderly person with confusion and dementia might (or might not) need residential placement. They were presented with a list of possible priorities, and asked which they considered to be most important to in making the decision about residential care placement.

5.3 Hypotheses

The following hypotheses were generated from the literature review and the pilot phase of the survey:

Hypothesis 1 Selection of priorities would vary with respondent age.

Hypothesis 2 Older respondents would be less likely than younger respondents to select either or both of the priorities referring to physical safety: “*Physical safety / risk at home*” and “*Medical and health care needs*”.

Hypothesis 3 Older respondents would be more likely than younger respondents to select either or both of the two priorities referring to autonomy: “*Right to decide for himself or herself*” and “*Wish to continue living at home*”.

Hypothesis 4 Older respondents would be more likely than younger respondents to select either or both of the two priorities referring to strain on others: “*Burden to caregiver(s)*”, and “*Behaviour detrimental to themselves and or others*”.

Hypothesis 5 Selection of priorities would vary with respondent gender.

Hypothesis 6 Selection of priorities by respondents who described themselves as carers would differ from that of other respondents.

5.4 Method

The opportunity to undertake a community survey was provided by the SA Health Omnibus Survey, conducted by the Population Research and Outcome Studies Unit of the South Australian Health Department (Wilson, Wakefield, & Taylor, 1992). Participation was funded by the Psychology Department of the University of Adelaide.

5.4.1 The 2002 Health Omnibus Survey

Since 1991 the South Australian State Government’s Health Department had organised an annual shared cost or ‘omnibus’ survey of South Australian adults’ attitudes and behaviours related to health (Centre for Population Studies in Epidemiology, 2002; Wilson et al., 1992). Each participating health agency drafted one or more questions to be included in the survey, and paid a fee. A private health research firm accredited by the Market Research Society of Australia conducted the survey, which involved face-to-face interviews with at least 3,000 adults throughout the state.

Interviewers were trained and 10% of their interviews were sampled for validation checking, which involved those respondents being re-contacted. Each participating organisation was provided with the results of its own question(s), and with demographic data concerning the sample. Contact details of the other participating organisations were also provided so that, as in this case, survey results could be shared between investigators.

5.4.2 The 2002 sample

In the 2002 survey, 340 metropolitan census collectors' districts, as used by the Australian Bureau of Statistics (ABS) in the 1996 Census in South Australia, were selected, with their probability of selection proportional to their size. Within each of the selected collectors' districts, a starting point was randomly selected, and 10 dwellings were chosen, based on a 'skip pattern' of every fourth household.

The non-metropolitan sample was selected using 100 starting points. All cities or towns with a population of 10,000 or more in the 1996 ABS census were selected automatically, and the remainder of the 100 starting points were selected from smaller country centres (with a population of 1,000 or more in the 1996 census) with their probability of selection being proportional to their size. Again, clusters of 10 households were randomly selected.

Within each of the selected households, from among those household members who were aged 15 or over, the person with the most recent birthday was identified and invited to participate. Only one person per household was invited to participate.

This process generated an initial sample of 4,400 dwellings: 3,400 metropolitan dwellings and 1,000 non-metropolitan dwellings. Of these 128 were found to be vacant,

or to be businesses or holiday homes, or otherwise without permanent tenants. This left a survey sample of 4,272 dwellings. As the survey was based on private domestic dwellings, it excluded people living in residential aged care facilities.

There were 1,257 dwellings (29.4%) from which an interview response was not obtained. In 702 instances (55.9% of non-responses) this was due to refusal (too busy, not interested, etc). In 333 instances (26.5%) non-response was due to the surveyor's inability to make contact, having made 6 visits at different times of the day/evening and on different days of the week. Two interviews were terminated for unspecified reasons.

In the remaining 220 cases, non-response was due to the inability of the selected adult to respond, due to inability to speak English (66 cases: 5.2% of non-responses), illness or mental incapacity (47 cases: 3.7%), being away for the duration of the survey (43 cases: 3.4%), or having a locked gate and/or a ferocious dog (64 cases: 5.1%).

In total, 3,015 interviews were obtained, giving a response rate of 70.6% of dwellings.

In the pilot testing phase, over 50 interviews were conducted during September 2002. Following modifications, the survey interviews began on 24th September 2002 and were completed by 17th December 2002.

5.4.3 Demographic information

Survey respondents were asked for their age, marital status, usual occupation, educational level, country of birth, and how long they had lived in Australia. They were asked whether they were of Aboriginal or Torres Strait Islander background. They were also asked what their total household income was, and how many adults lived in the

household. Respondents' gender, postcode and residential location (Adelaide metropolitan or country centre) were recorded by the interviewer.

5.4.4 The survey format

Because of the size of the sample and the statistical rigour with which it was selected, the Health Omnibus Survey was a potentially useful source of information about community values and priorities. However, the format of the large-scale survey placed considerable restrictions on the type and complexity of question that could be asked.

Because survey interviewers were asking a number of questions, the survey guidelines specified that questions and answers must be concise. A multiple-choice response format was selected. Respondents were asked a question that took the form of a very brief hypothetical example, after which they were asked to indicate which priorities or values they felt were most important in making the decision.

Ranking of responses in order of their importance was not permitted under the survey protocol. Instead, each respondent was asked to review a set of concepts or priorities, listed on a card, and indicate which three of the concepts or priorities were the most important in making the residential placement decision. These three selections were recorded, but not the order of priority among them.

5.4.5 The pilot phase

In the pilot phase of the survey, respondents were asked a question: "In deciding whether or not an elderly person with confusion and severe memory problems should go into residential care (to live in a nursing home or hostel), which three of these factors do

you consider to be most important?” This question was designed to set the scene in which the elderly person requiring placement has dementia.

Respondents were then presented with a card on which were listed six concepts or priorities to choose from (Appendix E). Two concepts reflected the physical safety of the elderly person as a priority (“*Physical safety / risk at home*” and “*Medical and health care needs*”), and two reflected autonomy as a priority (“*Right to decide for himself or herself*” and “*Wish to continue living at home*”). Two more, derived from the literature and the pilot phase of the qualitative study, reflected mediating or protective factors which it was thought might be seen by respondents as determining the relative influence of physical safety and of autonomy, when evaluating a placement decision in an individual case. These were “*Mental capacity to make his or her own decisions*” and “*Amount of help available, from family, neighbours, or community*”.

The interviewers in the pilot phase reported that some respondents had had difficulty with understanding the question, and that the phrase “should go into residential care” might have ethical (coercive) implications. The question was reworded as “needs go into residential care”; to make it clear that it was a question of the perceived appropriateness of this type of care, rather than a question about non-voluntary residential placement.

Some respondents in the pilot phase commented that the six factors listed were not the only important factors in making the residential care decision. They nominated other factors as being equally important to the decision, specifically: “*Burden to caregiver(s)*”, “*Behaviour detrimental to themselves and or others*” and “*Would ask the GP / doctor for advice*”. They indicated that when considering the question it was difficult to disregard these other important factors or values.

5.4.6 *The full survey*

It was decided to include the three new values or priorities suggested by respondents in the pilot group as additional mediating values, along with the original six priorities, in the full survey.

During the preparation of the survey materials by the health research firm, one of these new priorities (“*Would ask the GP / doctor for advice*”) was accidentally omitted from the printed survey form and prompt card. Unfortunately, this was not detected in the proofread. The error was only noticed during the data analysis after the survey had been completed, when it became apparent that this priority had not been selected by respondents. The research firm confirmed that it had been omitted.

The other two priorities had been included correctly, resulting in eight optional values or priorities that were offered to survey respondents for potential selection (Appendix F).

5.4.7 *Data entry and significance level*

Data once obtained were double-punched and entered onto an SPSS database. Where possible, missing responses were followed up by telephone. The survey manager checked all questionnaires, and 10% of each interviewer’s work was checked by re-contacting the survey respondents. A significance level of $\alpha = 0.05$ was adopted for all analyses.

5.4.8 *Sample weighting*

The sample of respondents was weighted in line with 2001 Census figures on age and gender (of individuals) and location (of occupied private dwellings). Individual data

were weighted by the inverse of the individual's probability of selection, then re-weighted to benchmarks derived from the 2001 Census in terms of age and gender. Similarly, questions concerning the household were weighted by the inverse of the household's probability of selection, then re-weighted to benchmarks derived from the 2001 Census of Population and Housing for occupied private dwellings by location. The combination of stratified random sampling and weighting produced a database representative of the community-dwelling South Australian population in terms of age, gender and place of residence.

5.5 Data management

5.5.1 The eight priorities

The scale of the survey and the means of data collection had imposed restrictions on the complexity of the question which could be asked, and hence on the subsequent analyses. Because respondents had been required to choose among the eight priorities presented, and were permitted to indicate only three selections, selection of each priority reduced the probability of selecting any of the other priorities and hence in general, a negative association between selections could be expected. Also, responses to the eight values or priorities were dependent on each other and could not be analysed as independent variables.

Thus, it was not possible to carry out multivariate analyses. Instead, using SPSS CROSSTABS, separate χ^2 analyses were conducted for each of the eight priorities. The large number of relationships analysed increased the risk of Type II errors. This was

addressed by adjustment of p -values according to Holm's method (Aickin & Gensler, 1996), an alternative to the Bonferroni procedure. In the Bonferroni procedure, where α is the assigned level of significance and n is the number of hypotheses or relationships being tested, individual p values (p_i) are compared with α/n instead of α . In the Holm method, individual p values (p_i) are placed in ascending order and for each value, p_i is compared with $\alpha/(n-i+1)$; a procedure which never rejects fewer hypotheses than the Bonferroni procedure, but is more effective in maximising statistical power.

5.5.2 *Grouping of priorities for secondary analyses*

The forced choice methodology had required respondents to make categorical decisions, where choosing each priority meant rejecting several others completely. On one level, this may be a reasonable approach, because real life decision-making requires the same trade-offs. On another level however, it was felt that, as in elections, a first-past-the-post approach to seeking information about attitudes might polarise expressed values, highlight majority or "motherhood" views, and de-emphasise subtleties such as the value of some priorities, which people might feel were relatively less important but still of considerable significance in the decision-making process.

For this reason, secondary analyses were conducted. Priorities that were similar in their underlying values (and may have been equated by respondents, who would then choose one or the other but not both) were grouped together and analysed, using SPSS ONEWAY and MEANS procedures. This allowed deeper analysis of the patterns of responding across the eight non-independent priorities.

Hypothesis 2 (see Section 5.2) was that older respondents would be less likely than younger respondents to select priorities referring to physical safety. Two priorities

within the list of eight had been written as priorities strongly reflecting the physical safety of the elderly person: “*Physical safety / risk at home*” and “*Medical and health care needs*”. The data were recoded to create a new single variable reflecting the selection of the elderly person’s physical safety as an important value when considering the placement decision. For each respondent, the number of the safety priorities selected was summed, giving a maximum safety score of two and a minimum of zero.

Hypothesis 3 was that older respondents would be more likely than younger respondents to select priorities referring to autonomy. Two priorities within the list of eight had been written as priorities strongly reflecting the autonomy of the elderly person: “*Right to decide for himself or herself*” and “*Wish to continue living at home*”. The data were recoded to create a new single variable reflecting the selection of the elderly person’s autonomy as an important value when considering the placement decision. For each respondent, the number of these autonomy priorities that had been selected was summed, giving a maximum autonomy score of two and a minimum of zero.

The two priorities which had been added by the participants in the pilot group, “*Burden to caregiver(s)*”, and “*Behaviour detrimental to themselves and/or others*”, were thought to reflect perceived strain, that is, the negative impact of the elderly person’s condition on others in the family or social environment: The data were recoded to create a new single variable reflecting the selection of strain on other people as an important value when considering the placement decision. For each respondent, the number of strain priorities selected was summed, giving a maximum strain score of two and a minimum of zero.

The remaining two priorities were “*Mental capacity to make his or her own decisions*” and “*Amount of help available, from family, neighbours, or community*”. While very different in their content, they were both seen as reflecting potentially protective factors, one being a patient competency and the other an environmental advantage. In terms of the Ecological Theory of Aging, each was likely to reduce environmental press (Lawton & Nahemow, 1973) and the perceived need for placement in an individual case. Hence, both variables might be seen by respondents as mediating the relative influences of physical safety and of autonomy. They were combined, summed and analysed as “mediating priorities” with a maximum “mediating” score of two and a minimum of zero.

5.5.3 Definition of age cohorts

The χ^2 procedure, which was used to examine the relationship between age and other variables of interest, required that respondents be grouped into no more than five age cohorts. The following age cohorts were defined: age 15-34 (n = 1,005), age 35-54 (n = 1,101), age 55-64 (n = 365), age 65-74 (n = 281), and age 75+ (n = 263). This allowed a more fine-grained examination of age effect for participants aged 55 or older, while still giving a reasonable balance of numbers across the age cohorts.

The age cohorts were also defined in this way to enable some consideration of the effects of potential (as well as actual) carer status. The age cohorts 35-54 years, 55-64 years and 65-74 years contained higher proportions of self-described carers than did the other age cohorts. This suggested that issues related to the caregiving role might be more salient to, and a higher priority for, members of these age cohorts than for younger

and older people, even if they did not describe themselves as carers at the time of the survey.

5.6 Demographic information

5.6.1 Age and gender

In line with the 2001 census figures, 48.7% of the weighted sample was male, and 51.3% was female. Men slightly outnumbered women in the younger age groups, and women outnumbered men in the older age groups. Ages of respondents ranged from 15 to 96 years: see Table 7 for details.

5.6.2 Marital status

Marital status was reported as follows: married (54.6%), in a de facto relationship (7.9%), separated or divorced (8.1%), widowed (6.4%) and never married (23.1%). Widowed people made up a higher proportion of the older age cohorts. Those who had never married or were living in de facto relationships were a higher proportion of younger age cohorts.

Marital status was found to be significantly related to age cohort ($\chi^2 = 1768.51$, $df = 16$, $N = 3,015$, $p < .01$). The value of Cramer's V was 0.383, indicating a small to medium effect size, with age cohort explaining 14.7 % of the variance in marital status.

Table 7 Age and gender of respondents: Weighted sample (N=3,015).

Age range (years)	Total no	% of total	Number of males	% of males	Number of females	% of females
15-19	260	8.6	133	4.4	127	4.2
20-24	234	7.8	120	4.0	114	3.8
25-29	243	8.0	123	4.1	120	4
30-34	268	8.9	134	4.4	134	4.4
35-39	282	9.3	140	4.6	142	4.7
40-44	290	9.6	143	4.7	147	4.9
45-49	269	8.9	133	4.4	136	4.5
50-54	260	8.6	129	4.3	132	4.4
55-59	201	6.7	100	3.3	101	3.3
60-64	164	5.4	81	2.7	83	2.7
65-69	141	4.7	68	2.3	73	2.4
70-74	140	4.7	66	2.2	74	2.5
75-79	121	4.0	51	1.7	70	2.3
80-84	90	3.0	27	0.9	63	2.1
85-89	44	1.5	18	0.6	25	0.8
90-94	6	0.2	2	0.1	4	0.1
95-99	2	0.1	2	0.1	0	0
Total	3,015	100	1470	48.7	1545	51.3

5.6.3 Household size

The majority of respondents (69.2%) lived in small households comprising either two people (54%) or one person (15.2%). Fewer respondents lived in households comprising three people (17.1%) or four people (10.6%). Only 3.2% of respondents reported living in a household of five people or more.

Older people were more likely to live in smaller households, and 36.5% of those aged 65-74 years, and 69.2% of those aged over 75, reported that they lived alone.

Household size was found to be significantly related to age cohort ($\chi^2 = 294.02$, $df = 24$, $N = 3,015$, $p < .01$). The value of Cramer's V was 0.16, indicating a small effect size, with age cohort explaining 2.4% of the variance in household size.

5.6.4 Household income

Respondents were asked to indicate the category to which their total annual household income belonged. This item was declined by 14.2% of respondents. An annual household income of \$20,000 or less was reported by 20.8 % of respondents. Another 27.9% reported a household income of between \$20,001 and \$50,000, and 21.1% reported a household income of between \$50,001 and \$80,000. The remaining 15.9% of respondents reported an annual household income of over \$80,000.

Respondents who were older were more likely to report living in lower-income households. Annual household incomes of \$20,000 or less were reported by 50.8% of those aged 65-74 years, and 69.2% of those aged over 75.

Household income was found to be significantly related to age cohort ($\chi^2 = 847.50$, $df = 32$, $N = 3,015$, $p < .01$). The value of Cramer's V was 0.27, indicating a

small to medium effect size, with age cohort explaining 7% of the variance in household income.

5.6.5 Educational attainment

Students made up 7.9% of the weighted sample, with 3.5% of respondents being at school, and 4.4% engaged in subsequent studies. Another 43.8% of the sample had no post-school qualifications, having left school aged 15 years or under (17.1%), or after the age of 15 (26.7%). The remainder of the sample comprised those whose highest qualification was a trade qualification or apprenticeship (12.6%), a one-year diploma or certificate (9.1%), a longer diploma or certificate (12.3%), or a university degree (14.2%).

As a group, older respondents reported lower levels of educational attainment, with 25.4% of those aged 65-74 years, and 27.7% of those aged over 75, reported that they had left school at or before the age of 15. Another 8.8% of those aged 65-74 years, and 8.4% of those aged over 75, reported that they had left school after the age of 15 but had gained no further qualifications. Only 6.4% of those aged 65-74 years and 5.1% of those aged over 75 reported having a university degree.

Educational attainment was found to be significantly related to age cohort ($\chi^2 = 856.13$, $df = 28$, $N = 3,015$, $p < .01$). The value of Cramer's V was 0.27, indicating a small to medium effect size, with age cohort explaining 7% of the variance in educational attainment.

5.6.6 *City and country*

Because of the sampling procedure and weighting process, residents of the Adelaide metropolitan area comprised 76.7% of the weighted sample. The remaining 23.3% lived in South Australian country centres with populations of 1,000 or more. Older respondents appeared slightly more likely to live in country towns than younger respondents, with 27.2% of those aged 65-74 years and 26.3% of those aged over 75 reporting that they lived in the country.

However living in a country town was not significantly related to age cohort ($\chi^2=7.19$, $df=4$, $N=3,015$, $p=.13$).

5.6.7 *Country of birth*

People born outside Australia made up 22.5% of the respondents. Of these, almost half of the migrant group (11.1% of total respondents) had been born in the United Kingdom or Ireland, and another 5.4 % of total respondents had been born elsewhere in Europe.

5.6.8 *Indigenous status*

People who described themselves as being of Aboriginal descent made up 1.4% of the respondent group. Another 0.1% described themselves as being of Torres Strait Islander descent, and 0.1% indicated that they did not know. Because of the small number of respondents indicating indigenous status, this was not selected as a variable for further analysis.

5.6.9 Carer status

Another researcher, Anne Stacey, had used the same health omnibus sample to collect data on the role of carer, and its impact on the carer's self-reported health status, (Stacey, 2002). She provided access to the responses to her question: "*Are you the carer of a sick or dependent person?*". Of the 3,015 respondents, 152 (5%) identified themselves as being carers (see Table 8).

Table 8 Self-reported status as a carer, by decade of age: weighted sample (N=3,015)

Decade of age (<i>n</i>)	Number of carers	% of age group
15-24 years (494)	4	1.1
25-34 years (511)	10	2.0
35-44 years (572)	25	4.7
45-54 years (529)	47	9.1
55-64 years (365)	31	6.9
65-74 years (281)	24	7.0
75-84 years (211)	9	3.6
85-94 years (50)	2	3.2
95+ years (2)	0	0
Whole sample (3,015)	152	5.0

A series of χ^2 tests was undertaken to examine the relationship between self-reported carer status and other demographic variables. With regard to age, respondents aged 50-54 years were the most likely to report being carers, and those aged under 30 or over 80 were the least likely. There was a significant relationship between age cohort and the likelihood of being a carer ($\chi^2 = 35.08$, $df = 4$, $N = 3,015$, $p < .01$). The value of Cramer's V was 0.11, indicating a small effect size, with age cohort explaining 2% of the variance in carer status.

Female respondents were more likely than male respondents to report being carers (6.6% of females and 3.3% of males). However, the relationship between gender and carer status was only found to be significant for two age cohorts: 35-54 years and 55-64. For the age cohort 35-54 years, $\chi^2 = 7.99$, $df = 1$, $N = 1052$, $p < .01$. The value of Cramer's V was 0.09, indicating a very small effect size, with gender explaining less than 1% of the variance in carer status. For the age cohort 55-64 years, $\chi^2 = 7.60$, $df = 1$, $N = 451$, $p < .01$. The value of Cramer's V was 0.13, indicating a small effect size, with gender explaining 1.7% of the variance in carer status.

Respondents who were married, separated or divorced were more likely to be carers than were single people or those in de facto relationships. However, the relationship between marital status and carer status was only found to be significant for the age cohorts 65-74 years and 75+ years. For the age cohort 65-74 years, $\chi^2 = 12.97$, $df = 3$, $N = 345$, $p < .01$. The value of Cramer's V was 0.19, indicating a very small effect size, with marital status explaining 4% of the variance in carer status. For the age cohort 75+ years, $\chi^2 = 9.16$, $df = 1$, $N = 315$, $p = .03$. The value of Cramer's V was

0.17, indicating a small effect size, with marital status explaining 3% of the variance in carer status.

The relationship between carer status and five other demographic variables (household income, household size, highest qualification, country of birth, and living in the city or country) was examined using χ^2 tests, which controlled for age cohort and were corrected using the Holm procedure. Once age cohort effects were accounted for, no significant relationship was found between carer status and these demographic variables (see Appendix G for corrected *p*-values).

5.7 Priorities in the timing of the residential placement decision.

5.7.1 The whole sample.

5.7.1.1. The eight priorities (the whole sample)

Physical safety / risk at home was the most commonly selected priority: see Table 9. It was selected by 77.3% of respondents in the weighted sample, followed by *Medical and health care needs* (57.6% of respondents), *Mental capacity to make his or her own decisions* (40.7%), *Behaviour detrimental to themselves and or others* (40.5%), *Amount of help available, from family, neighbours, or community* (33.7%), *Right to decide for himself or herself* (16.2%), *Burden to caregiver(s)* (10%), *Wish to continue living at home* (9.3%) and *Other / Don't know* (2.8%).

Table 9 Selection of priorities by age cohort: weighted sample (N=3,015).

AGE COHORT	15-34	35-54	55-64	65-74	75+	WHOLE
(n):	(1,005)	(1,101)	(365)	(281)	(263)	SAMPLE
% OF RESPONDENTS						(3,015)
Physical safety / risk	80.1	83.8	77.4	64.1	53.3	77.3
Medical / health care needs	64.1	56.0	60.3	49.5	43.9	57.6
Mental capacity	42.3	42.7	41.1	35.9	31.2	40.7
Behaviour detrimental	38.2	44.6	40.1	38.4	34.4	40.5
Help available	34.2	32.8	31.4	38.6	33.5	33.7
Right to decide	18.7	13.3	12.9	19.3	20.8	16.2
Burden to caregiver(s).	5.6	9.5	11.0	17.4	19.5	10.0
Wish to stay home	7.3	7.5	7.9	16.4	19.4	9.3
Other/don't know	2.6	1.9	2.1	3.5	8.4	2.8

5.7.1.2. *Safety, autonomy, strain and mediating values (the whole sample)*

For the whole sample, the mean safety score was 1.33 ($SD = 0.67$), compared with a mean autonomy score of 0.26 ($SD = 0.51$). This suggested that, as a group, respondents were more likely to select priorities reflecting the value of the older person's physical safety, than priorities reflecting the value of the older person's autonomy. Mediating values and strain values occupied intermediate positions between safety and autonomy, with the mean mediating score being 0.74 ($SD = 0.62$) and the mean strain score being 0.52 ($SD = 0.58$).

5.7.2 *Responses by age-cohort*

5.7.2.1 *The 8 priorities by age cohort*

Using the SPSS MULT RESPONSE facility, respondents' selection of priorities was tabulated by age cohort (Table 9) and by decade of age (Appendix H). For each priority, a χ^2 procedure was performed using SPSS CROSSTABS ($\alpha=0.05$) to test for any relationship between respondents' age cohort and their selection of that priority.

With increasing age, respondents were less likely to select *Physical safety / risk at home*. The χ^2 value of 143.12 ($df = 4, N = 3,015$) had an associated probability value of $p < .01$, showing that the association was unlikely to have arisen by chance. The value of Cramer's V was 0.22, indicating a small effect size, with age cohort explaining 5% of the variance.

With increasing age, respondents were less likely to select *Medical and health care needs*. The χ^2 value of 41.47 ($df = 4, N = 3,015$) had an associated probability value of $p < .01$, showing that the association was unlikely to have arisen by chance. The

value of Cramer's V was 0.12, indicating a very small effect size, with age cohort explaining 1.4% of the variance.

With increasing age, respondents were less likely to select *Mental capacity to make his or her own decisions*. The χ^2 value of 15.84 ($df = 4$, $N = 3,015$) had an associated probability value of $p < .01$, showing that the association was unlikely to have arisen by chance. The value of Cramer's V was 0.07, indicating an extremely small effect size, with age cohort explaining less than 1% of the variance.

With increasing age, respondents were more likely to select *Wish to continue living at home*. The χ^2 value of 46.44 ($df = 4$, $N = 3,015$) had an associated probability value of $p < .01$, showing that the association was unlikely to have arisen by chance. The value of Cramer's V was 0.12, indicating a very small effect size, with age cohort explaining 1.5% of the variance.

With increasing age, respondents were more likely to select *Burden to caregiver(s)*. The χ^2 value of 57.39 ($df = 4$, $N = 3,015$) had an associated probability value of $p < 0.01$, showing that the association was unlikely to have arisen by chance. The value of Cramer's V was 0.14, indicating a very small effect size, with age cohort explaining 2% of the variance.

Respondents in the age cohorts 15-34 years, 65-74 and 75+ selected *Right to decide for himself or herself* more frequently than did respondents in the age cohorts 35-54 years and 55-64. The χ^2 value of 11.72 ($df = 4$, $N = 3,015$) had an associated probability value of $p = .02$, showing that the association was unlikely to have arisen by chance. The value of Cramer's V was 0.06, indicating an extremely small effect size, with age cohort explaining less than 1% of the variance.

Respondents in the age cohort 35-54 years were the most likely to select *Behaviour detrimental to themselves and or others*, and those in the age cohort 75+ were the least likely, to select this value. The likelihood of selection by respondents in the age cohorts 15-34 years, 55-64 and 65-74 was between these extremes. The χ^2 value of 10.64 ($df = 4$, $N = 3,015$) had an associated probability value of $p = .03$, showing that the association between age cohort and selection was unlikely to have arisen by chance. The value of Cramer's V was 0.06, indicating an extremely small effect size, with age cohort less than 1% of the variance.

There was no apparent relationship between age cohort and the likelihood of selecting *Amount of help available, from family, neighbours, or community* as an important value. The χ^2 value of 5.45 ($df = 4$, $N = 3,015$) had an associated probability value of $p = .24$, showing that there was no statistically significant association.

In summary, **Hypothesis 1** was confirmed for seven of the eight priorities, but effect sizes were small.

5.7.2.2. *Safety, autonomy, strain and mediating values by age cohort*

Mean safety, autonomy, strain and mediating scores were plotted together (see Figure 1). It appeared that at all ages respondents placed a higher priority on the physical safety and welfare of the hypothetical elderly person than on the elderly person's autonomy or the strain on other people, but the extent of this preference decreased with increasing age of the respondent.

Hypothesis 2 was that older respondents would be less likely than younger respondents to select the priorities referring to the underlying value of physical safety: "*Physical safety / risk at home*" and "*Medical and health care needs*". It appeared from

inspecting the means for each of the five age cohorts that with increasing age, respondents were less likely to select safety priorities (see Figure 1). SPSS ONEWAY and MEANS procedures were applied.

For the relationship between age cohort and selection of safety priorities, the omnibus test of the main effect was statistically significant, $F(4, 3010) = 36.31, p < .01$. The Levene statistic ($F(4, 3010) = 1.76, p = .13$) confirmed homogeneity of variances between the groups. Tukey's Honestly Significant Difference (HSD) Test ($\alpha = .05/20 = 0.025$) revealed that there were no significant differences between the three youngest age cohorts (aged 15-34 years, 35-54 years and 55-64 years), or between the two older age cohorts (65-74 years and 75+ years). However there was a significant difference between the three younger age cohorts and the two older age cohorts. **Hypothesis 2** was confirmed but the effect size was small, with age cohort explaining only 4.6% of the between-groups difference ($\eta^2 = .046$).

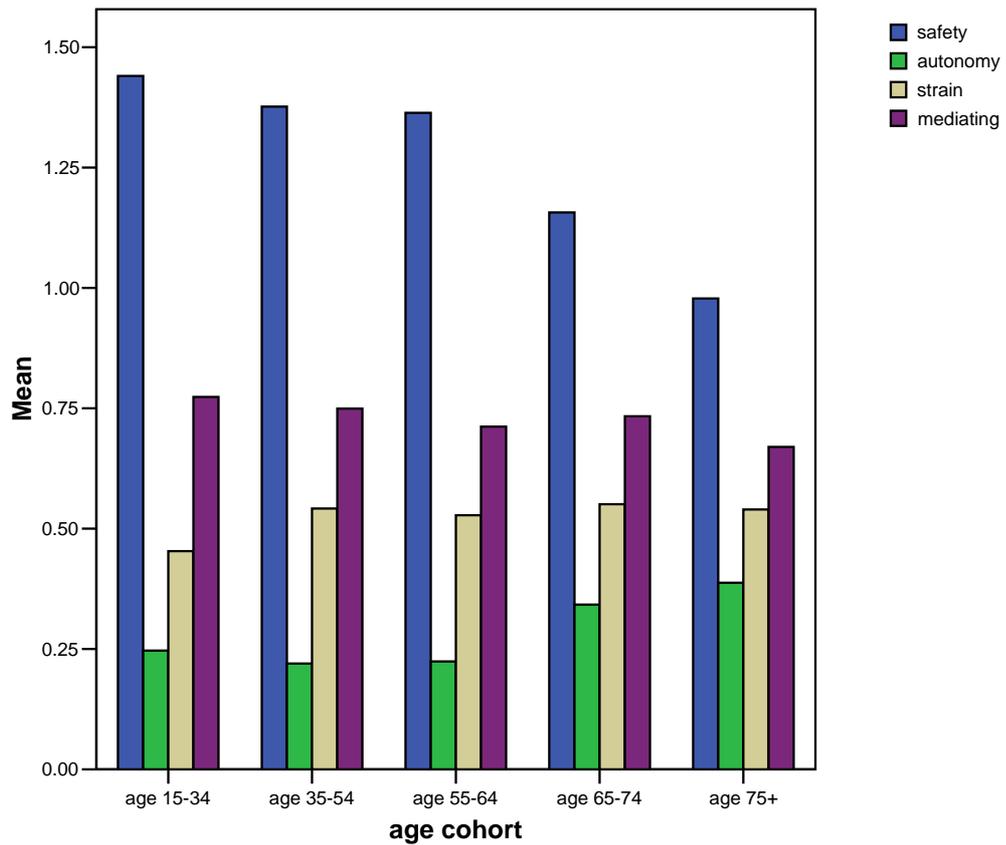


Figure 1 Mean safety, autonomy, strain and mediating scores, plotted together by age cohort: weighted sample (N=3,015).

Hypothesis 3 was that older respondents would be more likely than younger respondents to select either or both of the two priorities referring to autonomy: “*Right to decide for himself or herself*” and “*Wish to continue living at home*”. It appeared from inspecting the means for each age cohort that selection of autonomy priorities was highest for the age cohort 75+ years, followed in decreasing order by the age cohorts 65-74 years, 15-34 years, 55-64 years, 35-54 years (see Figure 2).

For the relationship between age cohort and selection of autonomy priorities, the omnibus test of the main effect was statistically significant, $F(4,3010) = 9.60, p < .01$. The Levene statistic ($F(4,3010) = 36.36, p < .01$) revealed that variances were not homogeneous. Tamhane’s pairwise T^2 test ($\alpha = .05/20 = 0.025$) revealed that there were no significant differences between the three youngest age cohorts (aged 15-34 years, 35-54 years and 55-64 years). However there was a significant difference between the three younger age cohorts and each of the two oldest age cohorts (aged 65-74 years and 75+ years), and a significant difference between the two oldest age cohorts. **Hypothesis 3** was confirmed, but the effect size was very small, with age cohort explaining only 1.3% of the between-groups difference ($\eta^2 = .013$).

Hypothesis 4 was that older respondents would be more likely than younger respondents to select the two priorities referring to strain on others: “*Burden to caregiver(s)*”, and “*Behaviour detrimental to themselves and or others*”. It appeared from inspecting the means for each age cohort that selection of strain priorities was highest for the age cohort 65-74 years, followed in decreasing order by the age cohorts 35-54 years, 75+ years, 55-64 years, and 15-34 years, (see Figure 1).

For the relationship between age cohort and selection of strain priorities, the omnibus test of the main effect was statistically significant, $F(4, 3010) = 3.55, p < .01$. The Levene statistic ($F(4, 3010) = 12.83, p < .01$) revealed that variances were not homogeneous. Tamhane's pairwise $T2$ test ($\alpha = .05/20 = 0.025$) revealed that the only significant difference was between the age cohorts aged 15-34 years and 35-54 years. **Hypothesis 4** was confirmed, but the effect size was extremely small, with age cohort explaining 0.5% of the between-groups difference ($\eta^2 = .005$).

5.7.3 Respondent gender and selection of priorities

5.7.3.1. The 8 priorities (by respondent gender)

Hypothesis 5 was that selection of priorities would vary with respondent gender. Selection of priorities was separately tabulated for male and female respondents (see Table 10).

The SPSS CROSSTABS procedure was used to examine the relationship between gender and selection of each of the 8 priorities: employing χ^2 tests ($df = 1, N = 3,015$) which controlled for age cohort and were corrected (for the number of analyses) using the Holm procedure. Once age cohort effects were accounted for, no significant relationship was found between respondent gender and selection of any of the 8 priorities (see Appendix I for corrected p -values). **Hypothesis 5** was not confirmed for any of the 8 individual priorities.

Table 10 Selection of priorities by respondent gender: weighted sample (N=3,015)

% of respondents selecting priority	Males (n=1470)	Females (n=1545)	Whole Sample (n=3,015)
<i>Physical safety / risk</i>	75.7	78.8	77.3
<i>Medical / health care needs</i>	58.8	56.4	57.6
<i>Mental capacity</i>	43.0	38.6	40.7
<i>Behaviour detrimental</i>	37.6	43.2	40.5
<i>Help available</i>	31.7	35.6	33.7
<i>Right to decide</i>	18.1	14.4	16.2
<i>Burden to caregiver(s).</i>	9.4	10.5	10.0
<i>Wish to stay home</i>	9.5	.9.1	9.3
<i>Other/don't know</i>	2.8	2.9	2.8

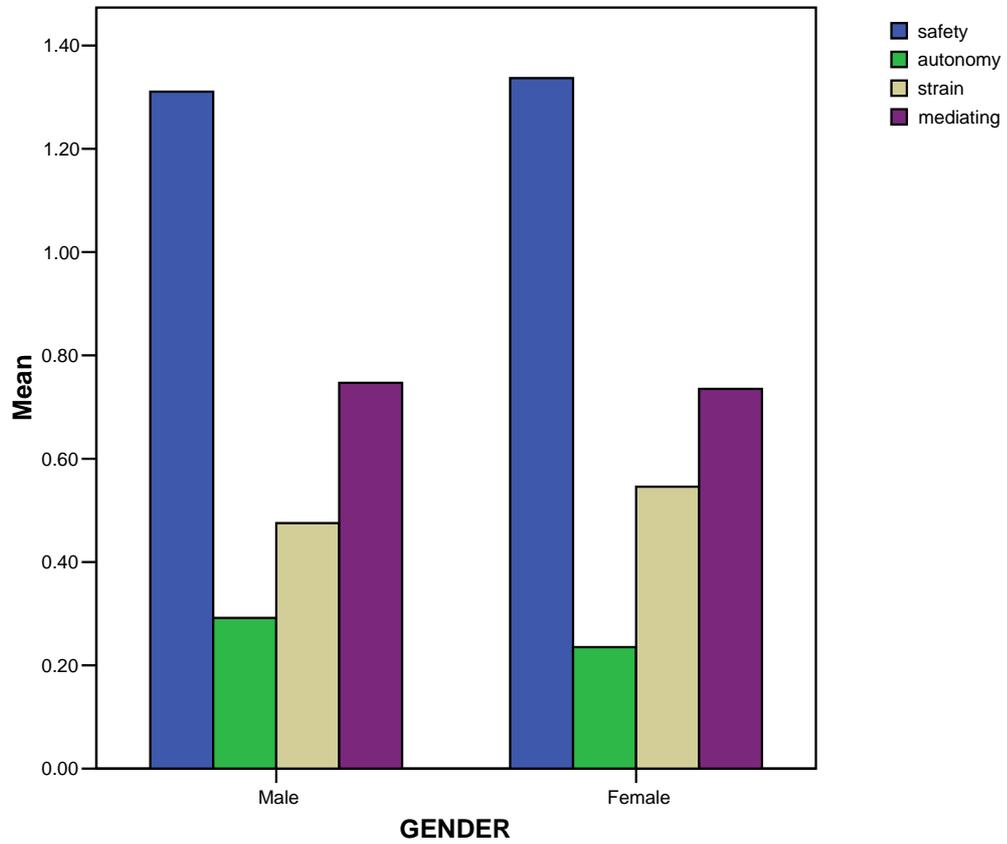


Figure 2 Mean safety, autonomy, strain and mediating scores, plotted together by respondent gender: weighted sample (N=3,015).

5.7.3.2. *Safety, autonomy, strain and mediating values by respondent gender*

Mean safety, autonomy, strain and mediating scores were plotted for male and female respondents (see Figure 2).

For male respondents the mean 'safety' score was 1.31 ($SD = 0.69$), slightly lower than the female respondents' mean safety score of 1.34 ($SD = 0.65$). For the relationship between gender and selection of safety priorities, the analysis of variance was not statistically significant, $F(1, 3013) = 1.13, p = .29$. **Hypothesis 5** was not confirmed for safety priorities.

Male respondents' mean autonomy score was 0.29 ($SD = 0.54$), slightly higher than the female respondents' mean autonomy score of 0.24 ($SD = 0.48$). For the relationship between gender and selection of autonomy priorities, the analysis of variance was statistically significant, $F(1, 3013) = 9.10, p < .01$. **Hypothesis 5** was confirmed for autonomy priorities, but the effect size was trivial, with gender explaining 0.3% of the between-groups difference ($\eta^2 = .003$).

Male respondents' mean strain score was 0.48 ($SD = 0.57$), slightly lower than female respondents' mean strain score of 0.55 ($SD = 0.58$). For the relationship between gender and selection of strain priorities, the analysis of variance was statistically significant, $F(1, 3013) = 10.98, p < .01$. **Hypothesis 5** was confirmed for strain priorities, but the effect size was trivial, with gender explaining 0.4% of the between-groups difference ($\eta^2 = .004$).

5.7.4 Carer status and selection of priorities

5.7.4.1. The 8 priorities by self-reported carer status

Selection of priorities was separately tabulated for those who had, and had not, described themselves as carers (see Table 11). To test Hypothesis 6, for each of the 8 priorities a χ^2 test was performed to test for any relationship between its selection and the respondent's carer status, controlling for age cohort effects. The large number of relationships analysed increased the risk of a Type II error. This was addressed by adjustment of p -values according to Holm's method, a more powerful alternative to the Bonferroni procedure (Aickin & Gensler, 1996). No significant relationship was found between carer status and selection of any one of the 8 priorities (see Appendix J for table of p -values): hence, **Hypothesis 6** was not confirmed for any single priority.

5.7.4.2. Safety, autonomy and strain priorities by self-reported carer status

For carers, the mean safety score was 1.28 ($SD = 0.63$), slightly lower than the non-carers' mean safety score of 1.33 ($SD = 0.67$): For the relationship between carer status and selection of safety priorities, the analysis of variance was not statistically significant, $F(1, 3013) = 0.65$, $p=0.42$. **Hypothesis 6** was not confirmed for safety priorities.

Table 11 Selection of priorities by self-reported carer status: results from the weighted sub-samples and full sample.

% of respondents selecting priority	Carers (152)	Non-carers (2863)	Whole Sample (3,015)
Physical safety / risk	75.7	76.2	77.3
Medical / health care needs	52.6	56.5	57.6
Mental capacity	36.8	40.1	40.7
Behaviour detrimental	44.1	40.5	40.5
Help available	29.6	34.4	33.7
Right to decide	17.1	15.5	16.2
Burden to caregiver(s).	11.8	10.8	10.0
Wish to stay home	18.4	9.9	9.3
Other/don't know	2.0	3.1	2.8

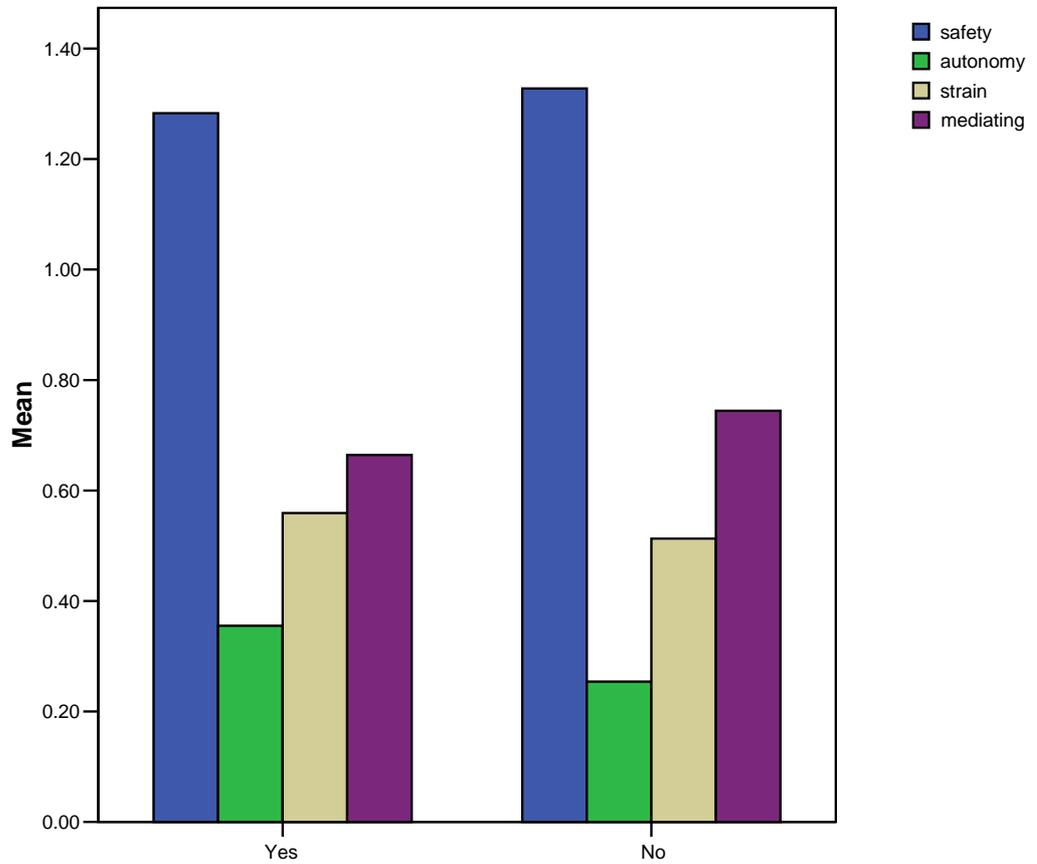


Figure 3 Mean safety, autonomy, strain and mediating scores, plotted together by carer status: weighted sample (N=3,015).

The carers' mean autonomy score was 0.36 ($SD = 0.58$), higher than the non-carers' mean autonomy score of 0.25 ($SD = 0.51$). For the relationship between carer status and selection of autonomy priorities, the analysis of variance was statistically significant, $F(1, 3013) = 5.66$, $p = .017$. Hypothesis 6 was confirmed for autonomy priorities, but the effect size was extremely small, with carer status explaining only 0.2% of the between-groups difference ($\eta^2 = .002$).

The carers' mean strain score was 0.56 ($SD = 0.62$), slightly higher than the non-carers' mean strain score of 0.51 ($SD = 0.58$). For the relationship between carer status and selection of strain priorities, the analysis of variance was not statistically significant, $F(1, 3013) = 0.92$, $p = .34$. **Hypothesis 6** was not confirmed for strain priorities.

5.7.5 Mediating priorities

It appeared from inspecting the means of the mediating priority scores for each of the five age cohorts (see Figure 1), that in general with increasing age, there was a trend for the mediating priorities to be selected less: age cohort 15-34 years 0.78 ($SD = 0.6$), 35-54 years 0.75 ($SD = 0.64$), 55-64 years 0.71 ($SD = 0.64$), 65-74 years 0.73 ($SD = 0.64$), 75+ years 0.67 ($SD = 0.64$). SPSS ONEWAY and MEANS procedures were applied. For the relationship between age cohort and selection of mediating priorities, the analysis of variance was not statistically significant, $F(4, 3010) = 1.95$, $p = .10$.

For male respondents the mean mediating priority score was 0.75 ($SD = 0.61$), slightly higher than the female respondents' mean mediating priority score of 0.74 ($SD = 0.62$) – see Figure 2. For the relationship between gender and selection of mediating

priorities, the analysis of variance was not statistically significant, $F(1, 3013) = 0.26$, $p = .61$.

For carers the mean mediating priority score was 0.66 ($SD = 0.61$), slightly lower than the non-carers' mean mediating priority score of 0.74 ($SD = 0.62$) – see Figure 3. For the relationship between carer status and selection of mediating priorities, the analysis of variance was not statistically significant, $F(1, 3013) = 2.42$, $p = 0.12$.

5.7.6 Summary of results

5.7.6.1 Responses of the whole sample

In summary, respondents were most likely to select the two priorities that reflected safety, as the most important priorities. Next most frequently selected were the two mediating priorities (*Mental capacity to make his or her own decisions*, and *Amount of help available, from family, neighbours, or community*) along with *Behaviour detrimental to themselves and / or others*. Each of these three priorities was selected by a third or more of respondents. The remainder of the priorities were selected by relatively few respondents. These were the two priorities that reflected autonomy, *Wish to continue living at home*, and *Right to decide for himself or herself*, along with *Burden to caregiver(s)*, and *Other / Don't know*.

5.7.6.2 Hypothesis 1 Selection of priorities would vary with respondent age.

This hypothesis was confirmed for 7 of the 8 priorities, the exception being *Amount of help available, from family, neighbours, or community*. However, effect sizes were small or very small. Older adult respondents were less likely than younger adult respondents to select *Physical safety / risk at home*, *Medical and health care needs*, and

Mental capacity to make his or her own decisions, and more likely than younger respondents to select *Wish to continue living at home*, and *Burden to caregiver(s)*. Respondents aged 35-54 years and 55-64 years were less likely than other respondents to select *Right to decide for himself or herself*. Respondents aged 35-54 years were most likely, and respondents aged 75 years or more were least likely, to select *Behaviour detrimental to themselves and or others*.

5.7.6.3 Hypothesis 2. Older respondents would be less likely than younger respondents to select either or both of the priorities referring to physical safety.

This hypothesis was confirmed. Older respondents were less likely than younger respondents to select the safety priorities, *Physical safety / risk at home* and/or *Medical and health care needs*, although the effect size was small.

5.7.6.4 Hypothesis 3. Older respondents would be more likely than younger respondents to select either or both of the two priorities referring to autonomy.

This hypothesis was confirmed in part. Older respondents were more likely than younger respondents to select *Wish to continue living at home*, but the effect size was small. Respondents aged 35-54 years and 55-64 years were less likely than other (older and younger) respondents to select *Right to decide for himself or herself*, and the effect size was extremely small.

5.7.6.5 Hypothesis 4. Older respondents would be more likely than younger respondents to select either or both of the two priorities referring to strain on others.

This hypothesis was confirmed. Older respondents were more likely than younger respondents to select “*Burden to caregiver(s)*”, but the effect size was very small. Respondents aged 35-54 years were most likely, and respondents aged 75 years or more were least likely, to select *Behaviour detrimental to themselves and or others*, and the effect size was extremely small.

5.7.6.6 Hypothesis 5. Selection of priorities would vary with respondent gender.

This hypothesis was not confirmed for any of the eight individual priorities, or for the safety priorities. The autonomy priorities were more likely to be selected by male respondents than by female respondents, but the effect size was very small. The strain priorities were more likely to be selected by female respondents than by male respondents, but the effect size was very small.

5.7.6.7 Hypothesis 6. Selection of priorities by respondents who described themselves as carers would differ from that of other respondents.

This hypothesis was not confirmed for any of the eight individual priorities, or for the safety or strain priorities. The autonomy priorities were more likely to be selected by carers than by non-carers, but the effect size was very small.

5.7.6.8 Mediating priorities

The two mediating priorities had been derived from the literature and from the pilot stage of the qualitative study. They were selected quite frequently, more so than

the strain priorities or the autonomy priorities. The selection of mediating priorities did not vary significantly between age cohorts, between the genders, or between carers and non-carers.

5.8 Discussion

5.8.1 The elderly person's safety as the highest priority

Every age cohort in this sample of South Australian adults indicated that the physical safety and health of the elderly person with dementia (as reflected in the frequency of selection of the two safety priorities *Physical safety / risk at home* and *Medical and health care needs*) had the highest priority.

In terms of the Andersen model this could be seen as an acknowledgment, by non-involved community members considering a hypothetical choice, of the primacy of 'need' factors in decisions about health service usage, specifically in this case the residential care option.

Interestingly, however, the relative importance of safety priorities diminished with increasing age of respondents. It was unclear whether older respondents assigned less importance to safety, or more importance to the other priorities listed (mediating, strain and autonomy priorities), or both. Further research could usefully explore and test these explanations. It may be that with increasing age, and presumably with increasing salience of the issues, attitudes and/or appraisal might be more complex than at earlier stages of life.

5.8.2 The order of selection of priorities

Because selection of the eight priorities was non-independent and ranking was not possible, detailed interpretation of the order of frequency of selection of the eight priorities was difficult and potentially unreliable.

The nature of the forced choice procedure utilised in the survey meant that selection of priorities was influenced by the need to select the most important priorities and this meant not selecting the others. Hence less frequent selection could not be interpreted as meaning that these priorities were unimportant, but only that, in making the choice, they were seen as less crucial than some other priorities.

Where two priorities appeared to be related, some respondents who saw the underlying principle as important may have selected both. For example, quite a number of respondents selected both of the safety priorities. In the same situation others may have elected to 'spread their vote' by selecting only one of a pair and thus giving themselves more opportunity to indicate the importance of other priorities. For example, respondents may have considered both behaviour and caregiver burden to be important, but may have selected only one of the two strain priorities.

For this reason it may be more meaningful to consider the frequency of selection of paired priorities, inasmuch as this allows both types of response to be combined, and provides a means of comparing the choice of underlying values rather than competing priorities. This also depends, of course, on whether the pairing of priorities, and the meaning of the underlying values, as assumed by the researcher, was understood in the same way by the respondents. Without a research methodology which allowed respondents to explain their responses and make open-ended comments, this could not be assumed and interpretation can only be speculative.

Adopting this interpretive approach, with the above reservations, it was concluded that the sample as a whole had most frequently selected safety priorities and mediating priorities. Strain priorities and autonomy priorities were selected less frequently. In terms of the Andersen model this suggested that community members considered 'need' factors related to physical health to be the most important determinants of the residential placement decision, and they also acknowledged mediating or enabling factors to be quite significant in evaluating an individual's situation. Predisposing factors, whether they reflected the elderly person's predisposition (the autonomy priorities) or factors likely to influence the caregiver's predisposition (the strain priorities) received much less acknowledgment.

5.8.3 *The selection of mediating priorities*

Despite strong competition from the safety variables, each of the mediating variables was selected by more than a third of respondents. This suggested that while acknowledging the primacy of physical health and safety, respondents perceived that the outcome of the residential care decision, in individual cases, could and should vary with the extent of individuals' competence and the amount of support the environment could provide. In terms of the Environmental Theory of Aging (Lawton & Nahemow, 1973), both priorities would be seen as acting to reduce environmental press and increase the probability of successful adaptation to a situation. Mental competence would represent an individual competence (the capacity to make one's own decisions, possibly also implying the capacity to execute decisions and hence to undertake ADLs and IADLs at home) while help would represent a protective environmental variable. Interestingly, while selection of *Amount of help available, from family, neighbours, or community* did

not vary across age cohorts, selection of *Mental capacity to make his or her own decisions* did vary across age cohorts. With increasing age, there was an extremely small but statistically significant trend for less selection of this priority.

On face value, *Mental capacity to make his or her own decisions* appears to be related to the two autonomy priorities. It underpins them, because in order to use their autonomy effectively, people need to be mentally competent. However, mental capacity, as a priority, was selected far more frequently than either of the explicit autonomy priorities. Also, like the safety priorities, it was selected less frequently by older age cohorts than by younger ones. This pattern of selection supported the notion that mental capacity was seen at least in part as an individual competence and a mediating factor, related to the ability to continue to live in the community rather than in residential care.

It seemed quite possible that survey respondents may have linked the concepts of mental capacity to make decisions and mental capacity to manage everyday activities, and assumed that to the extent that a hypothetical individual might be mentally competent to make his or her own decisions, he or she would also be mentally competent to manage living at home. Within the professional arena in which testamentary capacity is defined and assessed, it is emphasised that competence or capacity is not a global concept but must always refer to a specific task or role (Darzins et al., 2000). For example, some elderly individuals are legally incompetent due to cognitive impairment, but capable of managing everyday living at home. Others are legally competent to make decisions, but unable to perform everyday activities. For legal purposes, a distinction is drawn between decision-making competence (legal competence including testamentary capacity), and everyday competence in activities of daily living at home. However, in the clinical setting, health professionals and patients'

relatives at times confuse or confound these issues of *risk* (i.e. mental competence to live safely alone or to carry out activities of daily living in a safe manner) with issues of *decision-making* (i.e. mental competence to make one's own decisions). It is reasonable to consider that members of the community might also confuse or confound these issues.

In that sense, among the eight priorities presented to respondents, *Mental capacity to make his or her own decisions* may have been seen as a mediating factor for the potential placement decision, reflecting the elderly person's mental competence in everyday living, which in turn would reflect the severity of the dementing illness.

5.8.4 *The selection of strain priorities*

The strain priorities had been suggested by respondents in the pilot phase of the survey project. The inclusion of these priorities in the survey was consistent with the findings of the literature review, inasmuch as caregiver variables had been found to have a significant effect on the likelihood of residential placement of elderly people. Despite this, strain priorities were not selected as frequently as safety or mediating priorities, and they were not selected more by carers than by non-carers.

There was a marked difference between the frequencies of selection of the two strain priorities. *Behaviour detrimental to themselves and / or others* was selected by 40.5% of the sample, whereas *Burden to caregiver(s)* was selected by only 10% of the sample. Selection of *Behaviour detrimental to themselves and / or others* may to some extent have reflected safety concerns for the elderly person. While behaviour detrimental to oneself and/or others would potentially be a significant cause of strain to others, it also implies risk to oneself and the need for a higher level of supervision.

Hence, *Behaviour detrimental to themselves and / or others* should perhaps be interpreted as a priority reflecting both safety issues and strain issues.

If that was the case, it suggested that caregiver strain had received even less priority from the community sample than the overall score for 'strain issues' would indicate. Examination of the frequency of selection of priorities by age cohort (Table 9) revealed that among the younger (and larger) age cohorts, *Burden to caregiver(s)* was selected quite rarely. Perhaps problematic behaviour by elderly people is visible to all, and easily imagined by those who have not experienced its effects. In contrast, the issue of caregiver burden may have been less apparent to members of those age cohorts among whom family caregiving was not yet a common problem. In a series of articles on family caregiving (C. A. Lee, 1999, 2001; C. A. Lee & Porteous, 2002), Lee has asserted that the social and ideological construction of caregiving as a naturally feminine activity to be conducted within the family has served to maintain its status as a predominantly female activity, and as an economically invisible and unrecognised occupation. Hence, caregiver burden has been defined as a personal or individual issue, rather than as a social or economic problem. As such it may receive little acknowledgment in the general community; one possible explanation for the low frequency of its selection in this survey.

5.8.5 *The selection of autonomy priorities*

The autonomy priorities, which could be seen as reflecting the rights of the individual, were selected less frequently than priorities reflecting the elderly person's needs, and the social context. Given the primacy of individual rights in our society and legal system – to the extent that a formal legal process is required to remove legal

autonomy from cognitively disabled individuals and replace it with decision-making by a family guardian or, in the last resort, by an official of the state – this is an interesting finding. Just as need factors may be seen to over-ride the unacceptability of residential aged care for the elderly, and justify the consideration of placement, it seems possible that in the case of elderly people with dementia, need factors are seen to over-ride the importance of their individual rights and autonomy.

5.8.6 Gender and selection of priorities

Male respondents were slightly more likely than female respondents to select autonomy priorities, while female respondents were slightly more likely than male respondents to select strain priorities. While these differences were statistically significant, the effect sizes were so small that the differences should probably be seen not as findings, but as suggesting hypotheses for testing in more fine-grained research. Certainly they would be consistent with conventional sex-role differences, with males being socialised to value individual autonomy more highly than the social and family consequences of actions, and females being socialised in the other direction.

5.8.7 Carer status and selection of priorities

Respondents who identified themselves as carers were slightly more likely than non-carers to select autonomy priorities, but no more likely than non-carers to select strain priorities. While the difference in selection of autonomy priorities was statistically significant, the effect size was so small that, in the case of gender differences, this should probably be seen not as a finding, but as suggesting a hypothesis for testing in more fine-grained research.

On first inspection, it may be surprising that carers, who would be bearing any strain involved in maintaining a person with a disability, did not select strain priorities more than others did. On the other hand, it could be posited that it is because of their belief in autonomy priorities that carers elect to continue supporting another person's life in the community, and enduring the resultant strain.

It is likely that the self-described carers in this survey are a disparate group. The literature suggests that there are different patterns of age and gender for spouse and non-spouse carers. Non-spouse carers – the parents, adult children, nieces, nephews, siblings, neighbours and friends of frail individuals - are middle-aged to elderly and predominantly female. Spouse carers as a group are older, and less predominantly female. Declining the role of spouse carer not only means placing someone in residential care, but it also means ending marital cohabitation, and appearing to break the marital contract. Hence, there may be less perceived choice about taking on the spouse carer role than there is about becoming a non-spouse carer. It would not be surprising if these two subgroups had different views and priorities.

In the present study respondents had not been asked whether they were paid or unpaid carers, whether they were caring for an elderly person or a younger person, in the carer's own home or elsewhere, or whether the care recipient was a spouse, another relative, a friend, a neighbour or (for paid care) the client of an agency. Also, respondents were not asked whether they had ever been a carer in the past, or whether they had ever declined the carer role and/or been involved in a residential placement decision. In comparing the priorities of carers and non-carers with regard to the residential placement decision, it would be useful to survey a larger group of carers in more detail and to explore some of these distinctions.

5.8.8 *Summary of conclusions*

For all the limitations of the survey method, it was overwhelmingly clear that in every age cohort of the adult community in South Australia, the most important determinant of the residential placement decision was thought to be the physical health and safety of the elderly person with dementia. Other considerations, including mediating variables (the degree of environmental stress or adaptation), strain on others, and the elderly person's rights and wishes, were secondary considerations, (albeit less so with increasing age of the respondent). Community members, as a group, appeared to put safety first, and then to consider situational variables, within which the elderly person's autonomy was not assigned a high priority.

This is in marked contrast to the formal legal situation with regard to placement, in which the autonomy and wishes of the individual are seen as paramount. Only where there is clear evidence of legal incapacity can the individual's decision be overturned. This is reflected in the medico legal system where unless mental incapacity has been formally determined through a legal process, an elderly individual can determine his or her discharge destination without regard to the opinions or wishes of family members or health professionals. This clear conflict between two value systems – of the formal, legal system and community beliefs – may go some way to explain the tensions and ethical conflicts which are reported in hospital discharge planning (Clemens, 1995; Dill, 1995; Huby, Stewart, Tierney, & Rogers, 2004; McCullough et al., 1993).

Reporting an ethnographic study of ethical issues in discharge planning for elderly people, Dill (1995) observed that the bioethical approach to patient decision-making, particularly decisions made about treatment in the acute setting, was based on the concept of individual self-determination by a competent patient through the giving of

informed consent. The bioethical approach has been criticised on two grounds, the first being the issue of decision-making competence and how it is or should be determined. The second criticism raises the issue of social relationships and interdependency, and the extent to which the interests of any other people (most obviously the patient's family) should be represented in treatment decisions. Both of these issues, Dill observed, were highly relevant to discharge planning for elderly patients, where patient competence was often questionable or questioned, and where the choice of discharge destination could have considerable ramifications for the patient's family. The bioethical approach had moved to a concern with achieving consensus, if possible, between the patient's decisions, the family's preferences and the medical view of the patient's best interests. Dill observed the extent to which, in her study of discharge planning, social and structural factors impacted on the way in which these views, preferences and decisions were formed, modified and received, and the potential for conflict of interest. Dill concluded that this model was still inadequate. In addition to recognition of individual autonomy, Dill suggested, a model of ethics in geriatric care required socially grounded principles and an understanding of the social and structural constraints on discourse and decision-making. Dill suggested that a model of "negotiated care", with explicit recognition of multiple interests and views, might be useful, as long as the potential for inequity and the dominance of social and political forces was also recognised.

If this perspective were adopted in clinical practice and in future research, the potential interaction between two apparently disparate or conflicting variables, that is patient autonomy and caregiver strain, could be examined in a perhaps more productive way. If caregiver strain is the price of patient autonomy (in that without the caregiver's

efforts, the elderly person would not be able to live in the community and would undergo residential placement), is the elderly person's strain (the psychological costs involved in residential placement) the price of family members' autonomy? It is clear from the caregiver literature that maintaining a relative with a disability in the community is deleterious to the autonomy of the family members who provide care (C. A. Lee & Porteous, 2002; Schofield, 1998), and that caregivers do not always feel that they have a choice about commencing or continuing with care (C. A. Lee & Porteous, 2002; National Alliance for Caregiving & American Association of Retired Persons, 2004). As well as being separate variables located in separate people, can autonomy and strain be seen as interactive/relational priorities located within a family system, and influenced by issues of individual personality, family roles, gender and social structure? These questions demand further investigation.

The other main finding was the variation in the frequency of selection of priorities. Although members of each age cohort selected safety priorities most frequently, there was less of an apparent differential in the older age cohorts. This appeared consistent with the finding of McCullough et al. (1993) that in describing a long-term care decision after the event, elderly people were more likely to mention autonomy values, and less likely to mention safety values, than were their younger relatives, or the health professionals who had been involved in the decision. One possible implication is that young professionals (legal and medical) and legislators should be educated about, and guided by, the priorities of the elderly stakeholders. Relatives may need to understand that with regard to the primacy of physical safety over more intangible issues (such as autonomy, independence, and home) their older relatives' priorities may be different from their own.

5.8.9 Plan for further research

In this survey, the very size and comprehensiveness of the sampling process limited the scope of the questions that could be asked and the complexity of the responses that could be recorded. Had it been possible to rank responses and to ask for clarifying information, more meaningful analyses and interpretation would have been possible. Nevertheless it was possible to move beyond the simple dichotomies of placement (acceptable or unacceptable), and of safety versus autonomy, and to obtain some sense of how community members believe that the timing of residential placement decision should be determined.

The study findings were presented in a poster session at the 2005 National Conference of the Australian Psychological Society (APS) College of Clinical Neuropsychologists (Denson & Winefield, 2005). The findings were also presented at the South Australian Annual General Meeting of the APS Psychology and Ageing Interest Group in 2005.

The next step, applying the mixed methods approach (Creswell, 2003), was to examine this study's outcome (its findings, and the further hypotheses it generated) by triangulating it with a complementary interview study, utilising a qualitative method: research-based thematic analysis.

The interview study utilised a much smaller sample, of stakeholders: people who were likely to be involved in a long-term care decision in the near to medium future. It was possible to present a more detailed hypothetical profile of a frail elderly person, to record and discuss more detailed responses, and to clarify the meaning, for respondents, of concepts such as mental capacity and caregiver strain. Chapter 6 reviews the qualitative retrospective literature on determinants of the residential placement decision,

which was used as the research base for the thematic analysis. Chapter 7 describes the interview study which was designed to ascertain the prospective attitudes and priorities of some of the stakeholders in the South Australian community, when considering the determinants of the residential care placement decision for a frail elderly person. Ten elderly people living in the community, ten relatives of such individuals, and thirteen health professionals involved in discharge planning and placement of elderly medical patients were interviewed and their responses were interpreted using thematic analysis.

Chapter 6. Retrospective views of the residential placement decision: A brief review of the literature

6.1 Overview

The literature on experiences and priorities in the residential placement decision, as reported by those who have been involved in such a decision, was examined for themes and underlying priorities and values. Based on these themes, priorities and values, a thematic code was to be developed for use in the analysis of the prospective interview data.

6.2 Review of the retrospective literature

In preparation for the prospective interview study (see Chapter 7), the retrospective literature on residential placement decisions was reviewed with a focus on recent work and on reported values and priorities in, or determinants of, long-term care decisions. As these priorities and determinants were being described retrospectively, and by and large recruitment had also been retrospective, it was not felt that these studies had a direct bearing on the present research which attempted to ascertain prospective priorities: those which exist before the event.

Hence the aim was not so much to review the retrospective literature comprehensively, but rather to extract themes and underlying priorities and values. These would be used to develop a research-based code for thematic analysis of the interview data.

Database searches covered the period January 1990 to September 2003 (PsycInfo, PubMed, Australasian Medical Index, Health Business, Health Source Nursing,

Sociological Abstracts, Social Work Abstracts, ISI Web of Science, Expanded Academic Index, Academic Search Elite, ProQuest) with a supplementary updating search in January 2005 (ISI Web of Science). Key-words included institutionalization, placement, patient admission, facility admission, nursing homes, homes for the aged, residential care, institution, long-term care, attitudes, public opinion, family, caregiver, medical, physician, elderly, hospital patient, discharge planning, decision, and autonomy.

The search process revealed a number of studies of long-term care decisions. The studies that were identified were almost all retrospective, and any prospective studies that were found were included in the literature review in Chapter 4. Studies of family caregivers' experiences and values were plentiful. A smaller number of studies involved either elderly people who had undergone residential placement, or professionals involved in the process. Few studies involved more than one of these groups, and very few involved all three.

The elderly people and/or their relatives were recruited and interviewed in the aftermath of a residential placement decision in which they had been involved. The studies were concerned with process aspects: the timing of the placement decision, the way in which the decision had been made and implemented, and its impact on participants and their subsequent adjustment. These studies focussed directly on the reported experience. In their approach they were always descriptive (reporting what participants had said) and to a lesser extent interpretative, dealing with explicit and implicit themes. Some studies were classificatory, attempting to contrast and compare responses, and to classify the types of decision or placement experience and the underlying values. The research methodology was usually qualitative, and the studies

were published in the nursing and social work literature and in journals focussing on ageing and health care. It was occasionally, but not always, acknowledged that when people were asked about a decision which had already been made and implemented, their perception and account of the process might have been affected by subsequent events such as their experience of the outcome and the psychological adjustment process.

Studies of professionals' experiences were slightly different in their approaches, with few addressing the lived experience as their primary focus. Some focussed on professional practice issues for social workers and/or health professionals involved in discharge planning. Others were ethnographic studies observing the social and cultural processes by which elderly people were discharged from hospital.

These studies were reviewed in an attempt to characterise the way in which these experiences were described, and the underlying beliefs, attitudes and values or priorities which were reported by participants.

6.2.1 Elderly people

6.2.1.1 Elderly respondents' descriptions of the placement decision

When they were interviewed about the residential placement decision, elderly people's descriptions included that of the placement decision as an experience of anticipated loss, amounting to a profound change (Reed & Morgan, 1999): including loss of one's home and possessions (Espejo, Goudie, & Turpin, 1999; Reed & Morgan, 1999), and loss of dignity (Forbes & Hoffart, 1998), quality of life (Forbes & Hoffart, 1998), independence (Espejo et al., 1999), control (Forbes & Hoffart, 1998), and sense of self (Forbes & Hoffart, 1998).

The decision had been made and implemented at a time in respondents' lives when many were dealing with other recent losses (Espejo et al., 1999) such as the death of a spouse, sibling, friend or child; loss of social support; and loss of their own health and valued activities. The experience had been one of anxiety and uncertainty about the future and about what residential care would entail (Espejo et al., 1999), and respondents reported having had limited information (Reed & Morgan, 1999).

The decision was often, but not always, described as having been made and implemented by others (Reed & Morgan, 1999; Reinardy, 1992, 1995), with respondents either deferring to or having their preferences over-ridden by family members and health professionals (Huby et al., 2004). This was an experience of powerlessness and helplessness (Minichiello et al., 1990). The commonest response, however, was acceptance (Espejo et al., 1999): either a stoical acceptance of the inevitable (Forbes & Hoffart, 1998; Huby et al., 2004; Reed & Morgan, 1999), or an active decision to make the best of things (Forbes & Hoffart, 1998). Some of these respondents reported a conflict between their acceptance of placement and an earlier belief that they would never do this (Espejo et al., 1999). Elderly respondents for whom the placement had not been acceptable, or accepted, reported a sense of having being short-changed (Forbes & Hoffart, 1998). In contrast, elderly people who had planned for, made and implemented the placement decision themselves described the placement decision in terms of acceptance and security (Minichiello et al., 1990).

The placement decision was reported as potentially representing a significant crisis for the person concerned (Minichiello et al., 1990; Reinardy & Kane, 1999; Woenne-Green, 1995). This was most likely when the elderly person was dependent on others, when forward planning had not been possible, or where the elderly person had

not been able to participate in the decision (Minichiello et al., 1990). These are all common components of the placement decision when admission occurs directly from an acute hospital to a residential care facility (R. L. Kane & Kane, 2001) and when there is cognitive impairment (Clemens, 1995).

Several researchers have analysed descriptions of the placement decision and attempted to develop a typology or classification of types of residential decision-making process (or decision-maker) for use in comparing decisions, predicting outcomes and improving professional practice. This work has extended an influential earlier study by Chenitz (1983) in which elderly people were found to characterise and evaluate a residential placement decision in terms of its centrality (its importance to their maintenance of autonomy and self-control), its desirability (the extent to which it was wanted or chosen), its legitimation (a plausible reason, often sought from relatives or doctors), and its time/duration (temporary or permanent).

In a study of decision-making and perceived control and its impact on subsequent adjustment to residential care, Minichiello et al. (1990) interviewed 90 elderly Australian nursing home residents and 79 of their next of kin, and classified the elderly people into four groups. The larger groups were the “excluded” (53 of the elderly participants had not been involved in the decision to move or in the selection of the nursing home) and the “fully involved” (19 had been involved in the decision to move and in the selection of the nursing home). There were two smaller groups: the “decision-involved”, those who had been involved in the decision to move but not in the selection process (10 elderly people), and the “selection-involved”, those who had been involved in the selection process but not the decision to move (8 elderly people).

Minichiello et al. found that the fully involved elderly people were more likely than the others, prior to the nursing home admission, to have been in better health, to have been living alone, and to have been independent and self-supporting in their daily activities. These elderly people expressed a preference for looking after themselves and not accepting help from family, and viewed the receipt of informal care as dependence, whereas residential placement was seen as a way of maintaining independence. By planning ahead, the fully involved elderly people had avoided the possibility of a crisis placement decision while acutely ill. They had been able to make the residential care decision and select a nursing home while still well enough to do so.

In contrast, the excluded elderly people had already been in such poor health at the time of placement that they were dependent on others. Prior to admission over two-thirds had been receiving formal or informal care from others, and many had been living with others, often their offspring. The excluded respondents were more likely than fully involved respondents to have expected family members to provide their long-term care. They had not been aware of the extent of their care needs, or of the burden and conflicting demands their family caregivers were experiencing. Hence they did not view formal services or residential care as appropriate care options, but rather as indications of abandonment by the family. Decisions about residential placement had been deferred for as long as possible. Placement had often been precipitated by a crisis, such as a hospitalisation or bereavement. It occurred at a point when the elderly person's health had deteriorated and/or the family caregivers could no longer provide adequate support. A similar group, Minichiello et al. observed, had been identified in an earlier study (Day, 1985) and described as "fatalists". These were people who had avoided thinking about what might happen if their care needs increased, assuming that "everything would

work out” (Minichiello et al., 1990, p. 338). Having no sense of control over their future, they did not believe in planning ahead.

Of the two other groups of elderly people identified by Minichiello et al., the decision-involved elderly people resembled the fully involved in their preference for self-support and their wish not to rely on family members for care. However they were more ambivalent about the type of care they preferred, and several had been receiving informal care from family members. It appeared that the decision-involved respondents were aware of the issues but had deferred action until after the point when their frailty meant that they needed support. All had been admitted to the nursing home from hospital. A similar group, Minichiello et al. observed, had been described by Day (1985) as “procrastinators”.

The selection-involved group resembled the excluded group in that they had not expected to move, had relied on family members for care, and had been receiving high levels of support from family members. The inclusion of the selection-involved elderly people in the process of choosing the home appeared to have been a trade-off for their agreeing to move. However, it had also served to legitimise the move, increasing their acceptance of the move and reducing the guilt of family members.

Nolan et al. (1996) conducted a series of studies of placement experiences of elderly people and proposed a classification system for placement decisions. They found that anticipation (having considered placement, whether positively or negatively, before it occurred), participation in the decision, exploration of emotions, being provided with information, and maintenance of personal continuity all contributed to acceptance of and adjustment to residential placement (Nolan et al., 1996). In terms of these four processes, Nolan et al. classified the residential placements into four

categories. An acceptable placement was a “positive choice” (in which there had been participation, exploration and information, and at least some anticipation, and hence some sense that the move was desirable), or, more commonly, a “rationalised alternative” (in which there had been limited anticipation, participation, exploration or information, but the decision was perceived as legitimate and/or reversible). The less acceptable placements were the “discredited option” (which had begun as a positive choice or a rationalised alternative, until subsequent information, for example worse-than-expected conditions in the placement setting, had led to a more negative perception) and the “fait accompli” (the worst case scenario, in which there had been no anticipation, participation, exploration or information, and hence there was no basis for a positive view of the placement decision).

In an attempt to apply a consumer decision-making model to the residential placement decision, Maloney, Finn, Bloom, & Andresen (1996) interviewed 63 elderly individuals in residential care and 56 of their relatives. Maloney et al. found that the residential care decision did not always follow the standard consumer decision-making model in which a consumer, having decided to seek a product or service, researches the options and makes an informed choice. They identified four distinct decision-making styles. The “Advance Planners” – 32% of their elderly participants – had followed a consumer decision-making model. The remainder had deferred the decision until the external environment had provided an identifiable prompt. A “Wake-Up Call” (a health event or near crisis) had flagged the future need for care for 22% of respondents. Another 29% – the “Reluctant Consenters” group – had been pushed into making the residential care decision by relatives or health professionals who had noticed a decline in their level of functioning. In other words, it was the significant others who had

identified and responded to a wake-up call. The remaining 17% were identified by Maloney et al. as “Scramblers”: people who had been forced into residential care by a serious illness or injury which required an instant decision and urgent placement.

6.2.1.3 Elderly respondents’ priorities and values: what mandates, precipitates, or legitimise placement?

In these retrospective reports, it was difficult to discriminate between the prospectively held values that had guided the elderly respondents’ decisions and their responses to others’ decisions, and retrospectively expressed values that might have been adopted after the event as a way of accepting or legitimising an irrevocable change. For example, values such as harmony, acceptance and the wish not to burden others might have served to mitigate the psychological losses inherent in residential placement, and to legitimise placement after the event.

It had been apparent from the review of the literature on prospective attitudes to long term care and residential placement (Chapter 4) that very few people wanted to move into a residential aged care facility, and very few people wanted to place an elderly relative in care. However when more complex questions had been posed, they had evoked more complex responses. Almost everyone had appeared to accept that there were situational variables that made the residential placement decision – which was on one level unacceptable – also inevitable at some point. In terms of evaluating predisposition, the research question then became, not whether or to what extent residential aged care was an acceptable option, but what factors could over-ride its unacceptability.

In a parallel fashion, some of the values and priorities expressed by elderly people in retrospective studies appeared to reflect deep underlying principles. Other comments acknowledged that less personally meaningful, but more situationally relevant, values might have operated in complex situations, and in cases where an elderly person was forced to depend on others or to accept the loss of independence.

In an attempt to map the values underlying decisions about long-term care, McCullough et al. (1993) interviewed 24 elderly people within a month of accepting long-term care. Long-term care was defined as including low- or high-level residential care, care in the home of a relative or acquaintance, and care received while living in one's own home (through paid home help or an adult day-care centre). The resulting qualitative study of the underlying values of 24 elderly people, 23 of their relatives or friends involved in the long-term care decision, and 13 health professionals also involved in the decision, was ground-breaking in its inclusion of three groups of stakeholders and its direct comparison of their views and values. It remains one of the very few studies to have attempted or accomplished this.

McCullough et al. applied a data-driven thematic analysis, deriving their themes from the interview data. They identified 348 specific values expressed by elderly people, 398 values expressed by family members and friends, and 241 expressed by health professionals. Through a systematic process of selection, ordering, clustering and categorisation, these values were reduced to a smaller number of generic values, which in turn were grouped into 15 categories of generic values.

The value categories mentioned by the elderly people were, in order of frequency of mention of a value from the category at least once by an individual: environment

(mentioned by 96% of respondents), self-identity (78%), relationship (74%), care (70%), health (65%), caregiver burden (49%), finances (43%), and security (26%).

Relatives or friends expressed the following values: care (mentioned by 91%), security (78%), psychological well-being (70%), caregiver burden (65%), relationship (65%), quality of environment (65%), elder respect (65%), health (61%), finances (61%), caregiver benefits (22%), filial responsibilities (22%), and elder identity (17%).

Values mentioned by the health professionals involved in the long-term-care decisions were (in order): care (100%), health (100%), relationship (77%), psychological well being (77%), quality of environment (69%), elder respect (69%), caregiver burden (69%), decision-making process (35%), and finances (23%).

Interpreting these “values maps” (p. 328), McCullough et al. observed some commonalities, in that for the sample as a whole, 86% of the elderly people’s generic values were also expressed by relatives or friends, and 82% of generic values expressed by relatives or friends were also expressed by elderly people. Of the generic values expressed by the health professionals, 66% were mentioned by elderly people and also by relatives or friends, and another 19% were either mentioned by elderly people or by relatives or friends.

Interestingly, however, the relative priority of values was found to differ between the groups. The first three values most commonly mentioned by the elderly people were, in order, environment, self-identity and relationship, whereas relatives were most likely to mention care, security, and psychological well-being. Professionals were most likely to mention care, physical health and (with equal frequency) relationship and psychological well being. McCullough et al. acknowledged that health-related values might be mentioned less by elders because of an assumption that health issues would be

addressed adequately, but they also raised the possibility that, in making decisions about long-term care, professionals' values might be health-related, whereas elders' values and priorities might not always be health-related but might reflect other values such as self-identity and autonomy.

Commenting on the language used by respondents, McCullough et al. observed that the language of elderly people and their friends or relatives was expressive, using metaphor and example to communicate the elderly person's position and experience in a direct and specific manner. This was contrasted with the language used by the health professionals, which was often abstract and general.

McCullough et al. (1993) concluded that decisions about long-term care involved complex values, that qualitative issues were at least as important as quantifiable ones, and that professionals needed to make an effort to understand and speak the language of their clients and of the clients' friends and relatives. They raised the possibility of an important underlying difference of priorities or values. When considering long-term care elderly people might value autonomy and self-identity most, whereas professionals might give the highest priority to health-related values, and relatives appeared most concerned about care and security.

Forbes and Hoffart (1998) followed on from the McCullough et al. (1993) study and interviewed 27 people aged over 60, of whom 11 had recently been admitted to a nursing home. The remaining 16 had also undergone the state pre-admission screening process for nursing home entry but had been offered home-based long-term care instead. Forbes and Hoffart drew an explicit distinction between beliefs, attitudes and values (see Chapter 1 for more detail), and focused their interviews and qualitative

analysis on the values, attitudes and beliefs acknowledged by these elderly people as salient to decisions about long-term care.

In summary, the elderly respondents believed that ageing resulted in experiences of inequity, and a loss of control and independence. Nursing home placement represented “the ultimate loss of control” (p.741), although it was also acknowledged (more so by the nursing home residents) as offering a safe environment. Respondents identified health needs, available formal and informal support, and the financial ability to pay for personal care services at home, as important factors in the placement decision.

Acceptance, whether active and engaged or passive and stoical, was the most strongly expressed attitude, and four other attitudes were also found to be characteristic of respondents: resistance to change, perseverance, self-responsibility and reciprocity.

Seven important values were identified by Forbes and Hoffart as underlying these elderly people’s beliefs and attitudes. The most strongly-expressed values were independence and sense of self. The others were security, work ethic, privacy, quality of life, and trust. The value of independence was expressed equally strongly by those who had, and had not, been admitted to residential placement. However, members of the latter group were more likely to express an attitude of acceptance, which Forbes and Hoffart interpreted as a psychological buffer assisting them to cope with change.

A number of studies have focused on perceptions that, according to the elderly respondents, mandated, precipitated and/or legitimised a decision to proceed to residential placement. Aspects of the experience that have been described in the literature as mandating or legitimising residential placement have included health problems and the need for professional care (Espejo et al., 1999; Forbes & Hoffart,

1998; Johnson, Schwiebert, & Rosenmann, 1994), safety (Bell, 1996; Espejo et al., 1999; Forbes & Hoffart, 1998), inability to care for oneself (Espejo et al., 1999; Forbes & Hoffart, 1998), the inability of family to provide enough care (Johnson et al., 1994), reluctance to burden family members (Johnson et al., 1994), financial needs (Forbes & Hoffart, 1998), and fear of living alone or of being left alone for periods of time (Espejo et al., 1999; Johnson et al., 1994).

Placement was described as justified or legitimate if it could be seen as temporary or reversible (Bell, 1996; D. T. F. Lee, Woo, & Mackenzie, 2002), or as a way of maintaining independence (Forbes & Hoffart, 1998) and reducing family burden (Minichiello et al., 1990). Respondents were also more likely to describe placement as acceptable (voluntary, legitimate, desirable, and /or consistent with their sense of self) if they felt that they had been provided with adequate information and had a sense of choice or control (D. T. F. Lee et al., 2002), or if placement involved moving to a known location and/or an environment where existing social ties could be maintained (Reed & Morgan, 1999).

6.2.2 *Family members*

6.2.2.1 *Family caregivers' experience of placement*

Some family members reported that the placement experience had been planned (Minichiello et al., 1990), but more often they said that it had been precipitated by a crisis (Dellasega & Mastrian, 1995), forming part of a complex series of events (Pearson et al., 1998) in which placement occurred as a last resort (Bell, 1996). The placement decision was often described as having been made or prompted by an

outsider such as a health professional (Penrod & Dellasega, 1998; Reed & Morgan, 1999; Rodgers, 1997).

Description of the experience included an experience of crisis, with pressure to make a decision very quickly (Nolan et al., 1996; Pearson et al., 1998; Reed & Morgan, 1999) and to opt for residential placement, often in the first available bed, with few or no choices being offered by hospital staff, and patients and families not being informed of their right to refuse placement (Clemens, 1995). In one study (Clemens, 1995) family members perceived that the placement decision had not been made by them but by hospital discharge planners, whereas the same discharge planners perceived that the family members had been more influential in the decision.

Family caregivers reported feeling unprepared for the emotional impact of the move (Lundh, Sandberg, & Nolan, 2000). They reported feelings of isolation (Dellasega & Mastrian, 1995; Nolan et al., 1996; Pearson et al., 1998), burden (Butcher, Holkup, Park, & Maas, 2001; Liken, 2001b; Nolan et al., 1996), responsibility (Butcher et al., 2001; Liken, 2001b; Reed & Morgan, 1999), lack of information (Clemens, 1995; Nolan et al., 1996), powerlessness or helplessness (Nolan et al., 1996; Pearson et al., 1998) and surrender to the system (Penrod & Dellasega, 1998), as well as guilt (Nolan et al., 1996; Pearson et al., 1998), anger (Nolan et al., 1996), relief (Butcher et al., 2001; Nolan et al., 1996; Pearson et al., 1998), inevitability (Pearson et al., 1998), and a sense of inner conflict (Pearson et al., 1998), in that both alternatives, continued home care and nursing-home care, were unacceptable (Penrod & Dellasega, 1998), constituting a “no-win” situation (Nolan et al., 1996). A sense of loss was commonly reported by family caregivers: loss of the spouse from the marital home (Davies & Nolan, 2004; Lundh et al., 2000; A. A. Ryan & Scullion, 2000), loss of the parental home (Davies &

Nolan, 2004), and loss of an actual caregiver role (Davies & Nolan, 2004) and/or an idealised caregiver role (Dellasega & Shellenbarger, 1992).

For the majority of family caregivers in one study (Liken, 2001b) the experience was found to meet criteria for a critical incident (a sudden or unexpected event, danger or threat to life, loss of sense of control, and disruption of beliefs or values). The remaining minority of respondents in that study had adopted a pragmatic approach to the decision, believing that they had no choice: a logical or stoical approach that was also adopted by respondents to other studies (Liken, 2001b; Lundh et al., 2000; A. A. Ryan & Scullion, 2000).

The decision-making process was likely to be described as particularly stressful by those relatives who were placing a parent or spouse, who were in paid employment and/or experiencing multiple competing demands, where the placement occurred from hospital or in response to multiple problems (McAuley & Travis, 2000), or where there was conflict within the family about whether or where placement should occur (Butcher et al., 2001; Liken, 2001a). Some family members also reported language and cultural issues, with language barriers resulting in lack of information provision or discussion by hospital staff (Clemens, 1995). A Taiwanese study found that for family members within a Confucian culture the placement decision was particularly difficult, for cultural reasons (Kao & Stuijbergen, 1999).

6.2.2.2 Family caregivers' priorities and values: what mandates, precipitates, or legitimises placement?

As in the case of the elderly respondents, the boundary between active values and priorities, and passively accepted legitimisations was sometimes difficult to delineate.

As mentioned above (McCullough et al., 1993) the values most likely to be expressed by the relatives or friends were care, security, and psychological well-being, specifically: care (91%), security (78%), psychological well-being (70%), caregiver burden (65%), relationship (65%), quality of environment (65%), elder respect (65%), health (61%), finances (61%), caregiver benefits (22%), filial responsibilities (22%), and elder identity (17%).

The safety of the elderly person was described as an over-riding concern or value (Butcher et al., 2001; Rodgers, 1997) mandating or legitimising placement where the elderly person could no longer manage alone, the support of the family was no longer adequate, and additional support was not available from relatives (Butcher et al., 2001; Pearson et al., 1998). Approval, support or validation of the decision by family members' peers was important in making the decision (Dellasega & Mastrian, 1995).

In a Taiwanese study (Kao & Stuijbergen, 1999), conflicting or unbalanced values were identified at the point where family care-giving failed. Kao and Stuijbergen observed that in Chinese and other Confucian cultures filial obligation was a primary value and most care of the elderly was still informal and provided by family members within the home. However because of social changes including increased life expectancy, urbanisation, and employment of women outside the home, demand for residential care was increasing. The placement decision was described by family caregivers as occurring at a point where the Confucian values of harmony, balance, and duty (including filial obligation and obligation to others) could not all be realised. In making decisions about placement, family members reported experiencing a non-linear and evolutionary process of breaking harmony, setting limits and re-establishing harmony.

In a North American study Liken (2001b) identified pairs of conflicting values underlying caregivers' placement decisions. The first was valuing the elderly person's safety versus their autonomy. The extent to which safety was valued over autonomy at a given point of time was seen as reflecting the caregiver's primary duty of protection. The high level of inner conflict which resulted was interpreted in terms of the high value placed by society on individuals' autonomy and self-sufficiency, such that removal of an individual's autonomy could be seen as a "personal death" (Liken, 2001b, p.173) for that individual. The second values conflict to be identified was between obligation to the care recipient and obligation to oneself and one's other responsibilities. The third values conflict identified was between logic and emotion. Some family caregivers reported having identified and separated logic from emotion, and made a decision which they explained in rational terms as their having had no choice. Liken found that unlike other respondents in the study, this subgroup of respondents had not experienced placement decision as a critical incident.

McCullough et al. (1993) noted that the values expressed by relatives and friends were more complex than those expressed by the other two groups, both in the number of generic values and the number of categories. They suggested that this was because the roles of relatives and friends were less well defined, and potentially the most complex, including caregiver, family member, advocate and negotiator. The other participants' roles were simpler, with the professionals focussing on the provision of professional services, and the elderly people on "maintaining continuity in the midst of change" (p.330).

McCullough et al. (1993) also observed that filial responsibility (the obligation to care for older family members) was generally assumed to be an important ethical value

in long-term care, but that respondents in their study had rarely mentioned it. They suggested that filial responsibility was moderated by issues of relationship and of caregiver burden. The latter, as acknowledged by elderly people and their relatives, represented not only a psychological response but an ethical process: elderly people, as well as their relatives, acknowledged the importance of balancing the needs of the elderly person against the needs of caregivers and of younger members of the family.

6.2.3 Health professionals involved in discharge planning

6.2.3.1 Studies of health professionals involved in residential placement decisions

It is clear from the reports of patients and families that health professionals are often involved in the decision-making process, for example medical and nursing staff and allied health professionals (such as occupational therapists, physical therapists and in particular social workers) employed in their professional roles in hospitals, as well as a range of professionals engaged in the allocation of community and government funds for the care of elderly individuals (discharge planners, local doctors, Aged Care Assessment Teams, domiciliary care agencies).

The experience of participating in these decisions is qualitatively different for health professionals. They are more likely than elderly people and relatives to participate in large numbers of placement decisions, and their involvement is primarily professional. However they too may experience difficulties in fulfilling their roles and meeting a range of expectations: of patients and relatives, employers, and the ethical codes of their professions.

Studies of professionals' experiences and values when they are involved in residential placement decisions do exist, but relatively few were identified. Rather than focussing directly on, and asking about, personal experiences (as with elderly people and family caregivers) these studies have generally been undertaken with the goal of studying and improving professional practice. Most such studies identified in this review (1990-2005) had been undertaken by social workers and published in social work journals, reflecting the fact that traditionally social workers have negotiated with patients, families and community agencies in arranging post-discharge services for patients.

There is a newer area of literature concerned with professional issues related to hospital discharge planning. With increased economic pressure on hospitals to admit and treat as many patients as possible while keeping costs low and admissions short, and with the community being expected to provide long-term care for elderly people, there has been more pressure on hospital staff to facilitate patient discharges, often at very short notice (Feigin et al., 1998). Pressures on and within medical units mean that participants in discharge planning are expected to fulfil their roles as early in the patient admission as possible, even to the extent of deciding on a discharge destination within 24 hours of the patient's admission, before assessment and treatment have had a chance to be completed. It is important to hospitals that discharges be timely, and also that they be successful. From a hospital's perspective, a successful discharge is one which occurs as early as possible without resulting in an unplanned re-admission to hospital. Unplanned re-admissions are often unfunded by health authorities and thus they represent a financial penalty for failure of a discharge plan.

Thus, the activity of discharge planning (ensuring that at the point when a patient no longer needs a hospital bed, he or she is transferred to the next destination, be it home or a community facility, in a timely fashion) has become increasingly salient in health care (Feigin et al., 1998). Previously part of the role of the hospital social worker, discharge planning has emerged as a separate clinical role (Grimmer, 1997). Ideally, an assessment of the patient's likely needs on discharge (conducted by a multidisciplinary team, and involving the patient, family, local doctor and discharge planner) is followed by the development, implementation and evaluation of a discharge plan by a formally identified discharge planner, who liaises with hospital staff and community agencies with the goal of ensuring continuity of care (Grimmer, 1997). The discharge planner is usually a social worker or a nurse, employed by the hospital and engaged full-time in discharge planning and case management, rather than in general ward duties. It is yet to be established that formalised discharge planning results in improved outcomes or in reduced costs to hospitals (Parkes & Shepperd, 2002; Richards & Coast, 2003). There are many studies of the effectiveness and organisational impact of the discharge planning process (Grimmer, 1997; Richards & Coast, 2003). A smaller number of studies has dealt with practice or process issues in discharge planning, and within these, there is often a focus on discharge planning for the elderly.

A third approach has been to conduct an ethnographic study of the process of discharge planning and residential placement decision within the acute hospital, observing interactions as well as interviewing participants. Two such studies were identified (Dill, 1995; Huby et al., 2004).

The literature on social work practice and discharge planning practice was found to be quite homogeneous in its approach. Retrospective interviews (and occasionally

responses to surveys or hypothetical vignettes) were analysed qualitatively in terms of theme and content, and published in social work or nursing journals. This social work and discharge planning literature will be reviewed together, followed by a separate discussion of the processes observed in the two ethnographic studies.

6.2.3.2 Studies of professional practice in residential placement decisions

Some health professionals have described the placement decision and process, as being arranged in an ad hoc fashion (Reed & Morgan, 1999), perhaps in comparison with other more easily standardised health care activities undertaken in hospitals.

In a study of the discharge planning process for elderly people (Proctor, Morrow-Howell, & Lott, 1993) social workers were asked about the experience and ethical implications of a number of discharge decisions. They reported that most of these discharge decisions had involved a degree of interpersonal conflict (Proctor et al., 1993), most often between the family and hospital staff, but also between the patient and staff, between the social worker and medical staff, between the patient and everyone else, and between family members. A high frequency of ethical dilemmas was also reported, most often about the conflict between the patient's self-determination and the patient's best interests, the different options for discharge destination, and the inadequacy of available options for post-discharge care. Conflicts of loyalty were also reported by social workers.

In a British study of several groups of health professionals involved in discharging the elderly into residential care (Reed & Morgan, 1999), medical staff expressed a responsibility to give an opinion on the need for placement, and to keep hospital admissions as short as possible for the benefit of other patients, but did not feel that they

needed to be involved in subsequent discussions about placement. Social work staff reported a lack of autonomy, both for themselves and clients, in that the medical staff had made decisions and the social work role was simply to implement them, without the time to facilitate patients' discussions or decisions. Hospital nursing staff reported knowing little about care homes and seeing their role as reassuring the elderly patients while they awaited the move. It appeared that the process for these health professionals was fragmented, with control and responsibility being divided (Reed & Morgan, 1999) and perhaps diffused among professions within a hospital team.

Health professionals reported experiencing a number of inner conflicts: between roles (who was their client the patient, the family, the hospital or the community?) and between values (the patient's autonomy and the patient's best interests; the patient's physical safety and the patient's wish to return home) (Clemens, 1995). They also reported inner conflict concerning the limited time available for competing tasks (making practical arrangements versus assisting patients and families to make decisions) in the context of high caseloads and significant time-pressures (Kadushin & Kulys, 1993), and in some instances they struggled with the belief that institutional care was more likely to succeed than the patients' preferred option of home-based care on discharge (Clemens, 1995).

Reviewing the literature on social workers' role in residential placement decisions made in the community, Healy (1998) observed that because decisions about the lifestyles of elderly people did not appear as dramatic as those made in medical emergencies, the central priority, in biomedical ethics and in social work practice, of patient autonomy might be eroded by smaller day-to-day decisions, or swept aside by

more urgent concerns about patient safety or caregiver burden. Nevertheless the tension between these inconsistent values could be problematic for social workers.

Similarly in a North American study, Degenholtz, Kane, Kane, & Finch (1999) presented hypothetical vignettes to Medicaid case managers, whose role was to authorise the funding of home-and-community-based care packages for elderly people with disabilities, who would otherwise be obliged to enter nursing homes. Degenholtz et al. observed that case managers had an ethical obligation to respect client preferences, but in practice this often conflicted with their perception of risks to clients' health safety. "While case managers commonly endorse an ethic of respect for client preferences, in practice they often do the opposite to get a client to relocate to a nursing home" (Degenholtz et al., 1999, pg. 243). Degenholtz et al. found that case managers were least likely to respect client preferences where there was an issue of cognitive impairment.

6.2.3.3 Ethnographic observations of residential placement decisions

In an ethnographic study of ethical implications of the discharge planning process for elderly patients in a large North American hospital, Dill (1995) observed that there were inherent tensions in the process. Until a discharge date was established, post-hospital care could not be arranged by discharge planners, but until a destination (home or residential care) was selected and the transition arranged by discharge planners, medical staff could not discharge the patient (Dill, 1995). Once a date was set, discharge planners were expected to facilitate discharge as quickly as possible. In order to do so, they would attempt to predict the destination beforehand and begin working towards it.

Within the hospital team, pressures towards consensus were observed (Dill, 1995). Consensus appeared to be important for three reasons: so that optimal discharges would occur, so that interpersonal harmony would be maintained in the interest of ongoing cooperation, and so that conflicts (which might expose the hospital to litigation in the event of a poor patient outcome) would not become visible.

To this end a range of players with different agendas, status, and stances would seek to develop a shared understanding, both in individual cases and in terms of the team's approach.

Variables in the process included the patient's wishes, mental competence, capabilities and financial resources; the family's wishes, involvement, level of internal conflict and ability to provide care; and the varying availability of informal and formal support services including residential care places and home help services. While objective information was sought, the discharge decision appeared to be socially constructed, with information being selectively obtained, discussed and described in the interest of consensus within the team (Dill, 1995).

For example, Dill observed, the mental competence of the patient was central to medical bioethics. Both legally and ethically the patient's decision could not be disregarded unless he or she was mentally incompetent to make decisions. In practice, however, inability to execute decisions was sometimes equated with inability to make decisions, and patients' need to delegate actions might be interpreted as a need or obligation to have others decide for them. In this context formal and objective assessment of mental competence was important. However, Dill observed, formal assessment of decision-making competence was not undertaken in all cases, or even in

all cases where competence had been questioned, but only in cases where patients were not complying with staff plans.

Dill commented that “Given the psychological and social importance of these transitions, issues of control and choice in the discharge process have profound practical, clinical, legal and ethical implications” (Dill, 1995, p. 1290). Dill concluded that patients’ ability to exercise autonomy in discharge decisions was restricted, not only by time pressures, uncertainties, conflicts between interested parties, and lack of options, but also, and fundamentally, by the nature of the discharge planning process. Furthermore, Dill concluded, the traditional bioethical approach to patient decisions about medical care was inadequate to the more complex decision-making process of discharge planning for elderly people. The patient, family and community all had legitimate interests in the decision. Dill proposed that an alternative model of “negotiated consent” be adopted, with recognition of all interested parties and acknowledgment of multiple and often conflicting interests. Finally, Dill cautioned that this process had the potential for misuse and should not be used to shift responsibility inequitably.

In a pilot qualitative study of discharge planning for elderly people in a Scottish general hospital (Huby et al., 2004), the discharge planning process for 22 elderly people in three wards was observed, and participants were interviewed, over a five-month period.

Huby et al. observed that patients rarely played an active part in their rehabilitation or the discharge decision-making process. Instead, they placed their trust in others to decide on their behalf: deferring to higher-status professionals and delegating responsibility to younger people, either their relatives or staff. They also

avoided engagement in discussions and decisions, in case disagreement was seen as an implied criticism of the staff who were providing their care.

As a result, staff members obtained little information from the patient's perspective for use in guiding the discharge decision or assessing the patient's mental competence. Indeed this lack of active participation resulted in doubts about patients' mental competence. As a matter of policy, mental competence was evaluated using objective measures such as the Abbreviated Mental Test (Hodkinson, 1973) and physical capacities were also measured objectively. However this objective information then served to trigger decisions in a predetermined fashion. It could not always be considered flexibly in the context of the patient's knowledge, wishes or priorities. A risk management approach was applied to discharge decision-making, but concerns about risk focussed on risk to patients' physical safety, rather than the personal and psychological risk to patients of losing their homes and lifestyles.

Huby et al. concluded that the decision-making process excluded both patients and staff from active decision-making, with patients being excluded from the process, and staff being constrained to rely on set procedures guided by limited formal assessments of physical and cognitive functioning.

6.2.3.4 Health professionals' priorities and values: what mandates, precipitates, or legitimises placement?

As mentioned above (McCullough et al., 1993) the values most likely to be mentioned by health professionals concerning a long-term care decision were care, physical health and (with equal frequency) relationship and psychological well being. Specifically, health professionals mentioned (in order): care (100%), health (100%),

relationship (77%), psychological well being (77%), quality of environment (69%), elder respect (69%), caregiver burden (69%), decision-making process (35%), and finances (23%).

In a study of the discharge planning process for elderly people (Proctor et al., 1993) social workers were asked about the ethical implications of a number of discharge decisions and they listed the following conflicts of values: between the patient's self-determination and the patient's best interests, between the social worker's obligation to the employer and to the client, between the patient's self-determination and the family's self-determination, between institutional care and home care, as well as conflict about who was to decide about the discharge. Other values they expressed were the importance of respectful treatment of patients, open communication, full disclosure, client self-determination (underpinned by mental competence), and the best possible discharge for each individual patient.

Kadushin and Kulys (1993) found that staff valued the activity of assisting the patient and family to make the decision about discharge destination. Clemens (1995) found that staff attempted to balance the social work principles of patient autonomy and beneficence (the good of clients).

In a small qualitative study Jette, Grover and Keck (2003) found that hospital physical and occupational therapists considered patients' level of functioning (mobility or activities of daily living) to be the major determinant of the initial recommendation for discharge destination. Patients' wants and needs, their physical, mental and emotional capacity to participate in ongoing rehabilitation, and their context (home, family and support network) were considered to be important but secondary factors.

Dill (1995) found that staff espoused the value of patient autonomy, but that this was significantly qualified by other factors including decisional capacity, familial interdependence, the best interests of the patient, the patient's ability to execute decisions, and the availability of support services, to the extent that the normal biomedical model of patient autonomy was not applied. Staff also valued team consensus.

6.3 Conclusions

It appeared from the retrospective literature that involvement in the residential placement decision could be a problematic experience for all concerned, with common themes of powerlessness, lack of control, time pressure, and the potential for inner and interpersonal conflict. Among each of the three groups of participants, attempts to defer, deny or legitimise decisions and to diffuse responsibility were described. Older people in care often reported that their relatives or health professionals had made the placement decision, and this was confirmed by the relatives and the health professionals involved. Relatives often felt that health professionals had had more control, whereas health professionals reported that relatives, and/or other members of the health care team, had more influence on the placement decision than they themselves did.

Elderly people and their family caregivers described the placement experience as involving painful and sometimes conflicting emotions. Where possible these emotions were reportedly dealt with through a process of acceptance, with older people being stoical or making the best of things, and relatives attempting to apply logic rather than emotion and seeking validation from health professionals, other family members, and peers.

There appeared to be consensus that placement, although not desirable, was legitimate or legitimisable in one or more of the following circumstances: where there were health problems; where professional care was required; where the elderly person could not care for himself or herself and where the family could not provide enough care; where there was a wish not to burden the family; where the elderly person wished to maintain independence by going into residential care, and where residential placement would solve financial problems.

In terms of the decision itself, it was seen as legitimate if the older person had participated in the decision, if the move could be construed as temporary or reversible, and if the care home was in a location which was familiar and/or in which existing social relationships could be maintained. Descriptions of placement decisions in the retrospective literature suggested that they could usefully be divided into three categories. “Planned” placement decisions were those in which the elderly person had made a decision and initiated the move before any acute need arose. “Prompted” decisions were those in which the decision had been made in response to a sentinel event which indicated (to the elderly person, the family, and/or to a health professional) that it was time to initiate placement. “Pushed” decisions were experienced as crises leading to immediate, and often less than satisfactory, residential placement decisions.

The prospective survey findings (Chapter 5) were interesting and thought provoking, and they suggested that prospectively held values might resemble the retrospectively held values identified in this literature. However, fine-grained interpretation had been precluded by the limitations of the survey method. It was hypothesised that if detailed interviews were undertaken with stakeholders (frail elderly people, younger relatives of frail elderly people, and health professionals engaged in

discharge planning) about a hypothetical future residential placement decision, the values they expressed could be explored and would resemble those recorded in the retrospective study by McCullough et al. (1993) and in the survey.

In the next stage of the project (see Chapter 7), an interview protocol was designed in which stakeholders were interviewed in depth about a hypothetical future residential placement decision. The themes, priorities, beliefs, attitudes and values identified in this review of the retrospective literature were used to design a research-based thematic analysis of the interview data.

Chapter 7. Prospectively held values and the residential placement decision:

Interviews with stakeholders

7.1 Overview

This chapter describes an interview study that investigated the values of potential stakeholders (elderly people in poor health, the adult relatives of elderly people, and health professionals involved in discharge planning) when considering whether a frail elderly person should move into a residential aged care facility at the end of a hospital admission. Reviews of the literature (Chapters 4 and 6) suggested that these values might differ, or operate differently, between elderly people living in the community, the younger adult relatives of such elderly people, and health professionals involved in discharge planning and residential placement for the elderly. To complement the community survey with its large numbers and quantitative method, a qualitative method was used to provide a detailed thematic analysis of the interviews.

As described in Chapter 1, this study followed the schema of values, attitudes and beliefs adopted by Forbes and Hoffart (1998) in their retrospective study, which followed on from McCullough et al. (1993).

In their groundbreaking retrospective study, McCullough et al. (1993) had elicited and directly compared the values of older people with those of their relatives and of the health professionals, concerning long-term-care decisions in which members of all three groups had been involved. Although there was a significant overlap in the values reported, the relative priority of values was found to differ between the groups. The first three values most commonly mentioned by the elderly people were, in order: environment, self-identity and relationship; but relatives were most likely to mention

care, security, and psychological well being. Professionals were most likely to mention care, physical health and (with equal frequency) relationship and psychological well being. McCullough et al. acknowledged that health-related values might be mentioned less by elders because of an assumption that health issues would be addressed adequately, but they also raised the possibility that, in making decisions about long-term care, professionals' values might be health-related, whereas elders' values and priorities might not always be health-related but might reflect other values such as self-identity and autonomy.

In designing the present study, it was hypothesised that the same difference in values and in relative priority of values might be apparent in prospectively held values, when stakeholders were considering a future long-term care decision.

The survey of community members (Chapter 5), although limited by its methodology, had offered some support for this hypothesis. For every age cohort of the adult community in South Australia, the physical health and safety of the elderly person was the most frequently selected determinant of the residential placement decision. Other considerations, including mediating variables (the degree of environmental press or adaptation), strain on others, and the elderly person's rights and wishes, appeared to be secondary considerations. Among the older age-cohorts of respondents safety priorities remained the most common choices, but to a diminishing extent and these older respondents appeared to be selecting a wider range of priorities.

Specifically in this study of stakeholders, it was hypothesised that in interviews about a hypothetical prospective long-term care decision, the relative frequency of values expressed would resemble that found in the retrospective study by McCullough et al. (1993) and the survey study (Chapter 5). Younger people and health professionals

would place a higher value on the elderly person's safety, whereas elderly people would be more concerned with autonomy. In line with this expected difference in values or priorities, it was predicted that the elderly respondents would be the least likely to suggest a residential care placement for a hypothetical elderly person, and the most likely to suggest that the elderly person should make the decision. In contrast, it was predicted, professionals would be the most likely to suggest residential care and decision-making by a proxy. Relatives were expected to occupy an intermediate position.

7.2 Method

7.2.1 Participant Samples

7.2.1.1 Elderly individuals living in the community

The data obtained in the casenote study (Chapter 3) were used to produce a health profile of the elderly person who was likely to be facing residential placement at the end of a hospital admission. The plan was to recruit and interview elderly people whose health profiles were similar to this. The average age of individuals in the casenote study was 74 years, with ages ranging from 65 (the study's lower age limit) to 93 years. Sixty-five percent of them had been living alone before the index admission. In brief, such individuals had four or five comorbidities, and were prescribed multiple medications. They often had sensory impairments (sight or hearing) and motor disabilities (limited mobility due to arthritis, injury, or previous stroke). Substance abuse was not uncommon. It normally involved alcohol and occasionally benzodiazepines. Other risk factors for potential residential placement included a relatively low level of social and

family support. This was linked to having no children, or having adult children who were estranged or who lived interstate or overseas. Migration also appeared to be a significant factor, in that migrants were less likely to have extended families in Australia.

Initially an attempt was made to recruit and interview elderly patients in the medical wards of the Royal Adelaide Hospital. Individuals for whom placement was imminent were excluded from the study. Although this decision might seem paradoxical, it was thought that the interview could be distressing for people in this position, and that they might experience it as an attempt to persuade or coerce them to agree to residential placement. It was also felt that in such circumstances a full and balanced discussion of the issues and underlying values was unlikely. This concern received some confirmation from the later findings of Huby et al. (2004). In their ethnographic study of medical wards a researcher who became identified as part of the discharge planning and placement process received some very guarded responses from patients.

Participants needed to be cognitively competent to consent to the study, and medically well enough to undertake the interview. The RAH Research Ethics Committee approved this recruitment method. However, the Human Ethics Committee of the University of Adelaide's Psychology Department imposed a further restriction on recruitment: that individuals with cognitive impairment, even if competent to consent, were to be excluded from the study.

Despite the support of relevant medical and allied health staff and departments, recruitment of elderly individuals from the medical wards proved difficult. Elderly individuals who were cognitively intact and not in need of residential placement usually

spent only a few days in hospital, and were discharged home as soon as the acute medical illness had resolved. These brief admissions did not allow sufficient time after the resolution of the illness for identification of the patient as a suitable study participant, an initial approach, overnight consideration and consultation with family or friends, and consent and an interview the following day.

Instead, elderly individuals with similar health profiles were recruited in the community. The Highbury Family Practice Unit, a general practice in the outer North Eastern suburbs of Adelaide, run by the University of Adelaide's Department of General Practice (Laurence et al., 2001) was approached. The Head of the Unit agreed to approach patients who met study criteria, and provide them with a study information sheet. Those elderly people who were willing to participate rang the interviewer to arrange an interview time at their home or at the practice. In the event, they all chose to be interviewed at home.

This method of recruitment could have resulted in a sample with lower than average socio-economic status, and/or unusually positive attitudes to health professionals and academic research. To avoid this, the sample was supplemented through personal approaches to middle-aged people whose elderly relatives appeared likely to fit the health profile and to be willing to express their opinions frankly. The researcher explicitly emphasised "*gathering as many different viewpoints as possible*".

Given the richness of the data obtained in qualitative interview studies, and the detail in which the data are analysed, a compromise is often required between the numbers recruited and the depth of analysis (Boyatzis, 1998). Statistical significance is not normally sought, instead, the depth and duration of each interview, and issues of feasibility, determine the sample size (Britten, 2000). Where the goal is to understand

an experience, a minimum sample size of six individuals has been suggested (G. W. Ryan & Bernard, 2000). In this study, the initial aim was to recruit 10 elderly people. Once 10 had been interviewed, their interview data were analysed and this confirmed that the saturation point had been reached, i.e., that the latest interviews were not adding much new information.

Ten elderly people with significant medical comorbidities (similar to the profile developed in Chapters 2 and 3) were recruited and interviewed. Their mean age was 77.1 years (range 70-83 years). Five were male and five were female. Two of the sample (one male, one female) were widowed and lived alone, and the other eight were married and lived with their spouses. One was childless, but the others all had at least one adult offspring living within the state of South Australia. One was receiving a significant level of formal support services. Another had refused formal services but was receiving a high level of informal support from her adult children. Several had spouses who were receiving formal services. Most were receiving some informal services from others, and/or providing such services to their more disabled spouses or friends.

The combination of recruitment techniques resulted in the participation of elderly people from a range of backgrounds and living situations. All were retired, and their previous occupations ranged from accountant to tramways worker and home duties. Four were post-World War II immigrants from Europe and the remainder were Australian-born of Anglo-Celtic origin. All respondents spoke English at a conversational level or better, and were able to read the vignette and describe its contents.

Some interviewees lived in the original houses (large or small) in which they had spent their married lives. Others had moved to smaller home units or apartments. Some homes were privately owned, others were public housing. Locations included upper middle-class eastern and beachside suburbs, and the less affluent northern and northeastern suburbs.

One elderly person lived in a retirement village (a cluster of small dwellings built by a community agency to house elderly people, with associated hostel and nursing home facilities on the same site). Another had moved with her somewhat older husband into a retirement village some years previously. Unhappy with the environment, they had moved again to a small private house near the home of an adult offspring.

7.2.1.2 Adult relatives of frail elderly people

A range of recruiting methods was used, including interviewees nominating their friends or relatives, word of mouth, and notices on Royal Adelaide Hospital noticeboards, for the attention of relatives accompanying elderly people to appointments. As with the elderly people, the relatives came from a range of occupational and socio-economic backgrounds, from senior public servant to courier driver. Each had at least one living parent or parent-in-law who was elderly and frail, and some had several frail elderly relatives, including aunts and uncles. All were fluent in English.

In a similar sampling process to that described in Section 7.2.1.1, the initial goal was to recruit 10 relatives for interview, and at this point transcripts were analysed. When the transcripts were reviewed for coding it became apparent that although saturation had been achieved, 2 of the 10 relatives who had been interviewed did not

meet criteria for the study. In one case, in between recruitment and interviewing, the interviewee's elderly relative had moved into care. Hence the relative's view of the residential placement experience had become retrospective rather than prospective. In the other case, it was apparent that the relative had previously worked in a nursing home. Although this employment had not involved direct care of the residents, it appeared that health professionals' views and values might have been adopted. Those two interviews were excluded from further analysis, nevertheless coding revealed that enough data had been obtained and a saturation point had been reached.

The group of eight relatives whose interviews were analysed for this study were four men and four women, with a mean age of 53 years (range 41 - 62 years). One relative had migrated from Europe, two were the Australian-born children of migrants from Europe, and the remainder were at least second generation Australian.

7.2.1.3 Health professionals involved in discharge planning

For each of five relevant health professions (medicine, nursing, occupational therapy, psychology and social work), members of the profession were approached to participate and also to provide names of colleagues who were working with elderly people who faced residential placement after a hospital admission.

Respondents were encouraged to nominate colleagues with a diversity of opinions and standpoints, with the emphasis being placed on "*collecting as many viewpoints as possible*". The majority of respondents had spent 4 years or more (up to 20 years in some cases) working in this capacity with elderly people. Two individuals who had worked for a shorter period were nominated. Each had been working full-time in the

area for six months or more and was seen, by the nominating colleague, as having amassed significant understanding through intensive experience.

The study sample comprised 18 health professionals, all currently involved in discharge planning for elderly people, and employed by hospitals in the Adelaide metropolitan area. Six were male and 12 were female. One was a migrant from Europe, and several more were first or second generation Australian-born children of European migrants. All were fluent in English. The mean age was 37.9 years (range 23 - 56 years).

There were three doctors, four registered nurses, three occupational therapists, four psychologists and four social workers. These professions had been identified, both in the literature and the workplace, as being the most involved in discharge planning practice and research. The number of professions could have been increased, with physiotherapy the next to be considered. However by the time these eighteen interviews were completed, the amount of novel material was diminishing. It was felt that saturation had been reached and further sampling was not necessary.

7.2.2 Interview protocol

The same interview protocol was used for participants from all three groups. With the assistance of two senior social workers involved in hospital discharge planning, a vignette concerning a hypothetical individual, Mrs Smith, was developed (see Appendix K). This vignette was based on the information gained from the literature review (Chapter 2) and medical record study (Chapter 3). Mrs Smith was described as being female, and aged in her mid-seventies – the mean age of patients in the outcome study and in other published studies of frail elderly hospital patients. Mrs Smith was assigned

a number of risk factors for poor outcome, including vascular problems, difficulties with mobility and cognition (which underpin independence with ADL and IADL), limited family support, and a suggestion of other possible physical health problems (weight loss) and mental health problems (suspiciousness). As an extra check, the vignette was presented, along with pilot data, as a poster at a conference of allied health professionals (Denson, Winefield, Penhall, Beilby, & Farley, 2003) for critical comment.

Initially, participants were asked to read the vignette (presented in large print) and make general comments on the situation. They were then asked five questions, in order: *'What should happen?'* *'Who should decide?'* *'What would make a difference?'* *'What are the arguments for and against Mrs Smith's returning home?'* and *'Are there any other comments you would like to make on this situation?'*

Interviews were recorded using a SONY minidisk recorder and downloaded to a PC, using Lanier computer-based dictaphone technology, for storage and transcription. The author, who conducted all the interviews, also took notes throughout each interview. An experienced research officer from a university research centre specialising in qualitative research was employed to transcribe the interviews. The author checked and corrected the draft transcripts using the recordings and interview notes.

Interview transcripts were assigned identifying codes as follows: OP (older person), REL (relative of an older person) or HP (health professional) and numbered chronologically within each category. For example, the textual reference "OP02, L26" later in this chapter refers to line 26 of the interview transcript of the second elderly person to be interviewed.

7.2.3 Analysis of interviews

7.2.3.1 Thematic analysis

To complement the quantitative results of the survey study, and to provide a more detailed and informative analysis of interview responses, a thematic analysis procedure was selected (Boyatzis, 1998; Flick, 1998). The aim was to identify the values expressed by respondents when considering a residential placement decision prospectively. Thematic analysis is a qualitative approach based on the original work of Strauss (1987, cited in Flick, 1998) and developed for studying “the social distribution of perspectives on a phenomenon or process” (Flick, 1998, p.187). The initial research question determines in advance which groups are to be studied and which topics are to be covered.

According to Boyatzis (1998), there are three possible approaches to developing the codes for a thematic analysis. Approaches may be based on theory, on previous research, or on the raw data in the current study. Each approach has its costs and benefits.

The theory-driven approach requires use of an existing theory, and constrains the analysis to pre-imposed variables and interactions. Hence inter-rater reliability and construct validity are potentially low.

The data-driven approach involves identification of variables from within the data in the current study. The resultant inter-rater reliability is likely to be higher than for the other approaches, and so the coding process is more likely to be internally validated. However, the researcher’s beliefs or biases may affect the choice of variables and the generalisability of the findings is more readily questionable.

The research-based approach to thematic analysis - development of a code based on prior research - was adopted for this study. It is seen as occupying the middle of the continuum, between the other two approaches (Boyatzis, 1998). It requires adopting and/or modifying the variables and codes used by other researchers, and hence there is some risk of being influenced by their assumptions or biases (but less risk of being influenced by one's own). Because the analytic code is pre-determined and not based on the current data being analysed, high levels of inter-rater agreement can be difficult to achieve. However, the strength of this approach is its potential for using, and commenting on, the findings of other researchers. This increases the likelihood of making a contribution to knowledge rather than "re-inventing the wheel".

7.2.3.2 Codebook development

The literature concerning prospective values about placement decisions is still too limited for an analysis to be based on existing theory (theory-driven approach) or on other researchers' codebooks. Instead the list of values developed by McCullough et al. (1993) in their retrospective study was adopted as a research-based starting point for development of the study codebook (Appendix M) which was used by the author and also by the second (checking) coder.

The values categories listed by McCullough et al. (1993) were adopted as the basic structure for analysing values in this prospective interview study. In their data-driven study of the values underpinning long-term care decisions for elderly people, McCullough et al. had identified 15 categories of generic values expressed by elderly people, relatives and friends, and health professionals, in retrospective interviews after a long-term-care decision. For the present analysis, the McCullough et al. codes were

modified by the subdivision of some values categories, and by the addition of some extra values expressed by participants in residential care decisions in other retrospective studies (Chapter 6), in prospective studies (Chapter 4) and in the pilot phase of the survey study (Chapter 5). The majority of the values identified in these published studies and in the pilot study had, however, already been found to exist within the values categories used by McCullough et al. (1993).

The McCullough list of 15 value categories was modified as follows. In the McCullough et al. study, values related to autonomy and control, and values related to self-identity and respect, had all been grouped together under the ‘Self-Identity’ and ‘Elder Respect’ category of values. Given the findings of the McCullough et al. study that this values category was of importance to older people, and the salience of autonomy as a specific value in subsequent published studies, it was decided to divide this category into two. “Autonomy” and “identity” values were therefore coded separately.

Additional values for coding were obtained from the Forbes and Hoffart (1998) study (see Chapter 6), from reviews of the prospective and retrospective literature (Chapters 4 and 6) and from the survey findings (Chapter 5). The values obtained from the Forbes and Hoffart (1998) study were stoicism, acceptance, perseverance, work ethic, reciprocity and trust. In other retrospective research, relatives had mentioned ‘logic’ as a value which over-rode emotion, and/or produced a pragmatic sense that there had been no choice (Liken, 2001b; Lundh et al., 2000; A. A. Ryan & Scullion, 2000), and this was also included. Additional values found to have been expressed by professionals were open communication, full disclosure, client autonomy or self-determination, beneficence or the best interests of the client, decisional capacity,

determining who should decide, and caregiver autonomy (Proctor et al., 1993) as well as the patient's physical abilities as the major initial determinant of destination (Jette et al., 2003) and institutional care as being more likely to succeed than home care (Clemens, 1995). Those values which had not already been specified in the McCullough et al. list of value categories were added, either as additional value categories, or as examples within existing value categories. This gave a total of 28 values which were included in the codebook at the commencement of the study.

The literature on health outcomes of frail elderly medical patients (Chapter 2) and prospective attitudes to residential care (Chapter 4) had shown that in studying health beliefs concerning long-term care, values relating to family care (including issues of personal and financial strain), living in one's own home, and neighbourhood were also important. The McCullough et al. (1993) study had identified values concerning family care and finances. However the value of 'being at home' had been classified within the broader category of 'quality of environment'. For the current study, separate codes were defined for living at home, and for the personal (psychological) value of one's neighbourhood.

In the pilot phase of the survey study (Chapter 5), respondents had indicated that the elderly person's behaviour, if it was detrimental to themselves and/or others, was important in making a decision about residential placement. In this study, behaviour detrimental to oneself was coded in the safety/security value category, and behaviour detrimental to others was coded as caregiver burden.

The concepts of planning, timing and balance were mentioned in the retrospective literature (Chapter 6). These appeared relevant to satisfaction with outcome. 'Planned' decision had better outcomes than 'prompted' or 'pushed' decisions, and placement was

seen as justified if it maintained balance or restored harmony. The concepts of planning, timing and balance appeared to be used to determine, explain, or legitimise, the relative priority of competing or conflicting values at particular points in time. Hence, rather than being coded as values in their own right, these superordinate values were defined for the purposes of this study as ‘meta-concepts’: concepts or values which had been used to determine how other values applied. Mention of these meta-concepts in an interview was coded separately, alongside the coding of values.

7.2.3.3 Coding Procedure

Interview transcripts were examined for values expressed when considering the option of residential placement (nursing home or hostel care) versus more independent living options (returning to one’s own home, or moving to a smaller house or home unit or a retirement village).

Using the study codebook (Appendix M) and following the model of analysis used by McCullough et al. (1993), interviews were coded for the presence or absence of each value, rather than for the frequency with which a value was expressed. The frequency of expression was not of interest, and in any case it was thought more likely to be a function of the length of the interview and/or the perceived responses of the interviewer, than of the strength with which a value might be held.

Values were coded as positive if they were expressed as defined in the codebook, and as negative if the opposite value was expressed or if the value was stated and rejected. For example, the value of Filial Responsibility: “*My children should take care of me*” was coded as ‘Filial Responsibility positive’, and the expression of its opposite “*I don’t feel my children are obliged to care for me*” was coded as ‘Filial Responsibility

negative'. For the value of Social Contact, "*She could make some new friendships if she went into care*" was coded as 'Social Contact positive', and "*She prefers her own company, she would hate living in a group*" was coded as 'Social Contact negative'.

Some values that were expected to be mentioned by elderly people, family members and professionals in these interviews appeared to be super-ordinate in that they could be seen to include several other value categories. For example, "independence" was identified as an over-arching value category that might be used to describe one or more of the following value categories: autonomy, decisional capacity, identity, physical capabilities and work ethic/ self-responsibility. Similarly "quality of life" could include several value categories, including autonomy, environment quality, health, identity, privacy, psychological well being and respect. In each instance these values were coded at the lowest (most specific) level possible.

Inevitably values were expressed concerning matters other than the decision for or against residential placement, such as who has the right to make such placement decisions, and the extent of community responsibility for funding aged care. These values were not coded.

Responses to the first two questions of the structured interview, *What should happen when Mrs Smith leaves hospital?* and *Who should decide?* elicited expression of thoughts, values, and meta-concepts, which were explored, recorded, and coded, as above. Where necessary within an interview they were followed by more specific questions to encourage respondents to expand on, and clarify, their thoughts.

In addition, the answers to these first two questions were recorded and analysed for specific comparison of the three groups' practical suggestions about the best discharge destination and about who should make the decision.

The third, fourth and fifth structured interview questions: *What would make a difference?*, *What are the arguments for and against Mrs Smith's returning home?*, and *Are there any other comments you would like to make on this situation?* were designed as probes to elicit further expression and discussion of values and meta-concepts.

Responses were compared across the three groups, but not between genders, because, as reported above, the gender composition of the groups did not differ significantly: 50% of the elderly people, 50% of the relatives, and 67% of the health professionals were female.

7.2.3.4 Reliability, validity and reflexivity

The research-driven thematic analysis provided some protection against a purely individual or subjective interpretation of the interview data, in that the study codes were all derived from previous research. Using the study coding sheet (Appendix L) and codebook (Appendix M), each interview was coded by the author and coded a second time two weeks later as a check on intra-rater reliability. Next, the accuracy of data entry was checked.

Inter-rater reliability was also checked, to assess the robustness of the coding procedure and code definitions. Three interviews (one with an elderly person, one with a relative, one with a health professional, comprising approximately 10% of the total coded transcript) were coded for comparison by a clinical psychologist employed in another large hospital, experienced in the use of qualitative thematic analysis in research, and not involved in this study.

Using the study codebook (Appendix L), each of the three interviews was coded for the presence (1) or absence (0) of each of 32 values. These were the 28 values listed

in the codebook, and also, negative examples of each of those 4 values which had been expressed negatively by one or more respondents (autonomy, filial responsibility, institutional care, and social contact). This process provided 96 coding events (see Table 12) which were analysed for inter-rater agreement using Cohen's Kappa.

Table 12 Basis of Kappa calculation: 96 coding events.

Counts	Coder 2 = 0	Coder 2 = 1	Total
Coder 1 = 0	61	8	69
Coder 1 = 1	2	25	27
Total	63	33	96

Cohen's Kappa (Lombard, Snyder-Duch, & Bracken, 2005; G. W. Ryan & Bernard, 2000; Semler, 2001) was 0.76 ($p < 0.01$). This confirmed that inter-rater agreement was adequate and that the code and codebook were well enough defined to be used effectively and reliably.

The issue of social constraint and perceived interviewer expectations was considered. The elderly people and relatives had been explicitly selected in order to canvas a wide range of views, and this appeared to have been successful. These participants had been active in making arrangements to participate and they appeared confident and unselfconscious in expressing their views, rarely pausing to seek reassurance or agreement from the interviewer.

In contrast, although the health professionals had also been advised that a range of views was being sought, they had been recruited by professional colleagues and were

being interviewed by another health professional, and this may have constrained their comments. Some health professionals did appear to feel constrained to express a “correct” professional opinion, and two commented that they hoped they were giving the right answers. Particularly in the first few minutes of these interviews, these respondents seemed to defer to the interviewer’s own professional role as a neuropsychologist, and/or to their own professional roles, articulating their responses formally and impersonally (“*You would need to do...*”). This was usually followed, later in the interview, by a more frank and informal discussion of the underlying issues. A number of efforts were made to minimise potential constraint: for example by recruiting health professionals who worked at other hospitals and /or who were not personally known to the interviewer; by giving numerous opportunities to withdraw from the study if desired; and by emphasising the importance to this research and to the interviewer of people’s own personal views and experiences as well as, or instead of, the official line of their professions or agencies. Nevertheless there may still have been a tendency for health professionals to articulate what they felt was expected or required, instead of what they believed.

7.3 Results

7.3.1 Values expressed

Interviewees mentioned most of the 28 value categories in the codebook (see Table 13), and few additional values. Four of the values (autonomy, filial responsibility, institutional care, and social contact) were expressed by one or more respondents in an opposite or negative sense and coded accordingly, giving a total of 32 value categories which were used for coding, and for validation coding by the second coder.

During the thematic analysis it became apparent that respondents were using the value of “home” in two different ways: to express the personal (psychological) value of living in one’s own home, and/or to assert that a frail elderly person might be able to function better at home. Accordingly, the value “home” was divided into two separate values for coding, the codebook was modified accordingly, and all the interviews were recoded using these two values. Hence the final number of values coded was 33 (including the negative examples of four values).

Table 13 Values. Responses (number and %) by group.

33 Values (including 4 negative values and one subdivided value)	Elderly n=10	%	Relatives n=8	%	Prof's n=18	%
1 Acceptance / Stoicism **	3	30.0%	0	0.0%	3	16.7%
2a Autonomy good	5	50.0%	5	62.5%	17	94.4%
2b Autonomy bad	1	10.0%	1	12.5%	0	0.0%
3 Best Interests Elderly Person	5	50.0%	4	50.0%	6	33.3%
4 Care (Personal Care) *	10	100.0%	5	62.5%	17	94.4%
5 Caregiver Autonomy	1	10.0%	0	0.0%	0	0.0%
6 Caregiver Benefits *	0	0.0%	0	0.0%	0	0.0%
7 Caregiver Burden *	3	30.0%	5	62.5%	11	61.1%
8 Decision-making Capacity	0	0.0%	0	0.0%	3	16.7%
9 Decision-Making Process *	2	20.0%	1	12.5%	6	33.3%
10 Environment (Quality)*	0	0.0%	0	0.0%	1	5.6%
11a Filial Responsibility Yes	1	10.0%	1	12.5%	0	0.0%
11b Filial Responsibility No	2	20.0%	1	12.5%	0	0.0%
12 Finances *	3	30.0%	7	87.5%	12	66.7%
13 Health *	5	50.0%	6	75.0%	11	61.1%
14a Home Valued	5	50.0%	7	87.5%	12	66.7%
14b Home Function better	1	10.0%	4	50.0%	5	27.8%
15 Identity Of Elderly Person*	1	10.0%	0	0.0%	3	16.7%
16a Institutional Care Good	1	10.0%	1	12.5%	0	0.0%
16b Institutional Care Bad	3	30.0%	1	12.5%	4	22.2%
17 Logic/ Pragmatism	2	20.0%	1	12.5%	0	0.0%
18 Mental Abilities	6	60.0%	6	75.0%	11	61.1%
19 Neighbourhood	0	0.0%	1	12.5%	3	16.7%
20 Physical Abilities	3	30.0%	6	75.0%	9	50.0%
21 Privacy **	0	0.0%	0	0.0%	1	5.6%
22 Professional Care	3	30.0%	2	25.0%	1	5.6%
23 Professional Opinion	2	20.0%	0	0.0%	2	11.1%
24 Psychological wellbeing	3	30.0%	6	75.0%	11	61.1%
25 Relationship *	2	20.0%	6	75.0%	4	22.2%
26 Safety / Security *	5	50.0%	8	100.0%	18	100.0%
27a Social Contact Good	3	30.0%	3	37.5%	10	55.6%
27b Social Contact Bad	3	30.0%	3	37.5%	3	16.7%
28 Work Ethic / Self Responsibility**	4	40.0%	4	50.0%	0	0.0%

* Value derived from (McCullough et al., 1993)

** Value derived from (Forbes & Hoffart, 1998)

There was a significant overlap between the three groups in the values that were expressed but, as in the McCullough et al. (1993) study, there was a difference in the patterns of frequency of some values being mentioned by members of different groups. Appendix M gives examples of each value mentioned. Appendix N contains transcripts of three interviews: one with an elderly person, one with a relative and one with a health professional.

7.3.1.1 Values expressed by elderly respondents

As a group, the elderly respondents mentioned 28 of the 33 listed values and they mentioned an average of 8.8 values each. The value mentioned by the highest percentage of elderly interviewees as being relevant to the decision about Mrs Smith's destination was personal care, mentioned by 100%, for example:

"She must have a carer, or someone who can look after her properly" (OP02, L26). Mental ability to carry out everyday activities was mentioned by 60% of elderly respondents: *"So even if you were fit and you were starting to forget, how can you run an establishment of any sort?"* (OP05, L166).

Autonomy was mentioned by 50% of the elderly respondents: *"I still go with the theory people can decide for themselves"* (OP03, L40), as were safety *"Now she could collapse again and she could lie there for some time and die. So I think it's for her own good."* (OP04, L60), beneficence *"Someone should step in and do what's best for her"* (OP08, L10), health *"It all depends on what state her health etc is"* (OP10, L134), and the personal value of living at home:

She'd be in familiar surroundings. She can potter around to her heart's content, as long as somebody can bring in some food, and I mean the supermarkets will deliver if you phone an order. It's a lot to be said for familiar surroundings. If she's able to shower herself even. Put a plastic chair in the shower and sit there by yourself somehow. Familiarity with your own home and what you know and probably a few people around that you know. (OP03, L73)

7.3.1.2 Values expressed by relatives of elderly people

Relatives mentioned the most values; an average of 11.9 values each. As a group, they mentioned 25 of the 33 listed values. Every relative who was interviewed mentioned safety or security as a value to be considered in the decision about Mrs Smith's discharge destination: *"She's a danger to herself. She can't cope."* (REL01, L43).

The personal (psychological) value of living at home was mentioned by 87.5% of relatives: *"If she really wanted to stay in her home I wouldn't want to take that from her."* (REL07, L86) and *"But whether I'd be like that when I'm 76 or something who knows. I might think I want my dining-room table, I want my house I've lived in all this time."* (REL03, L34).

Finances were also mentioned by 87.5% of relatives:

What would be put in around her, what it would cost. Whether anyone would be able to pay for this and whether that would really be something she'd prefer to do, to pay those costs, if what is happening is a deteriorating condition. (REL02, L40)

Health was mentioned by 75% of the relatives interviewed “*Well, again, it’s not in her interests in terms of her health.*” (REL03, L53), as were mental abilities “*her short-term memory, she’ll forget important things, like the bills*” (REL10, L47), and physical abilities “*She’s not able to look after herself or do things*” (REL10, L43).

Psychological well being was also mentioned by 75%; “*She’s happy. She’s familiar with the environment, it might delay her deterioration if she’s in a familiar place.*” (REL01, L41), and “*Maybe she might actually live longer being in her own home in terms of being happier there or whatever. And she might just give up if she goes into a nursing home.*” (REL03, L76), as was the value of relationship:

She may not be able to be placed into the sort of residential placement that would allow the niece to visit as often and probably Mrs Smith values her niece’s contact. It doesn’t say anything about neighbours or anything else. Can’t tell whether that’s a factor. It doesn’t say anything about pets, but of course they would be a very important consideration if they’re in here. (REL02, L71)

Autonomy was mentioned by 62.5% of relatives “*You have to respect Mrs Smith’s right to stay in her home.*” (REL06, L10), as was personal care “*The best outcome might be, if she could stay, with a carer that’s there quite a bit, or pops in and looks after meals and that sort of thing.*”(REL09, L23).

Caregiver burden was also mentioned by 62.5% of relatives: “*I know how frustrating the distance can be, especially if the phone’s out of order, or off the hook*” (REL10, L97), “*the feelings of the son, how he feels about her being on her own.*” (REL01, L46), and:

It's of course very distressing for all the family. Mrs Smith of course, and her son, the niece is obviously closely involved. It has ripples in a lot of ways, and in a sense it doesn't count for very much in terms of the finances and the mix of care for older people and so on. But it matters enormously in people's lives. (REL02, L136)

Values mentioned by 50% of relatives were: the best interests of the elderly person, *"The son and niece, even if there is a friend who visits, does it mention a friend, have got to encourage her for her own good, for everybody else's peace of mind as well."* (REL01, L33); the potential for functioning better at home *"She has routines. If there is any cognitive dysfunction she may be more functional in her familiar environment."* (REL02, L67); and the work ethic or self-responsibility of the elderly person *"I wouldn't want to be dependent on my family that much."* (REL03, L22).

7.3.1.3 Values expressed by health professionals

As a group, the health professionals who were interviewed mentioned 25 of the 33 listed values, and on average they mentioned 10.2 values each. Safety /security was mentioned by 100% of these respondents *"She could be at risk of serious injury or calamity, there's a need to reduce the risk."* (HP04, L22) and *"A very at-risk little lady"* (HP14, L1). Autonomy was mentioned by 94% of respondents *"The person in the centre should decide"* (HP04, L10), as was personal care *"If she had just a little bit more assistance with certain things"* (HP12, L21).

Finances and the personal value of living at home were mentioned by 67% of the health professionals interviewed “*Home is precious*” (HP14, L2) and:

How much money am I going to spend for the future. Even though I’ve got a condition that is going to probably lead to institutional care at some time in the future. Is it better to go through institutional care now and not worry about going, bypass the home, what’s the value of, to her, of still being in a home that she knows well... It’s a very hard judgment to make. (HP03, L36)

Caregiver burden was mentioned by 61% of health professionals; “*It’s a worry for the family, the neighbours see her as being at risk. A strain for the family and an uphill battle for service providers.*” (HP04, L18) and “*The niece lives across town, so that’s a long way away, has a job and a family, and visits after work, and does the shopping. So that’s an enormous burden.*” (HP18, L117).

Health was also mentioned by 61%; “*If she continues to lose weight, it could cause a lot of trouble. No nutrition, infection, pressure ulcers.*”, as were mental abilities “*I guess in this case the short-term memory is of concern as well, and whether that’s affecting her looking after herself*” (HP01, L38)

Psychological well being was also mentioned by 61% of health professionals:

If we were able to institute reasonable supports and she was able to stay at home, there’s some sense of self attainment, or self achievement for actually working through a situation and staying in her own environment, not having to move out. That could be important in terms of her self esteem as well.

(HP10, L86)

Social contact (as being desirable) was mentioned by 56% of health professionals; *“She may not see it that way, but she’s isolated from her, reasonably isolated from her family... If she went into care, she would quite likely make some friends”* (HP08, L88).

Physical abilities were mentioned by 50%; *“So I would be doing some kind of activity of daily living assessment to see what she was capable of doing for herself.”* (HP06, L18).

The conflict between autonomy and beneficence in this context was clearly expressed. *“It’s a dilemma, a complex situation. The decision that’s best for the person can mean standing back. It can be difficult in a professional situation... Why’s it difficult? The professional responsibility of duty of care.”* (HP04, L36), and:

Then to actually decide, yes, I think this should go to the Guardianship Board, or... I don’t like handing over someone’s, because it’s handing over someone’s power in a way. I think “Oh I don’t want to have to do that”. But then the social workers emphasise it is our duty of care, and we can’t just send someone home because you don’t want to take away their independence and things.

(HP05, L40)

The importance of personal care services in making a return to home viable was also clearly acknowledged by health professionals, and may explain why, like most of the relatives, most health professionals who were interviewed qualified their practical suggestion that Mrs Smith should go home, by saying that this should be with supports: *“Everything would snowball in a very short amount of time if she didn’t have those*

supports” (HP12, L103) and, in a complex expression of the need to reconcile safety and autonomy needs as well as provision and acceptance of personal care:

I think she should go home. I don't think she should just be discharged – “See you later and thanks very much”. (laughs) Because there is obviously a duty of care, there are some problems. Yes, there needs to be some work done. There needs to be some discussion with her which is.... sort of couched in “How can we help you to stay home” rather than “You can't stay at home you need to go into care”. It's about “We can provide you with supports in order for you to stay at home. I guess if those supports aren't provided then you are at risk, then something needs to be done.” And I would probably try and get the support of her family and friends as well. Without it appearing like some major exercise to do her over. Of course it's not. Yes, I think that should be the aim. If that's what she wants... to keep her at home. (HP08, L47)

7.3.2 Meta-concepts expressed

Each of the three meta-concepts was mentioned by at least one member of each group (see Table 14 and Appendix M). The meta-concept most commonly mentioned by the elderly respondents was balancing of values or priorities (50%), usually with reference to family members having to balance their caregiving responsibilities against commitments to work and family life, for example “*Well that's reasonable for the niece to go, but she goes most nights. She can't go every night, but she goes most nights which is reasonable.*” OP02, L12, and “*He (the son) has got to earn a living. He's got to*

think of his family first” OP09, L11. Planning was mentioned by 30% of elderly respondents: “Thinking ahead! Maybe not so much ahead, because you can’t... But you can sympathise and you can prepare yourself just in case it happens to you. What would you do.” OP06, L41. Timing was mentioned by 20%: “Because she isn’t going to get better, she’s going to get worse like we all do”. (OP05, L226).

Relatives were most likely to mention planning (62.5%):

You are going to have a few signs where you probably need to start thinking, is this the long-term spot that I should be...You are going to get to that point probably before this situation, where you really should be moving, and moving when you are still quite well. (REL03, L15)

Timing was mentioned by 37.5% of relatives: *“Things... probably won’t get better. Things are going to deteriorate. Family or friends are going to have to take action.” (REL08, L14), and balance was mentioned by 25%: “She’s got her own life to lead and she’s only going to be able to spend so much time with her aunt.” (REL08, L79)*

Table 14 Meta-concepts. Responses (%) by group.

Meta-Concepts	Older People	Relatives	Health Profs.
Planning	30.0%	62.5%	0%
Balance	50.0%	25.0%	16.7%
Timing	20.0%	37.5%	38.9%

Professionals were most likely to mention timing (38.9%) “*If she goes home and declines support she is at risk. It’s better to get carers in earlier while she can get to know them*”. (HP14, L31), and:

So she might have some years if she lived at home, rather than just a few weeks. Of course the other side of that is, it is also going to be easier to move her into a new environment at this time and not later, and it is always tricky that one. (HP03, L95)

Planning was not mentioned by any of the health professionals, and balance was mentioned by only 16.7% of health professionals “*They have family that can be as supportive as they can, sort of given their lives and their...everything that is going on with them, and it’s quite difficult.*” (HP11, L8)

7.3.3 Additional values and comments

A number of additional values (not listed in the codebook) were mentioned by one or more elderly respondents, as being relevant to the residential placement decision. The importance of considering the elderly person’s personality when making the decision was mentioned by 30%: “*She seems as though she’s a very independent person and*

wants to stay that way” OP08, L1. The responsibility to maintain one’s property was mentioned by 20%:

Quite frankly I don’t know what the answer is, but I do know this, for me I couldn’t have a place that’s falling down around my ears, where people are saying ‘Oh she is old, and she can’t manage’ you know (laughs). I wouldn’t like that. Some people don’t care, they say ‘Well this is my home and I’m staying’. But for me I have to do something else. (OP05, L36)

The personal value of living alone, and altruism (the importance of not being selfish) were each mentioned by 10% of the elderly interviewees (one respondent).

Additional (non-listed) values mentioned by relatives included the importance of considering the elderly person’s personality when making the decision (25%) “*We don’t know what sort of person she is, whether she is a solitary person who really does push people away.*” (REL06, L94); the responsibility to maintain one’s property (25%) “*Moving out before things get too run down*” (REL06, L55); and the responsibility of professionals to provide information to the family (12.5%) and to support the family’s opinion in discussions with the elderly person (12.5%):

It would help if the OT and the Social Worker confirmed what the family were saying. Instead of just being totally impartial. That’s of course if they agree. I think in this case they would agree this is a case for residential placement. (REL01, L35)

Relatives also mentioned that the funding of aged care, at home (25%) and in residential care (12.5%), was a burden on the community and so the community had an interest in the decision. *“It’s not in the interest of society to be funding I think, even with hospitals or whatever, but is it really, like you are sort of draining the tax payer dollar by...I think the additional risk if you like.”* (REL03, L55).

Non-listed values mentioned by health professionals included the importance of considering the elderly person’s personality when making the decision (27.8%): *“A lot depends on that person’s personality, and sense that she needs to be taken care of, or sense that she wants to be autonomous. That is really a very important dimension. Given an equal level of physical feasibility.”* (HP07, L169).

Potential risk to the hospital, through litigation, if Mrs Smith was discharged home and had a poor outcome was mentioned by 16.7% of health professionals *“We’d get in big trouble if you sent somebody home and then something happens. The hospital wouldn’t be... (laughs) so thankful, I don’t think. Especially with all this public liability and things happening at the moment”* (HP05, L58).

Non-listed values mentioned by only one health professional (5.6%) were: the personal value of living alone, the responsibility of family members to support the professionals’ opinion in discussions with the elderly person, and the potential risk to the community if Mrs Smith caused a major accident at home.

Some relatives and health professionals observed that the hypothetical story was a common one, or *“a classic case”* (REL01, L30) in their experience: 33% of health professionals and 62.5% of relatives, but no elderly respondent, made this kind of comment. One elderly respondent explicitly explained that while recommending residential care for Mrs Smith and acknowledging its necessity, he would not want to

accept it for himself; *“I’d probably think more of what I want, than what’s best for me. I’ve always said I’ll go out feet first with a label on my big toe! Probably not practical though is it?”* (OP09, L77) Another elderly respondent drew a distinction between herself and Mrs Smith, in that she was prepared to accept help at home but Mrs Smith was not. Several relatives mentioned the problem of living at a distance from the elderly person; *“I know how frustrating the distance can be, especially if the phone’s out of order, or off the hook”* (REL10, L97). Some health professionals mentioned that family members who lived at a distance could present problems in terms of their views and expectations:

When you’ve got family that lives interstate, or a great, you know, far country or something. I often find that they are more extreme either way for what they want done to their parents. I guess because they are not there to be able to help at all on a regular basis and they really want everything either....I mean....either they want them placed, no debate entered into, or at home, no debate entered into. I often find that the absent family is the one that’s got stronger points of views. (HP06, L58).

For the son, I think that it would be really good that he could be contacted because he must be very worried and living interstate... So there’s probably some guilt. And he may also have some unrealistic expectations because he is interstate, and isn’t seeing the day to day things for Mum. (HP18, L127).

One health professional mentioned that her understanding of her care of elderly patients had been influenced by a recent family experience:

My father just had a sort of health scare, and Mum said “I’ve realised what if something did happen to him” and I was talking to her last night and I thought “I see these people where they are now and I don’t know what they were like before” Now I’m a bit more conscious of it. (HP11, L130)

One relative mentioned death as an event that could resolve the issue: “*Well, I don’t want to sound callous but if she died that would solve everybody’s problem wouldn’t it? But you wouldn’t wish that on anybody.*” (REL08, L126). No elderly person or health professional mentioned death in this way.

7.3.4 Where should Mrs Smith live after leaving hospital?

The study by McCullough et al. (1993) was retrospective and the decision with regard to long-term care (be it at home, in a relative’s home, through adult day-care or in a residential care setting) had already been made, with the consequent psychological adjustments and influence of hindsight. In this prospective study, all the elderly people involved (the elderly respondents, the elderly relatives of the younger respondents, and the hypothetical Mrs Smith) were still living in the community, with the issue of eventual residential care as yet unresolved. This gave the researcher the opportunity to ask two specific questions: what Mrs Smith’s destination should be, and who should make the decision.

A majority of the elderly people interviewed (60%) said that Mrs Smith should enter residential care, and the remainder (40%) said that she should return to living at home, either her existing home (20%) or a smaller home (20%). Half of the relatives

interviewed (50%) said that Mrs Smith should return home (to her existing home) and half said that she should enter residential care. In contrast, most of the health professionals interviewed (83%) said that Mrs Smith should return to her existing home, and another 11% suggested that she should move to a smaller home. Only 6% of health professionals said that she should enter residential care. Table 15 summarises these responses.

Table 15 Where should Mrs Smith live after leaving hospital? Responses (%) by group.

WHERE SHOULD MRS SMITH LIVE AFTER LEAVING HOSPITAL?	Older People (N=10)	Relatives (N=8)	Health Professionals (N=18)
Home	20%	50%	83%
Unqualified	0%	13%	17%
With supports	20%	38%	67%
Residential Care	60%	50%	6%
Hostel	10%	13%	6%
Nursing Home	30%	0%	0%
Unspecified	20%	38%	0%
Smaller House /Home Unit	20%	0%	11%

For the relationship between group membership (elderly person, relative, or health professional) and suggested destination (own home or residential care), the χ^2 value was 10.8, ($df = 2$, $N = 36$, $p=.004$, two-tailed). This confirmed that the groups differed in their suggested destinations. The value of Cramer's V was 0.54 showing that within this sample, group membership explained 29% of the variation in suggested destination.

7.3.5 Who should make the decision?

Of the elderly people interviewed, 10% said that Mrs Smith should make the decision about her discharge destination, and 30% said that her hospital team or doctor should make the decision. Another 30% said that the decision should be made by a meeting of all concerned (including Mrs Smith, her relatives, and the health

professionals involved with her care). The remaining 30% indicated that the decision should be made by one or more of the relatives, a guardian or the next of kin.

Relatives were more likely (75%) to say that Mrs Smith should make the decision, with the remainder nominating either a meeting of all involved (13%), or relatives, a guardian or the next of kin (13%).

Health professionals were even more likely (83%) to say that Mrs Smith should make the decision. The remaining 17% nominated her hospital team or doctor (11%), or a meeting of all involved (6%). Table 16 gives a more detailed breakdown of these responses.

For the relationship between group membership (elderly person, relative, or health professional) and suggested decision-maker (Mrs Smith herself or others) the χ^2 value was 15.4, ($df = 2$, $N = 36$, $p < .000$, two-tailed). This confirmed that the groups differed in whom they were most likely to suggest as the decision-maker. The value of Cramer's V was 0.65 showing that within this sample, group membership explained 43% of the variation in suggested decision-maker.

Table 16 Who should make the decision? Responses (%) by group

WHO SHOULD MAKE THE DECISION?	Older People (N=10)	Relatives (N=8)	Health Professionals (N=18)
Mrs Smith	10%	75%	83%
Unqualified	10%	13%	11%
If competent	0%	63%	72%
Relative(s) / Guardian/ Next of Kin	30%	13%	0%
Hospital / Doctors	30%	0%	11%
Consensus – meeting of all involved	30%	13%	6%

7.3.6 Relationship between suggested decision-maker and suggested destination

The reviews of the literature (Chapters 4 and 6) had identified cognitive impairment as a commonly accepted reason for residential placement. Hence, it seemed likely that those study participants who recommended substitute decision-making because of mental incapacity would be more likely than others to recommend residential placement.

Table 17 Relationship between suggested decision-maker and suggested destination

FREQUENCIES	Mrs Smith should make the decision	Other (s) should make the decision
Whole sample (N=36)		
Mrs Smith should live in her own home	19	6
Mrs Smith should live in residential care	3	8

For the whole sample, there was indeed a significant relationship of this kind (see Table 17) between suggested destination and suggested decision-maker ($\chi^2=7.62$, $df = 2$, $N = 36$, Fisher's exact probability $p=.009$, one-tailed). The value of Cramer's V was 0.46. Thus, within this sample the nature of the suggested decision-maker (self or proxy) explained 21% of the variation in suggested destination.

7.3.7 Summary of results

In summary, elderly respondents were most likely to mention the value of personal care (100% of respondents in this group), followed by mental ability to carry out everyday activities (60%) and then autonomy, best interests of the elderly person, health, the personal value of living at home, and safety (all 50%). Elderly people were

more likely to mention the meta-concept of balance (50%) than other respondents, and they mentioned balance more than planning or timing. Most of the elderly people interviewed said that decision should be not be made by Mrs Smith (90%), and that Mrs Smith should enter residential care (60%).

The group of younger relatives of frail elderly people was most likely to mention the value of safety/security (mentioned by 100% of these respondents), followed by finances and the personal value of living at home (88%) and then by health, mental abilities, physical abilities, psychological well-being, and relationship (75%), while 62.5% mentioned autonomy, personal care, and caregiver burden, and 50% mentioned the best interests of the elderly person, the potential for functioning better at home, and the work ethic or self-responsibility of the elderly person. Relatives were more likely than members of other groups to mention planning (62.5%), and they mentioned it more often than the other meta-concepts. A majority of the relatives interviewed said that Mrs Smith should make the decision about her discharge destination (75%). Half said that she should return home and half that she should enter residential care.

The value most likely to be mentioned by health professionals involved in discharge planning was safety/security (mentioned by 100%), followed by autonomy and personal care (94%), and then finances and the personal value of living at home (67%), and caregiver burden, health, mental abilities, and psychological well-being (61%), the desirability of social contact (56%) and privacy (50%). The meta-concept mentioned most often by professionals was timing (38.9%), and they mentioned this more often than members of the other groups did. Most of the health professionals interviewed said that Mrs Smith should decide her discharge destination (83%), and that

she should be discharged home (94%), either to her existing home (83%) or a smaller home (11%),

There were, as had been predicted, clear differences between the responses of the different groups of stakeholders. The elderly respondents appeared most concerned about personal care, and they suggested residential care and decision-making by a proxy, someone other than the hypothetical elderly person. Relatives' responses did not appear to occupy an intermediate position between those of elderly people and those of health professionals (as had been hypothesised). Instead, members of both of the younger respondent groups emphasised safety or security, but suggested that the elderly person should return to live at home, and make the decision herself. The implications of this pattern of interview responses are discussed below.

7.4 Discussion

7.4.1 Study findings

Although there was an obvious overlap in values held by members of these three groups of stakeholders and potential decision-makers, there were differences in the priority with which these values were held and discussed, and in the meta-concepts which were mentioned; and between their practical suggestions about what should happen to the hypothetical Mrs Smith.

As in the McCullough et al. (1993) retrospective study, the elderly respondents were less likely than younger relatives to mention the value of safety / security, confirming the major hypothesis of this study, and consistent with the findings of the community survey.

These study results also resembled those of McCullough et al. (1993) in that the value of filial responsibility was rarely mentioned, and that of the three groups, relatives on average reported considering the highest number of values with regard to the residential care decision, and professionals were more likely than others to mention abstract concepts such as safety and autonomy.

Interestingly, however, when practical suggestions were asked for (what should happen to Mrs Smith on leaving hospital, and who should decide), the elderly people suggested more restrictive outcomes for Mrs Smith than did the two groups of younger respondents. The elderly respondents appeared to be assigning less autonomy and capability to Mrs Smith than did the younger respondents. This was surprising and it appeared counter-intuitive.

A number of possible explanations will be discussed here, and in a broader context in Chapter 8, but there are clearly methodological questions to be answered and refinements of the interview method to be developed, in order to confirm or refute the explanations.

One possible explanation, as mentioned above, is that younger respondents (relatives and health professionals) may have seen Mrs Smith as a typical, or “classic”, elderly person at the end of a hospital admission (and they, unlike the elderly respondents, made comments of this kind). Hence they suggested a minimally restrictive set of options, of the sort that most people would want for themselves. Elderly respondents, however, may have drawn a mental distinction between elderly people such as Mrs Smith, and elderly people such as themselves (and indeed they made comments of this kind, which younger respondents did not). Thus they may have evaluated Mrs Smith as ageing less successfully than themselves: being at more risk,

requiring more support; and being capable of exercising less independence and autonomy. There was some objective support for this distinction, in that the elderly respondents in this study were not cognitively impaired or facing imminent placement decisions, and most were not living alone. It may also be that Mrs Smith's situation represented a possible and undesirable personal outcome for the elderly respondents, and in the not-too-distant future. They may have wished to place Mrs Smith and her situation at the greatest possible psychological distance from themselves, by highlighting differences and her relative incapacity.

In the event, Mrs Smith appears to have been a "typical" elderly person in the opinion of younger interviewees, but a "different" (from self) elderly person as far as the elderly respondents were concerned. In future research it may be useful to trial a first person hypothetical vignette for comparison, because it has been found that people respond differently to "third person" hypothetical situations than to personal hypothetical situations (Smith, Taylor, Sloan, Johnson, & Desvouges, 2001b).

Another possible explanation is that, as found in some retrospective studies, for example by Huby et al. (2004), elderly people may defer to the judgment of younger people, particularly where the younger people are professionally qualified in the area, and/or personally involved in providing care to the elderly person such that there is an obligation to consider their wishes and views. Hence, although elderly people may place less value on safety than younger people, they may also feel that decisions of this kind are the province of younger and socially more powerful people, such as health professionals and relatives. This would be consistent with the meta-concept of balance expressed by the elderly respondents, and the frequency with which they indicated that the decision should be made by more than one person and not by Mrs Smith.

Given that all of the elderly respondents had agreed to be part of a hospital and university research project, and some had been recruited through their local medical practice, there may have been a particularly high level of respect for health professionals and for professional or scientific knowledge and care, in this elderly group. Although the relatives had been recruited in a similar fashion, they did not appear to defer to health professionals or institutions, perhaps because they were younger and more educated than the elderly group.

With regard to the meta-concepts, almost two-thirds of relatives, and almost a third of elderly people, but only one health professional mentioned planning. It appeared that the younger relatives of frail elderly people were the most likely to see the residential care decision in terms of a process occurring over time, for which planning was relevant. From relatives' perspectives, the decision-making process may, at least in their own minds, commence well before the actual decision is made, or even discussed with the elderly person, at the stage when relatives start to consider the elderly person's safety, and their own duty of care. The percentage of elderly interview respondents mentioning planning (30%) was almost identical to the 32% of elderly participants in the Maloney et al. (1996) consumer decision-making study who were identified as 'Advance Planners'. These were elderly people who had followed a consumer decision-making model with regard to long-term care, rather than deferring the decision until the external environment had provided an identifiable prompt. Professionals involved in hospital discharge planning rarely mentioned planning as a value, perhaps because most of their work was focussed on patients who needed placement immediately and with whom they would have only a brief involvement.

There was a smaller, but still interesting, difference between the three groups in the proportion of respondents mentioning balance. Half of the elderly people mentioned it, but only a quarter of relatives, and 16.7% of health professionals. This is a little surprising given the common portrayal of caregiving relatives as engaged in a constant attempts to balance their elderly relatives' needs and rights against their own, but the literature offers some explanations. It appears that elderly people may also be attempting a balanced and ethical stance, regarding what they can expect from the family and what other family members need (Rosin & van Dijk, 2005), and this is supported by the findings of Huby et al. (2004) mentioned above. It is also apparent that in the bio-ethical debate, relatives' needs have been classed as conflicting interests and hence external to, and not for legitimate consideration in, decision-making concerning the patient (Dill, 1995). Hence relatives may have been reluctant to mention balance in the context of the residential care decision.

The difference between the three groups in the likelihood of mentioning timing was smaller again, but it was not surprising that health professionals were the most likely to mention it. Time equals money in the human services, where the number of bed-days (length of admission) largely determines the cost of service provision. Hence, time is very salient to health care professionals, who are required by their employers and agencies to minimise the services utilised by individuals, in hospitals and in residential care. Although placement too late may be an individual tragedy, in that "pushed" placements do not allow psychological preparation or consideration of individual preferences, placement too early results in unnecessary cost to the community.

Among the additional values mentioned by stakeholder respondents as relevant to the residential placement decision, which were not in the codebook, the importance of considering the elderly person's personality when making the decision was the most obvious, having been mentioned by 30% of elderly respondents, 25% of relatives, and 27.8% of health professionals. Another commonly-mentioned value, perhaps reflecting high levels of home ownership in this cohort of elderly Australians, was the responsibility to maintain one's property, mentioned by 20% of elderly respondents and 25% of relatives.

Only one study respondent, a relative, mentioned death as an event that could resolve the issue, which raises the question of why none of the others mentioned this outcome. For every individual who survives to adulthood, independent living is followed either by death or by dependence, and it is common in everyday conversation to hear a preference expressed for death rather than dependence in one's own case (see above, OP09, L77). Perhaps respondents did not want to appear callous (as the relative who mentioned death said about himself). Or perhaps death, never easy to mention in this culture, is even more difficult to mention when it is being described as desirable for another person.

The apparent conflict between the values of autonomy and beneficence in this setting was clearly expressed by a number of respondents, most of them health professionals. Several of the health professionals expressed a sense of personal conflict about how these values could be reconciled, while another described a values framework that attempted to reconcile safety and autonomy needs, with provision and acceptance of personal care at home being seen as the solution.

It had been predicted that relatives' responses would occupy an intermediate position, between those of elderly people and those of health professionals. This was not confirmed. Instead, there appeared to be significant overlap between the responses of health professionals and those of relatives. One possible explanation is that the health professionals who were interviewed may have had some experience with frail elderly relatives of their own, and similarly some of the relatives were quite familiar with the demands and difficulties of health care settings. Another is that age may be more important than role in the development of values.

Interestingly, but not surprisingly, respondents who suggested that Mrs Smith needed a proxy decision-maker were more likely than other respondents to suggest that she needed residential placement. This response pattern supported the idea, discussed in Chapter Five, that many people see testamentary capacity to make decisions and mental ability to conduct ADL and IADL as being equivalent, or at least closely related.

7.4.2 Adequacy of method

The study and its findings were examined in terms of the fourteen guidelines suggested by Elliott et al. (1999) for the evaluation of qualitative research (see Chapter 1). These guidelines were:

explicit scientific content and purpose; appropriate methods; respect for participants; specification of methods; appropriate discussion; clarity of presentation; and contribution to knowledge" (and) "owning one's perspective; situating the sample; grounding in examples; providing credibility checks; coherence; accomplishing general versus specific research tasks; and resonating with readers (p.220).

The study findings suggested that the sample had been adequately situated, and related to both the local and the international context. The survey and interview studies had included members of the main post-war immigrant groups (and their children), as well as members of families who had been in Australia for three or more generations. Indigenous respondents were not specifically recruited to the interview study but the topic has been studied in this group in Central Australia, using culturally appropriate methods (Woenne-Green, 1995). The construction of the hypothetical vignette and the physical health profiles of elderly interviewees had been based on the literature review and local casenote study (Chapters 2 and 3) in which frail elderly people had been studied in a local hospital and their health profiles had been found to resemble those in the international literature.

As the study sample had mentioned most of the values identified from the literature and few additional ones, it was concluded that the sample had been large and diverse enough to generate a range of values.

It had been easy to recruit and interview the younger relatives of frail elderly people, and health professionals who worked with frail elderly people. However in the event, the elderly interviewees who were interviewed did not appear quite as frail, or as isolated, as the elderly individual in the vignette, even though their physical health profiles were similar. This was perhaps in part because recruitment of interviewees with known cognitive impairment had not been permitted, and elderly people facing imminent placement had been excluded. Also, participation in the study required a degree of active engagement that a more frail, or more isolated, elderly person may not have undertaken.

Hence it was possible (and some of the interview responses suggested) that elderly interviewees had responded to the hypothetical Mrs Smith as an “other”, a person ageing less successfully than themselves, rather than as someone like themselves. This possibility is discussed further below, and again in Chapter 8. The responses of some health professionals who were interviewed had suggested a sense of constraint and a need to express a correct professional view. While these and other health professionals did express a wide range of values, they were almost unanimous in their practical suggestions. Without a completely anonymous interview situation, the possibility of a degree of self-censorship could not be excluded.

To reduce any influence of the author’s perspective (as a health professional involved in discharge planning, and as a clinical neuropsychologist), the vignette had been based on the literature and the results of the casenote study, constructed with the help of other health professionals, and presented with pilot data for comment at an Allied Health conference (Denson et al., 2003). The interviews were audio-recorded and transcribed in full by a research officer who was experienced in transcribing interviews for qualitative analysis. The reliability of the coding process was checked by another health professional experienced in qualitative research but not involved in discharge planning. Additionally, one reason for selecting thematic analysis based on previous research had been that this method was less susceptible than data-driven methods to influence by the researcher’s own ideas (Boyatzis, 1998). Also, the community survey, despite using a less detailed vignette, served as a triangulation point for the qualitative analysis of the interviews.

7.4.3 *Conclusions and implications*

The conclusion and implications of the interview study and the community survey will be discussed together in more detail, and in a theoretical context, in Chapter 8.

Methodologically, the use of a “third person example” (Smith et al., 2001b), the hypothetical Mrs Smith, made it difficult to determine whether the differences in practical suggestions made by older and younger people were more due to their different underlying values about what should happen to themselves in future, or more due to their different stances with regard to the hypothetical third person. This issue can only be clarified by further investigation.

No difference was apparent between the values expressed in prospective and retrospective discussions of this type of decision. Hence it can be concluded that, where prospective information about values is not available, it may be reasonable to use the more extensive retrospective literature as a guide.

Most importantly, it appears from the thematic analysis of values mentioned that when considering the living arrangements of an elderly person, elderly people do value or consider safety less than younger people do. In terms of Andersen’s Behavioral Theory of Health Service Usage it appears that elderly people assign less priority to need factors (and presumably place more emphasis on psychosocial or appraisal variables) than do younger people.

It appears that the elderly people took a practical and probabilistic approach to an elderly person they saw as different from themselves. The values they mentioned were closely related to actual determinants of outcome at home: availability of personal care, and mental ability to undertake everyday activities. The scenario gave good support for the assumptions that Mrs Smith’s mental abilities were declining, and that if discharged

home she would refuse personal care from community agencies. Hence Mrs Smith, whose independent living skills appeared likely to decline in future, was only likely to receive personal care if she was placed in a residential setting.

From the perspective of the Ecological Theory of Aging or ETA - see Chapter 1, and Nahemow (2000) - it could be suggested that elderly people are prepared to tolerate a higher level of environmental press than young people are prepared to tolerate on their behalf. Also, the frequency with which 'personality' was mentioned by respondents suggested a general acknowledgment that, as posited by ETA, different individuals will tolerate, or enjoy, different environments and different levels of environmental press.

Similarly, the high proportion of elderly respondents who mentioned care, and mental ability to carry out daily tasks, suggested that they believed that an individual approach, based on the individual's abilities and care needs, was more relevant than a blanket value of safety or security.

These findings imply that when long-term care decisions are being discussed, elderly people may be less interested than younger people in a discourse on themes of safety and security, and more interested in appraisal of individual situations and capabilities, consideration of individual preferences, and maintenance of autonomy for as long as possible. This is consistent with the findings of Maloney et al. (1996) with regard to consumer decision-making in long-term care. It is also consistent with the findings of Minichiello et al. (1990) that elderly people's decision-making styles varied, and that the amount and type of involvement in the decision was predictive of adjustment to residential care.

Following on from this, the study findings suggest that if health professionals or governments wish to encourage elderly people to accept, and plan for, the possibility of

future long-term care (delivered in the home or in a residential setting), the consumer decision-making model offers a possible direction for community education. As in the case of superannuation, disability insurance, and pre-paid funerals, the emphasis could be placed on control and choice. Even an undesired event (in this case the need for personal care or residential care) could be perceived as having a better outcome because of planning and individual choices.

Because of the high proportion of elderly respondents who alluded to the meta-concept of balance, this concept too may be useful in discussions of long-term care and in evaluating and legitimising the acceptance of personal care. Examples might include the balance of needs and/or values: such as future safety versus the status quo, the caregiver's needs and concerns against one's own, and the balance of risks - the probability of dying in one's own home before personal care needs arise versus the probability of a serious health event requiring an urgent residential care placement.

Relatives appeared to be balancing a different and slightly more abstract set of important values: safety, finances and the personal value of living at home. In the Australian system, residential long-term care is potentially available to all. Any financial contribution is means-tested. An adequate level of publicly funded personal care at home is more difficult to obtain. Here, as elsewhere in the developed world, the financial ability of the elderly person or family to pay for additional personal care and/or repairs to the house is relevant (Allen, Griffiths, & Lyne, 2004; Gibson, 1998; McCullough & Wilson, 1995b). Several respondents mentioned that if the elderly person were able to pay for additional support services and/or repairs to her house this would make a difference, and the majority of relatives who recommended home as the discharge destination qualified this as "with supports". Relatives may have considered

that if safety needs could be met (through publicly and/or privately funded support services, and repairs to the home), then the personally valued option of living at home could be supported.

As a group, the younger relatives of elderly people appeared to accept the notion of planning but, as discussed in Chapters 4 and 6, they find the concept of placing an elderly relative in residential care difficult to accept, and the process is distressing. Examining the discourse of care-giving relatives, Gubrium (1989) identified the shared notion of an “It’s Time” point: the moment in an elderly person’s decline when the caregiver acknowledged the necessity of placement. This concept could perhaps be promoted for relatives of elderly people more generally and linked to the concept of planning. For relatives, community education and policy could advantageously focus on an It’s Time model in which assistance with care was portrayed as normal at a certain point in a frail elderly person’s life. The emphasis would be placed on the identification of the It’s Time point for a particular individual, the gradual introduction of personal care assistance by non-family members, and the process by which this was negotiated with the elderly person.

The health professionals interviewed in this study were more likely to mention timing than planning or balance, and this may well reflect their work in acute care settings and their short-term involvement with each elderly patient. A focus on getting the time of placement right, or recognising it when it arrives, is probably appropriate to the short-term or intermittent involvement of acute care health professionals. However an increasing proportion of health care now takes place in community settings, where health professionals work, in the longer term, with elderly individuals with chronic illnesses (Duckett, 2004). For these (and perhaps all) health professionals, their

professional education could usefully include the notion of planning for long-term care, and the need to assist elderly people to review and plan for the changing balances in their lives, on a regular basis and not just when a crisis occurs.

It appears from this study that health professionals acknowledge the formal values of beneficence and autonomy, but see them as opposed in practice and can have difficulty resolving this opposition. This may lead to mechanistic decisions based only on formal assessments (Huby et al., 2004) and/or to over-controlled discussions. Thus, the interests of the team or the institution may dominate the process (Dill, 1995) so that health professionals feel that the values of their professions are being compromised (Degenholtz et al., 1999; Healy, 1998). Health professionals may benefit from more sophisticated values education during their training and in their ongoing professional development. Collopy (1995) has suggested that when considering long-term care decisions the traditional medical ethics framework is too narrow. Along with physical safety, psychological safety is also important. In moving to prevent physical harm to elderly people, relatives and health professionals may inflict psychological harm, through the loss of autonomy and other valued attributes of an elderly person's life (home, neighbourhood, privacy, and so on). Hence avoiding physical risks may mean allowing psychological risks and vice versa, and there is no escape from what relatives in the retrospective studies described as a "no-win" situation (Nolan et al., 1996).

Collopy proposed a values model in which patient autonomy, rather than being on a continuum opposed to beneficence, is seen as another component of beneficence to be valued equally with patient safety. This requires the acknowledgment of independence, continuity of lifestyle, and personal identity as central to patients' wellbeing and at risk if their autonomy is denied in the interest of their own physical safety or the hospital's

risk of litigation. Collopy observed that an autonomous person may choose to subordinate medical or physical goals to other ends. Those who are not competent, or able to execute competent decisions, may in some situations wish to do the same. Along these lines, development of a more sophisticated model of values in long-term-care may equip health professionals to undertake and discuss assessments and discharge planning discussions in a more complex and meaningful fashion.

7.4.4 Future research directions

As mentioned above, the third person problem (Smith et al., 2001b) needs to be addressed in any future research. After the discussion of a vignette, all interviewees could be asked questions such as *What do you think the future holds for Mrs Smith? What do you think her relatives are thinking? What do you think the health professionals are thinking?*. This could be followed by more personal questions: *Do you ever think about these issues for yourself? What do you think the future holds for you? What do you think should happen if you were in the same position? What would you like to happen?* (to clarify wishes versus best interests). *What do you think your relatives would be thinking? What do you think your health professionals would be thinking?* The questions about what others might be thinking might reveal expectations, and attributions which were being made (perhaps not always accurately) about other people's values.

Similarly, when conducting retrospective research on the residential placement decision, as well as asking what did happen, and how it was decided, researchers could ask participants what had been perceived beforehand as being in the best interests of the

elderly person, and what had been the desired outcome (by respondents themselves and by others).

It would be useful in a future and larger interview study to recruit respondents from a wider range of cultural groups including South East Asian, Middle Eastern and African families. More recent migrants and refugees will require long-term care services in future, and may have a wider range, or a different balance, of values that will need to be considered. For example, Confucian (Chinese) culture places a very high value on filial responsibility, to the extent that residential care for the elderly is a recent development and the experience of residential placement appears particularly difficult (Kao & Stuifbergen, 1999).

Although disability and long-term-care are issues for indigenous people in Australia, unfortunately they arise in middle age because of chronic disease, and survival into extreme old age is rare (Gray, 2001). Research into values related to long-term-care planning in indigenous communities, although important, would need to be addressed in a different, and culturally appropriate way. Woenne-Greene's project in indigenous central Australian communities (Woenne-Green, 1995) provides a useful model.

In terms of obtaining the perspectives of elderly people who see placement as salient, it appears that it would be necessary to interview elderly people who are more frail and socially isolated, and who are living alone and/or cognitively impaired. It may be necessary to return to the medical wards, and/or to specifically target some at-risk patients of local doctors and community agencies. However the question remains as to whether even these elderly people would identify with Mrs Smith as a "current self" rather than a future self or as one possible future self. It is possible that even they would

deal with her psychologically confronting situation, by defining her as someone ageing less successfully than themselves.

With regard to relatives, in this study, because of focus on different age groups spouse and sibling carers were excluded and adult offspring were selected. A subsequent study comparing the values of caregivers in other age groups could help discriminate between the effects on values of age and of being a caregiver.

There is no easy way to deal with perceived constraints on health professionals. Any technique that led to greater perceived anonymity (eg. using an interviewer from outside the health system, or a completely anonymous survey, perhaps by email) should be considered, if only as an additional triangulation point for in-depth interview studies. With regard to other groups of health professionals to be studied, physiotherapists employed in hospitals were not included this time but could be included in future. Health professionals working in the community (such as local doctors and the staff of agencies providing personal care) are also key players in long-term care decision-making. They are well placed to raise these issues with patients and relatives ahead of time. It would be interesting to study their values, meta-concepts and practical suggestions in a parallel fashion.

The hypothetical vignette could itself be varied, to deal with a broader range of situations than that of Mrs Smith, who had dementia /cognitive impairment as well as limited mobility. Perhaps two parallel vignettes – one of a person with good cognition but physical ADL limitations, and one of someone with cognitive impairment only - would be informative. In another technique to reduce the third person effect, male respondents could be presented with a vignette describing an elderly man.

In summary, the interview study confirmed the prediction that prospectively held values would resemble those found in the retrospective literature and specifically those found by McCullough et al. (1993). It did not confirm the prediction that, when making practical suggestions about Mrs Smith's destination and decision-making, elderly people would favour the most autonomy for Mrs Smith and health professionals would favour the least autonomy for her. The opposite response pattern was found.

The interview study raised some interesting methodological issues, and led to some suggestions for better practice. The findings of the interview study and the survey study are discussed together in Chapter 8, and their theoretical and practical implications are considered further.

Chapter 8. Summary and conclusions

8.1 Overview

In this chapter, the content of the first seven chapters is briefly reviewed and summarised, and the findings of the survey and interview studies are compared and integrated. Next, the implications of the project's findings for theory, practice and policy are discussed in turn. Finally, future research directions are indicated.

8.2 Summary of the research project

The goal of this program of research was to explore the values considered by elderly people, their younger relatives, and health professionals, in decisions about residential long-term care.

The project used a mixed methods approach (Creswell, 2003), employing quantitative and qualitative methods concurrently and obtaining information from multiple perspectives (community members, and three groups of stakeholders), to examine whether prospectively held values followed the same pattern as the retrospectively held values identified in the study of McCullough et al. (1993). If so, elderly people considering the residential placement decision would be more likely to express values relating to autonomy, and less likely to express values relating to safety, than their younger relatives, and than health professionals involved in discharge planning. Within the Andersen model of health service usage (Andersen, 1995) modified by Keysor et al. (1999) and Bradley et al. (2002), these values were considered as predisposing factors likely to influence whether or not individuals decided to utilise residential care services, all other things being equal.

The literature on the outcomes of frail elderly medical patients was reviewed (Chapter 2). There were indications that the Andersen model did apply to frail elderly medical patients' outcomes, specifically their usage of residential long-term care after discharge from hospital. All three Andersen factors (need, enabling and predisposing factors) were found to be predictive of discharge destination and of placement in residential care. It was concluded that, to be useful, research on long-term care decisions should consider all three Andersen factors, should attempt to understand cultural differences and the interaction between individual competence and environmental pressures (Lichtenberg et al., 2000; Nahemow, 2000), and could usefully consider the notion of successful and unsuccessful ageing (Andrews et al., 2002).

A retrospective review of hospital medical records was conducted (Chapter 3) in order to develop a profile of a frail elderly hospital patient with suspected cognitive impairment, for whom residential placement was being considered. The focus was on elderly individuals for whom the decision was not straightforward – those for whom the decision could go either way; either discharge back home or into residential care. The profile was converted into a vignette about a hypothetical elderly person for use in the subsequent community survey (Chapters 4 and 5) and qualitative interview project (Chapters 6 and 7). A subsidiary aim of the medical record review was to explore whether, within this selected group of frail elderly hospital patients, predictors of their outcomes (mortality within 12 months, and/or residential placement at the end of the hospital admission) could be identified within the hospital medical record during the admission.

The medical record review resulted in a detailed profile of the typical frail elderly medical patient, for whom placement had been suggested, and for whom the decision

was less than clear-cut because of concerns about competency, consent, or consensus. The patient profile, and the subsequent attempt at studying outcomes and predictors, revealed that these frail elderly South Australian patients resembled those studied elsewhere in the developed world. Age and pre-admission independence in activities of daily living were related to placement and mortality. Hospital bed usage before discharge and residential placement on discharge were both predictive of mortality after discharge.

The literature on prospective attitudes to, and priorities concerning, the residential placement of elderly people was reviewed (Chapter 4). It appeared that when simple research questions were posed, they received simple answers. Very few people wanted to move into a residential aged care facility, and very few people wanted to place an elderly relative in care. However when more complex questions were posed, they evoked more complex responses. Almost everyone who was studied appeared to accept that there were situational or appraisal variables that made the acceptance of the residential placement decision – which was psychologically, socially and culturally unacceptable or at least resisted – also inevitable at some point.

In terms of evaluating predisposition (one of the three predictive factors in the Andersen Behavioral Model of Health Service Usage), the research question then became, not whether, or to what extent, residential long term care was a psychologically acceptable option, but what factors could over-ride its unacceptability and result in placement. Elderly people and their family caregivers appeared to share the view that these factors or variables included the level of health care needs, the needs of the caregiver and of other family members, the mental state of the elderly person, financial pressures, and the wish not to be a burden. It was apparent from the literature that when

studying values and health beliefs concerning residential care facilities, it was important to ask about values and attitudes related to home, to residential stability or mobility, and to family care (including issues of personal and financial strain). It was also acknowledged by some, but not all, researchers in this area that, in all prospective studies, research questions were to some extent hypothetical. Even the elderly and the ill were being asked what they would do in a hypothetical situation, rather than what they were doing, or had done, in a real situation. Nevertheless it appeared that consideration even of a hypothetical placement decision was a complex matter, with caregivers and care recipients weighing up the pros and cons of the status quo and of the potential move.

Prospective studies had not explored the views of all those who were, or would be, involved in the residential care decision. There had been a number of surveys and studies of those stakeholders for whom consideration of residential placement appeared imminent or salient (family caregivers, people in mid-life, and those who were elderly or ill). There had been less recognition that everyone in the community was potentially involved in one or more ways; as electors, as taxpayers, as family members, as health professionals, as employees and planners in the aged care industry and, in future, as potential family caregivers and residential care recipients. A number of gaps in the literature were identified. Most importantly, no survey of the general community's prospective attitudes to long-term care was found in the literature searched. Also, many of the studies which examined prospective views within groups of stakeholders were limited either in the number of people interviewed, or in the detail and complexity of the information obtained.

A stratified community survey (Chapter 5) was utilised to ascertain the prospective values and priorities of adults in the community, when considering a potential long-term care decision concerning an elderly person with dementia (used as a succinct representation of frailty and questionable competence). This study aimed to survey the South Australian population aged 15 years and over, and within the limitations of the omnibus survey method, to ask a question complex enough to enable some delineation of the community's 'health beliefs' in the area of residential placement of frail elderly people. The specific focus of the study was the priorities or values that might or might not over-ride the unacceptability of residential aged care for an elderly person, and justify the consideration of placement. It was hypothesised that, in line with the retrospective findings of McCullough et al. (1993), elderly people would be more likely than younger people to select autonomy as an important value, whereas younger people would be more likely to select safety.

The survey results suggested that in every age cohort of the adult community in South Australia, the most important value in considering a residential placement decision was the physical health and safety of the elderly person. Other considerations, including mediating priorities (the degree of environmental stress or adaptation), strain on others, and the elderly person's rights and wishes, were secondary, albeit less so with increasing age of the respondent. Thus, adults in the community, considered as a group, appeared to put safety first, and then to consider situational variables, within which the elderly person's autonomy was not assigned a high value.

Next, the findings and conclusions of the survey study were examined and triangulated, in a large qualitative study in which 36 interviews with stakeholders were conducted and analysed (Chapter 7). The interview study provided the opportunity to

present a more detailed hypothetical profile of a frail elderly person, to record and discuss more detailed responses, and undertake a formal thematic analysis of the values expressed.

To analyse the interview responses, a research-based method of qualitative thematic analysis was selected. Because only a small body of prospective literature had been identified, the retrospective literature was reviewed in search of an existing framework for data analysis (Chapter 6). The literature on experiences and priorities in the residential placement decision, as reported by those who have been involved in such a decision, was examined for themes and underlying priorities and values. It appeared that this decision process could be a problematic experience for all concerned, with common themes of powerlessness, lack of control, time pressure, and the potential for inner and interpersonal conflict. Among each of the three groups of participants, attempts to defer, deny or legitimise decisions, and to diffuse responsibility, were described. Older people in care often reported that their relatives or health professionals had made the placement decision, and this was confirmed by the relatives and the health professionals involved. Relatives often felt that health professionals had had more control than they, whereas health professionals tended to report that relatives, and/or other members of the health care team, had had more influence in the placement decision than they themselves had.

Elderly people and their family caregivers described the placement experience as involving painful and sometimes conflicting emotions. Where possible these emotions were dealt with through a process of acceptance, with older people taking a stoical approach, or making the best of things. Relatives attempted to apply logic rather than

emotion to the decision and sought validation from health professionals, other family members, and peers.

There appeared to be consensus that placement, while not desirable, was seen retrospectively as legitimate or legitimisable in one or more of the following circumstances; where there were health problems; where professional care was required; where the elderly person could not care for himself or herself; where the family could not provide enough care; where there was a wish not to burden the family; where the elderly person wished to maintain independence by going into residential care; where residential placement would solve financial problems; or if the care home was in a location that was familiar and/or in which existing social relationships could be maintained.

In terms of the decision itself, it was seen as legitimate if the older person had participated in the decision, and/or if the move could be construed as temporary or reversible. Descriptions of placement decisions in the retrospective literature suggested that they could usefully be divided into three categories. “Planned” placement decisions were those in which the elderly person had made a decision and initiated the move before any acute need arose. “Prompted” decisions were those in which the decision had been made in response to a sentinel event that indicated (to the elderly person, the family, and/or to a health professional) that it was time to initiate placement. “Pushed” decisions were experienced as crises leading to immediate, and often less than satisfactory, residential placement decisions.

Based on the themes, priorities and values described in the retrospective literature, a thematic code was developed for use in the analysis of the prospective interview data. A retrospective study (McCullough et al., 1993) was selected as having generated the

most comprehensive set of values. This set was modified and augmented to produce a codebook for thematic analysis (Appendix L).

The interview study (Chapter 7) focussed on some of the stakeholders in long-term-care decision-making. Ten elderly people living in the community, 8 relatives of such individuals, and 18 health professionals involved in discharge planning and placement of elderly medical patients were interviewed and their responses were examined using research-based thematic analysis.

As in the retrospective study by McCullough et al. (1993), and as in the survey study, there was considerable overlap and commonality between values expressed by the different groups in the interview study. The frail elderly respondents were less likely than relatives, and also less likely than health professionals involved in discharge planning, to mention safety as a value when discussing the residential placement decision. However the elderly interviewees were more likely than the younger groups to suggest that the hypothetical Mrs Smith should enter residential care, and that the decision about her destination should be made by someone other than Mrs Smith: an initially counter-intuitive finding.

It appeared that the younger 'stakeholder' respondents (relatives and health professionals) more often considered the hypothetical Mrs Smith to be a typical, or "*classic*" elderly person at the end of a hospital admission. They suggested options that were not particularly restrictive, of the kind that most people would want for themselves. The elderly respondents, however, were more likely to draw a clear (and sometimes explicit) distinction between elderly people such as Mrs Smith, and elderly people such as themselves. They evaluated Mrs Smith as ageing less successfully than themselves; being at more risk; requiring more support; and being capable of exercising

less independence and autonomy. This may explain the more limited autonomy they assigned to her.

In terms of meta-concepts (over-arching influences on the way in which values may be considered or implemented), elderly people were the most likely to mention balance, while relatives were most likely to mention planning, and health professionals to mention timing.

Overall, no difference was found between the values expressed in these prospective discussions of long-term care decision-making, and the retrospectively-expressed values identified by McCullough et al. (1993) and other researchers. Thus it appears that, in this context, where information about prospectively held values is not available it may be reasonable to use the more extensive retrospective research literature as a guide.

8.3 Comparing and integrating the findings of the survey and interview studies

When the results of the survey and interview studies were examined together, some interesting parallels were found.

Firstly, and most obviously, responses to the survey varied with respondent age. Interview responses to the vignette also varied, across many dimensions, and a complex pattern of values was expressed by members of each of the three stakeholder groups. In each study, the safety of the elderly person received more emphasis from younger respondents than from older ones.

Among the members of the South Australian community who were surveyed, the two 'safety' priorities were the most frequently selected priorities within each age group, but less so for older respondents. When prospective stakeholders (those who

were likely to be involved in a residential placement decision in the short to medium term) were interviewed in detail, safety was found to be a very important value for relatives and for health professionals, and for older people when they were asked to make a hypothetical proxy decision. It was not found to be so important for older people when discussing the issue of residential placement in a more general way, perhaps related to themselves.

One of the survey's 'mediating priorities', *Mental capacity to make his or her decisions*, was the next most important priority for community survey respondents, selected by 47%. As discussed in Chapter 5, it appeared that mental capacity may have been perceived less as a legal status than as an individual competence related to ability to perform everyday tasks. This conclusion received some confirmation from the thematic analysis of interviews with stakeholders. In the interview study it was possible to draw a distinction between mental ability to carry out everyday activities and legal capacity to make formal decisions. Mental ability to carry out everyday activities was mentioned by 60% of the elderly interviewees, 75% of relatives and 61% of health professionals. Decision-making capacity, as a value to be considered when making decisions about long-term care, was only mentioned by 17% of health professionals, and by no other respondents. It was concluded that community survey respondents were indeed prioritising mental capacity as an individual competence in everyday living, rather than as a testamentary ability related to legal decision-making and autonomy.

The other 'mediating' priority, *Amount of help available from family, neighbours or community*, was mentioned as a priority by 34% of community survey respondents. Stakeholders saw this as even more important. All of the elderly people, 63% of

relatives, and 94% of health professionals who were interviewed mentioned personal care as an important value when considering the decision.

Of the two 'strain' priorities, *Behaviour detrimental to themselves and/or others*, was selected as a priority by 41% of community survey respondents, far more so than *Burden to caregivers* (10%). In contrast, in the interviews with stakeholders, caregiver burden was mentioned by many respondents, but no stakeholder mentioned problematic behaviour as a consideration in the decision about Mrs Smith's destination. A few health professionals raised the possibility that Mrs Smith might have a mental illness, but as an explanation for her refusal of community services, not as a reason for placement. These stakeholders saw caregiver burden as being more predictive of placement than difficult behaviour: a view which has some support in the literature (Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Kesselring et al., 2001) although difficult behaviour has also been found to be an independent predictor of placement (Banerjee et al., 2003).

The two 'autonomy' priorities appeared to rank relatively low for community survey respondents, being selected by only 16% (*Right to decide for himself or herself*) and 9% (*Wish to continue living at home*). In contrast the elderly person's autonomy was mentioned (as being desirable) by 50% of elderly stakeholders, 63% of relatives, and 94% of health professionals. Another 10% of elderly respondents, and 12.5% of relatives, but no health professionals, mentioned autonomy as undesirable in this context. The personal (psychological) value to an individual of continuing to live in one's own home was mentioned by 50% of elderly stakeholders, 88% of relatives, and 67% of health professionals. It is possible that stakeholders were more interested in the elderly person's autonomy than were community members; but also, community

members were constrained by the number of priorities they could chose, whereas interview respondents were not.

When stakeholder interviewees were asked to make hypothetical practical suggestions (where Mrs Smith should go at the end of her hospital admission, and who should decide that), there was a clear division between the suggestions of the older and younger respondents. It may be that if the survey respondents in the community had been asked to give practical suggestions, as well as choosing among priorities, the same division would have emerged. However this information was not available.

8.4 Theoretical implications

This project explored predisposing factors in terms of the Andersen model. Its findings suggested that, with regard to long-term-care decision-making, prospectively held values resemble retrospectively held values and hence they can reasonably be assumed to operate throughout the actual decision-making process.

It was also found that prospectively-held values, as expressed in general discussion and in terms of practical suggestions, varied with an individual's age and role. Those who were younger, and/or who were considering a proxy decision on behalf of someone else, placed higher value on a 'need' factor, the safety of the elderly person. Those who were elderly and/or considering one of their own potential future selves placed a somewhat lower value on safety and a higher value on autonomy, an appraisal factor. Hence studies of predisposing factors for the use of long-term care need to examine underlying values and their expression carefully, and in some detail, and in the context of the respondent's perceived role.

The project's findings also supported the conclusions of Keysor et al. (1999), Bradley et al. (2002), and Taylor, Osterman, Acuff and Ostbye (2005), that, as for other discretionary categories of health care service usage (Mitchell & Krout, 1998), 'appraisal' factors and psychosocial factors are likely to play an important role in predisposing people to utilise long-term care. Indeed, planning for long-term care use can be seen as a health behaviour, to be promoted as actively as other health behaviours. In an expanded version of the Andersen model, Andersen and Davidson (1997) have observed that, if health outcomes are to be predicted accurately, personal practices (i.e. health-related behaviours) need to be considered alongside variables related to health service usage.

As described in Chapter 1, the Ecological Theory of Aging or ETA (Lawton & Nahemow, 1973; Nahemow, 2000) asserts that it is the interaction between individual competence and the level of environmental press that determines whether successful adaptation can occur. It was clear from the survey and interview studies that older people, younger people and health professionals all considered individual competencies and environmental variables when evaluating the need for residential placement. However their priorities differed slightly, with older people as a group apparently being prepared to tolerate higher environmental press for themselves, in the interest of maintaining autonomy, whereas relatives, health professionals and proxy decision-makers valued safety, with its implication of reduced environmental press (and the risk of reducing competence) over challenge. The high proportion of elderly respondents who mentioned care, and mental ability to carry out daily tasks, suggested that an individual approach, based on the individual's abilities and care needs, was perceived

by elderly people as a more useful basis for decision-making than a blanket value of safety or security would be.

ETA propounds that preference or tolerance for levels of environmental press will vary from individual from individual, and for a particular individual over time. This was supported by interviewees who mentioned that some people would want to be cared for, or want privacy, or social contact, more than others. Also, the frequency with which the importance of the personality of the elderly person was mentioned by members of all three groups suggested a general acknowledgment that, as posited by ETA, different individuals are able to adapt to, or enjoy, different environments and different levels of environmental press. These individual differences acknowledged in the ETA may equate to the psychological or appraisal variables emphasised in later versions of the Andersen model, and explain why there are differing views of when environmental press is excessive and the crucial “It’s Time” point – mandating residential placement - has been reached.

ETA emphasises that adaptation by an individual to an environment will occur over time. The environment and the individual’s competence also vary over time, which is the fourth dimension of the adaptation model (Nahemow, 2000). In terms of the three meta-concepts that were identified in the interview study, timing and planning reflected this dimension of time, while balance appeared analogous to the ETA concept of adaptation, whether by an individual or a family.

The MacArthur Model of Successful Aging (Andrews et al., 2002; Luszc, 1998; Rowe & Kahn, 1987) suggests that elderly individuals may usefully be classified into those who are ageing successfully and unsuccessfully. All groups of respondents appeared to draw this distinction, evaluating the capabilities and personal care needs of

the elderly person as being relevant to the decision about destination and long-term care. This theory, familiar to readers of the ‘ageing’ literature and applicable at a population level, also seems to be part of the thinking of stakeholders such as elderly people with health problems, their younger relatives, and health professionals involved in discharge planning. Concepts of successful and unsuccessful ageing are not always made explicit in the clinical literature about frail elderly people, the work of Lichtenberg et al. (2000) being a rare exception. The results of this project suggest that the MacArthur Model provides a useful framework for individual care planning, in that it offers a method for predicting which elderly people are likely to regain independence after a hospital admission.

8.5 Implications for practice

8.5.1 The values of elderly people

The elderly people at the centre of these debates and decisions have the most to lose. Their health and safety, their homes and their autonomy, are all potentially at risk. Acceptance of long-term care, and in particular residential placement, represents a compromise, a trade-off of psychological safety for physical safety. It is also a sacrifice of present enjoyment for future well being, for example the potential avoidance of disabling events. This is probably harder to justify in old age than in youth. The “health human capital” model developed by health economists including Arrow and Grossman, as cited in Picone, Sloan, & Taylor (2004), asserts that investment in health is influenced by uncertainty about future illness, and that expected longevity, educational level, risk aversion and “time preference” (the extent to which an individual is prepared to sacrifice time in the present for future benefits) also influence the extent to which

individuals will invest time and money in actions designed to improve their future health or avoid future illness (Picone et al., 2004). Logically, some older people will expect more illness and fewer years of life than others, and hence may be less prepared than younger or fitter people to make sacrifices for future benefit.

Individual differences in values, wishes, time preference or predisposition were identified as relevant by respondents in this project, and are acknowledged in the Andersen and ETA models. It is not clear that these individual differences are adequately considered when the need for residential placement is formally assessed (Huby et al., 2004). However at least one study suggests that it may be feasible to do so (R. A. Kane, 1995).

Similarly the concept of successful ageing, for example as demonstrated by Hanks and Lichtenberg (1996), could be utilised on an individual basis to predict each elderly individual's health trajectory and estimate the level of long-term care that may be required and the time at which it is likely to be necessary.

The timing of long-term care decision-making in the elderly person's health trajectory is a key theme, acknowledged throughout the literature. It emerged clearly in the interview study, with planning (thinking about future needs) and timing being mentioned by a number of respondents. Health economists have examined the way in which individuals may or may not consider, predict and plan for future health problems (Picone et al., 2004; Smith, Taylor, & Sloan, 2001a; Smith et al., 2001b). It appears that the normal consumer models do not always apply (Maloney et al., 1996), and only about 30% of elderly individuals are "planners". This figure is similar to the proportion of elderly people in the interview study (Chapter 7) who mentioned planning. Planners are likely to begin, or at least contemplate, preparations for long-term care before it

becomes a necessity. In Australia, because access to government-funded residential care facilities is controlled by Aged Care Assessment Teams (Aged and Community Care Division of the Commonwealth Department of Health and Ageing, 2002; Duckett, 2004), individuals cannot move to low or high level residential care until they have demonstrated a need for that level of care (Minichiello, 1995). However, planners can move to smaller homes or to retirement villages, and can place their names on waiting lists at their preferred residential facilities. At the other extreme of this continuum of consumers are the “avoiders” (Maloney et al., 1996), who are prepared to tolerate more risk (of injury or unplanned placement), or gamble on a good outcome occurring through chance or (perhaps) the intervention of others such as family members. In clinical practice, it is the avoiders who are most likely to require residential placement at the end of a hospital admission. For these individuals an “It’s time” concept (Gubrium, 1989) may be a useful concept within which to frame discussions.

The project’s findings suggest that, within the clinical setting, discussions of long-term care will be most effective if they are framed in terms of maintenance of autonomy and control, rather than physical safety. With increasing age, people place less priority on safety and more on situational factors and competencies, and on autonomy. They are probably prepared to tolerate higher risks to themselves, in the service of their autonomy and lifestyle, than they would on behalf of someone else, a not uncommon pattern in proxy decision-making (McCubbin & Weisstub, 1998) and exemplified elsewhere in everyday life, for example when smokers stop smoking only while pregnant. Elderly people appear realistic in perceiving the inevitability of residential care for certain subgroups of elderly people, such as physically and cognitively disabled individuals who refuse home supports (like the hypothetical Mrs Smith). The literature

confirms that an increasing emphasis on risks is not likely to increase compliance – elderly people already over-estimate their risk of, but under-insure for, residential care (Taylor et al., 2005). Here again the literature on smoking cessation offers some useful ideas, demonstrating that increasing anxiety in the community does not necessarily result in behaviour change in the target group (Smith et al., 2001b). Rather than increasing anxiety and avoidance through an ineffective “safety” discourse, it may be more useful to focus on the values of autonomy, control, choice and timing, as potential motivators for elderly people to plan their long-term care usage.

8.5.2 Values held by younger people, and by the younger relative of elderly people

The relatives and health professionals who were interviewed in this project placed the highest value on the safety of the elderly person – perhaps because in this context they were responding as potential proxy decision-makers. The literature suggests that decisions made by proxy decision-makers differ from decisions made by people for themselves, and may result in restrictive choices (R. L. Kane & Kane, 2001). In their review of the literature on proxy decision-making, McCubbin and Weisstub (1998) observed that proxy decision-makers, even those specifically appointed by patients themselves to make decisions for them, did not predict preferences accurately, and over-valued values expressed by the person in the past, in comparison with the person’s presently-held values. Also, even when specifically asked to use “substituted judgment” (what the person would have wanted) they appeared to discount the person’s previously-expressed values for a number of reasons (hindsight, cognitive dissonance, changed circumstances, conflict of interest), and to use beneficence reasoning instead.

Another issue to be considered is that values that apply to one's responsibility for oneself may not equate to values concerning one's responsibility for others. For elderly people, deferring or refusing placement involves considering, and perhaps taking, a risk for oneself (a basic entitlement of competent adults in our social, medical and legal systems, which underpins the right of autonomy).

However for relatives and professionals, deferring or refusing a placement involves allowing and/or countenancing a risk to another person for whom one has some moral and possibly legal responsibility: an adult who may or may not be competent. This is much more complex. There is clear tension between two value systems: between what one can risk for oneself (autonomy), and what risk one can condone on another's behalf (beneficence). This and the conflicts between the formal legal system and community beliefs, and between biomedical ethics and everyday ethics, may go some way to explain the tensions and ethical conflicts that occur in the hospital setting. Patients may feel that staff and family members should leave them alone and not interfere, while professionals and family members may each wish that the other would step in and "do something", or that the patient would accept residential placement "for their own good". For professionals, there exists the potential for ethical conflict between beneficence and patient autonomy, either as experienced within the individual professional, or between members of the treatment team. Consequences may include guilt, helplessness, frustration, and litigation. For family members, the same conflicts occur in a less formal context, when relatives decide whether to force someone into placement (legally, or through coercive persuasion), to take the risk of letting them go or remain home alone with an increased risk of injury or death, or not to make a decision at all (which can itself be a decision). The relatives are risking consequences

themselves and, in addition to practical and financial consequences, these can include shame, criticism and the rupture of family relationships.

This project's findings suggest that when younger relatives are asked to make proxy decisions for older relatives, they should consider the elderly person's psychological safety (Collopy, 1995) as well as physical safety, and not always prefer a more restrictive option just because it is physically safer. Here community education about the psychological value of autonomy for older people may be helpful, so that relatives can be more confident in making or supporting the least restrictive arrangement possible, for example home-based care.

In acknowledging the need for balance, and suggesting shared decision-making, elderly respondents in the interview study acknowledged the rights, as well as the responsibilities, of care-giving family members. This was consistent with the assertion by Dill (1995) and others (McCullough, Wilson, Rhymes, & Teasdale, 1995) that the legitimate interests of family members and of the community needed to be explicitly acknowledged, rather than being described as conflicts of interest and dismissed from further consideration. Residential placement may increase the physical safety of the older person (albeit at the expense of autonomy and psychological well being) and it may also decrease caregiver burden, worry and responsibility, and increase caregivers' autonomy and psychological well being. In asking what is reasonable, and whose needs can and should be considered, Rosin and Van Dijk (2005) have suggested that when a transition to residential care is being negotiated the ethical obligations of all participants (the elderly patient, the relatives, and the health professionals) should be considered carefully. This suggests that in examining values in long-term care decision-making, the scope of research inquiry may need to include values such as the autonomy, and

physical and psychological safety, of family members. Within a family, the price of one person's safety or autonomy may be the safety or autonomy of another family member. For example, an elderly person may be able to avoid residential care at the cost of increased burden and distress to relatives. A relative may be able increase their own autonomy and psychological well-being by insisting on residential care, at the price of the elderly person's psychological well-being.

8.5.3 Values held by health professionals

Hospital discharge planning is an area where worlds collide, and the health professional's world of illness, treatment, medical ethics, risk management and cost containment (Huby et al., 2004), meets the elderly person's world of home, identity, place, and "maintaining continuity in the midst of change" (McCullough et al., 1993, pg.330).

Responses to the interview study revealed that health professionals were aware of this collision, and of the inadequacy of simple models from biomedical ethics as equipment for their daily dilemmas. Health professionals tended to feel that they had failed their patient if discharge resulted in a poor health outcome or an experience of coercion. They felt that they had failed their organisations if there were costs related to long or frequent admissions, or litigation. The health professionals' struggle to fulfil their various and sometimes incompatible obligations was clearly expressed by some interviewees. It was also apparent in the high, and almost equal value placed on safety, autonomy and personal care by these respondents as a group. These three values could be described as essential for a frail elderly person to have good quality of life; and yet living situations that provide all three are difficult to arrange. This tension between

abstract values and practical arrangements has been acknowledged in the literature on long-term care (Wetle, 1995).

The present risk management system in hospitals privileges the patient's physical safety over autonomy or psychological well-being (Huby et al., 2004), perhaps at least in part because of concerns about potential risk to the hospital, through potential litigation, but also possibly because of inherent paternalism. In their review of ethnographic studies of hospitals, van der Geest & Finkler (2004) observed that biomedical / hospital values reflected the values of the societies within which they operated, and indeed "biomedicine and the hospital as its foremost institution is a domain where the core beliefs and values of a culture come into view" (p.1995). Hence the historically paternalistic approach of hospitals and care providers to elderly people is consistent with the project's findings, and with the suggestion of Kane and Kane (2001) that, unlike younger people with disabilities, elderly people requiring personal care are viewed by society (and perhaps see themselves) as being dependent and without autonomy or choices.

Collopy (1995) has made a case that in considering complex decisions about long-term care, safety and autonomy are not opposites. Both are important goals related to patient health and well being. This project's findings supported his view, in that both values were ranked very highly by almost all survey and interview respondents, and neither was dismissed in favour of the other. If this ethical approach is made explicit in the training of health professionals, and acknowledged in their daily practice, they may experience less inner and inter-personal conflict when performing their roles. Thus the ethical training of health professionals should include patients' psychological health and safety, alongside physical health and safety, as key components of beneficence.

As mentioned above, it is not clear that individual differences in personality and values are adequately considered when the need for long-term care is formally assessed (Huby et al., 2004). However the results of a study by R.A. Kane (1995) suggest that this is feasible and could improve practice. Similarly, the research on successful and unsuccessful ageing (Andrews et al., 2002), with its implication of differing health trajectories for different subgroups of elderly people (Lichtenberg et al., 2000), could usefully be included in the training of health professionals.

Dill (1995) observed that the principle of the individual patient's autonomy in medical decision-making is challenged by the discharge planning process. It appears that society and relatives can be, and are, involved, not only as proxies for the elderly person but also representing their own interests. Hence, the ethical practice of decision-making in a health setting needs to be expanded and formalised to include the interests, decisions and practices of the caregiver, family, neighbours, community and culture. This process may best occur outside the acute hospital, which is focused on the acute health care needs of the individual patient, and where the decision-making process is also at least ostensibly focussed on individual rights. Participants are not well-positioned to deal with more complex social and familial issues. Dill suggested that a notion of managed or negotiated risk could replace a simplistic focus on beneficence and safety values. This would require more training of discharge planners, and funding of related professional services such as advocacy and mediation, but the project's findings suggest that it would be more acceptable to elderly people, their relatives and health professionals.

In an expanded version of the Andersen model, Andersen and Davidson (1997) observed that, in predicting health outcomes, health behaviours needed to be considered

alongside health service usage. Planning for long-term care can be seen as a health behaviour and can be promoted as actively, on a community level, as other health behaviours. During their training and throughout their professional lives, health care professionals working in the community can be encouraged and trained to provide timely information to elderly people and their relatives about long-term care. This would promote the concepts of planning, of maintaining autonomy, and of aiming for as smooth a transition as possible to long-term care if it is required.

8.6 Implications for policy

Old age implies uncertainty and it appears to be considered in a probabilistic fashion. Most people do not know whether they will require residential care themselves, or whether they will be in good enough health, or receive enough support, to be able to live at home until their death. The literature suggests that people are realistic about risk factors that lead to placement (Lindrooth, Hoerger, & Norton, 2000) and if anything over-estimate their personal risk of residential placement (Taylor et al., 2005). Recent Australian figures (Wang, Mitchell, Smith, Cumming, & Leeder, 2001) have shown that two-thirds of elderly people do not enter residential long-term care, because death intervenes. Hence the deferment of planning and placement has realistic appeal for elderly people, their relatives and health professionals. They are all entitled to take a probabilistic approach concerning the likelihood that death will intervene before another undesirable outcome such as injury, disability, or forced placement. Probabilistic thinking may even extend further, to a psychological approach resembling gambling. This is evinced in the USA by the phenomenon of under-insurance for residential care

services (Taylor et al., 2005), despite the fact that residential care is ruinously expensive unless the care recipient is indigent. Surveying people aged 50-74 years, Taylor et al. (2005) found that they had an accurate understanding of their potential probability of requiring nursing home care. Despite this, fewer than 5% of elderly people in the USA had insured themselves against the possibility. It may well be that with increasing age and salience of the insurance decision, elderly people respond with reduced concerns about safety and increased desire for autonomy, and reject nursing home care as a personal option requiring them to take financial action. In this context the normal consumer decision-making model does not apply. In terms of the Andersen model, appraisal factors (specifically, in the case of this project, the values and priorities that influence decisions, and the timing, avoidance, deferral or deflection of decisions) will continue to be important in predicting and influencing patterns and timing of service usage.

Many of the models used for provision of health, education and care services to children can potentially be modified and applied to provision of care to elderly people. This will become more important to government and non-government agencies as the proportion of the old and of the very old within the community increases. For example, in children's services a number of different services are delivered on a single site in order to increase agencies' contact with the relevant age-group, to provide a normal environment for specialist services, and to encourage and facilitate service usage. This may be a useful model for services to the elderly, with increased integration of personal and residential care options and ambulatory health care services, in order to promote familiarity with the range of options and the service providers. Similarly, following the model of school open days, open days at aged care facilities and retirement villages, and

seminars on options for personal care provision, could promote visits and planning by elderly people and relatives well ahead of the need for a long-term care decision.

It appears appropriate for community education on health matters to include the possibility of survival to extreme old age, and to encourage planning for this possibility. In this context, the study's finding that elderly people focus less on safety in this context supports the findings of Minichiello et al. (1990), as described in Chapter 6. For elderly people, it appears to be useful to perceive acceptance of personal care from non-relatives as a strategy for maintaining independence and autonomy, rather an admission of dependence or indigence. It is becoming important for community members to understand that in the future there will be a decreasing ratio of nursing home beds to elderly populations, and an increasing emphasis on community aged care (Gibson, 1998). Hence, nursing home beds will only be available for those for whose care needs are so high that home care is not possible. Most of the paid personal care that is provided to elderly people will be provided in their own homes. Moreover (and see Section 5.7.4), given the continuing assumption by governments that family members will supplement paid care with unpaid care, the role of family caregiver may need to be acknowledged publicly and accepted by the community as being a potential part of every adult's responsibilities, something which does not occur at present (C. A. Lee, 2001; C. A. Lee & Porteous, 2002).

Given elderly community members' and stakeholders' emphasis on individual preferences and needs rather than a blanket 'safety' value, and also the imminent arrival of the baby-boomer generation as aged care clients, it appears timely for a more explicit consumer model to be applied to decision-making about personal care for the elderly. Kane and Kane (2001) have drawn an interesting distinction between models of care

provision for older and younger people with significant care needs. They observe that the model for provision of long-term care to younger people with disabilities has been normalised, with a consumer model being adopted, principles of consumer autonomy espoused, and individual living and individual lifestyles being promoted. However, the provision of long-term care to the elderly has remained based on principles of paternalism and beneficence, with group housing being the norm and very little choice provided.

With increasing life expectancy, planning and shopping around for long-term care is likely to be recognised as more important by the public. This could be promoted in the same way as pre-paid funerals and retirement funding, through community education and advertising, with a focus on retaining autonomy and control to the end of life. People hope for a healthy old age, and a sudden death without a period of disability. However, they need to understand that surviving to be very old while maintaining some level of independence is a possibility, and that it can be planned for. Middle-aged and older people can be encouraged to consider their housing in terms of its suitability as a venue for long-term care allowing them to age in place. Location, stairs, wheelchair access, public transport, and availability of personal care services are all relevant considerations. Community education could also include the possible consequences of a failure to plan, resulting in a pushed or forced decision, and perhaps a less desirable placement.

The least restrictive option – a good placement decision process, resulting in an acceptable placement, and occurring at the last reasonable moment – needs to be explicitly supported with funding. For example, extensive transitional support could be provided for “one last try” at being discharged home, and this might result in better

acceptance of eventual placement. Similarly, the time-pressure on elderly people and their families could be reduced by offering a transitional placement, and case-management outside the acute hospital system, while the right long-term care setting was found or a community care package was negotiated.

Hospitals are not the right places for residential placement to be arranged. There is conflict of interest about funding, and hence about determination of competence. Discussing psychiatric treatment and detention McCubbin and Weisstub (1998) have observed that because of the potential for conflict of interest, the individuals who recommend a course of action and a decision should not be the same individuals who determine a person's lack of decision-making competence, and who make the proxy decision on the person's behalf. They suggested that psychiatric patients should have independent advocates, and that an independent tribunal should be established including consumers, consumer advocates, and professionals from outside the health setting. Perhaps the same notions could usefully be applied to long-term care decision-making and the appointment of proxy decision-makers for elderly people.

It has widely been observed that the general shift of service delivery from institutions to the community assumes that the care recipient and the community will be ready to pick up the burden (McCullough & Wilson, 1995b). In practice, "community" has often meant the relatives, in particular the female relatives, of care recipients (Gibson, 1998; C. A. Lee, 2001; C. A. Lee & Porteous, 2002). A number of demographic indicators (Hays, 2002) suggest that as providers of personal care to the elderly, relatives are a diminishing resource in the developed world. There are a number of reasons for this: the increasing participation of women in the paid work-force throughout their lives; the fact that people are having fewer children and at later ages;

greater geographic mobility; and the fact that the first-degree relatives of the very old are likely to be old and possibly frail themselves. Already, community resources are rationed (Wetle, 1995). Community agencies allocate their budgets either to those most in need or to those at the top of their waiting-lists, and may not provide all of the personal care that an elderly client needs.

As the proportion of frail elderly people in the community increases, and the availability of family caregivers decreases, the community (in this case, the government) may need to commit itself to the provision of universal, needs-based, free or mean-tested personal care (whether in the community or in residential care) in the same way as it has committed itself to providing universal free school education, pre-school education, and (more recently) subsidised child care services. Personal care services could then be normalised and seen as an entitlement related to one's age (like infant health care, schools and the old-age pension) rather than as an admission of dependency, poor health status or financial need. A range of funding models already exists in the Australian economy. For example, personal care services could be explicitly funded and billed for, and re-imbursed on a means-tested basis (like child care services) or saved for throughout life with any residue being refunded to the estate (like superannuation). Indeed, higher levels of compulsory superannuation would also support the use of personal care services, in that more elderly individuals could afford to purchase them. The Australian Higher Education Contribution Scheme offers another funding model, offering free access to a service, and means-tested repayment during life or from the proceeds of the person's estate.

At present in Australia, acute care is funded through the states but residential care is directly funded by the federal government. This results in cost shifting and provides

an incentive for agencies to avoid providing services to elderly people with significant care needs. There are financial disincentives for acute hospitals to admit elderly people at all (and risk admissions which are longer and costlier than the casemix funding model provides for); to extend their admissions while good long-term care decisions and arrangements are made; and to re-admit them if care arrangements fail. It would be useful if these disincentives were removed, for example by bundling together the funds for acute and post-acute care for elderly people. However Kane and Kane (2001) have suggested that this approach may not be welcomed, either by acute care or long-term care providers.

8.7 Future research directions

In further exploration of the values and priorities of the community and stakeholder groups, with regard to long-term-care decision-making, mixed methods research combining quantitative and qualitative approaches is likely to produce the best results. Community surveys provide representative sampling, whereas interviews, focus groups and discourse analysis can provide in-depth responses and a chance to probe and query responses.

Given the disparity (in the interview study) between values expressed in a general sense, and practical suggestions made about another person, it would be useful to word survey questions so that they clearly applied to the respondent rather than to a hypothetical other person. For example, the survey question in Chapter 5 could have avoided both the third person problem (Smith et al., 2001b) and the proxy decision-maker problem by asking the respondent to imagine that this was their own situation.

Ranking of survey responses, although time-consuming for surveyors, could also produce more useful data than was obtained in the survey reported in Chapter 5.

Methodologically, researchers who attempt to study values related to important personal decisions are caught on the horns of a dilemma. Retrospective studies are potentially affected by hindsight and bias due to psychological acceptance of the outcome, but prospective studies are limited by the hypothetical and/or future nature of the question being asked (Schoenberg & Coward, 1997). Perhaps the best solution is to combine both approaches, retrospective and prospective. In this project, the retrospective research of McCullough et al. (1993) was used to plan a hypothetical prospective study, and a similar pattern of values was identified in both studies, supporting the view that these same values may operate throughout the process. It would be even better to carry out both types of study using the same group of participants, for example by tracking participants through and beyond the decision-making process, and also interviewing them at the time of the actual decision and potential crisis (Liken, 2001a, 2001b) With regard to the interviews reported in Chapter 7, if possible, a follow-up study of the elderly group and the relatives' group could be informative. Follow-up interviews could be performed at either or both of the following points: after a set period to test which if any interview responses were predictive of subsequent placement; or after placement had occurred to assess any change in expression of values. As described in Chapter 7, and above, the third person problem should also be addressed, in interview research, by directing the respondents' consideration to their own future rather than to that of a hypothetical other. The hypothetical vignette could itself be varied, to deal with a broader range of situations and, as mentioned in Chapter 7, it would be useful in a future and perhaps larger

interview study to recruit respondents from a wider range of cultural groups and to consider how these issues can be further studied for indigenous people.

In terms of obtaining the perspectives of elderly people with health problems who see placement as immediately salient to themselves, it appears that it is indeed necessary to interview elderly people who are very frail and socially isolated, and who are living alone and/or cognitively impaired. It may be necessary to return to the medical wards and interview inpatients, and/or to specifically target the 'at-risk' patients of local doctors and community agencies. Rather than restricting research to patients who are capable of consenting (as the university Departmental Ethics Committee specified for this project), it may be necessary to obtain proxy consent for research with people who are known to have impaired cognition. However, the question remains as to whether even these very frail elderly people would identify with Mrs Smith as a 'current self' rather than a future self or as one possible future self. It is possible that they, too, would deal with her psychologically confronting situation by defining her as an 'other': someone ageing less successfully than themselves.

As mentioned in Chapter 7, because of this project's focus on different age groups, spouse and sibling carers were excluded from the interview study, and adult offspring were selected. Spouse caregivers are an important group of caregivers for elderly people (Gibson, 1998) and their values too should be explored. A subsequent study comparing the values of caregivers in these categories would help discriminate between the effects on expression of one's values, of one's own age versus the impact of being a caregiver.

With regard to perceived constraints on the frankness of health professionals who are being interviewed by colleagues, as mentioned in Chapter 7, any technique that

leads to greater perceived anonymity should be considered. It may be useful to interview a wider range of stakeholder professionals, and study their values, meta-concepts and practical suggestions, in a parallel fashion.

In their outcome study of the ability of elderly medical patients to return home alone and to continue living alone in the longer term, Lysack et al. (2003) recommended more research on the meaning of place for elderly people from various backgrounds, and on the relationship between functional independence and people's strong feelings about living alone. Values and priorities concerning home, neighbourhood and living alone appear relevant to long-term care decision-making, as the work of Russell (1999) and Read (1996; 2000) has suggested, and as the Andersen Model, particularly as modified by Bradley et al. (2002), would also indicate. Indeed, the dilemma about residential long-term care only occurs where a person is living in an environment that does not provide the necessary care: in ETA terms, adaptation is not possible because competence is too low or environmental press is too high. In some families, and in some cultures, the most likely source of care is within the person's present home. This is the case for some married or cohabiting adults, and in communities where cohabiting multi-generation families are the norm and where not all women are in the paid workforce. For these elderly people, while other strains may operate, the problem is not one of place, and need factors will be less predictive of residential placement. Arguably the problem of long-term care decision-making could be redefined as a problem, not of where the person is to live, but of where the care is to be provided. In that sense, the increasing trend, in Western society, towards the provision of community aged care packages rather than nursing home beds (Gibson, 1998) offers a partial solution.

In this project, an attempt was made to elicit values and priorities about the personal importance of home and neighbourhood and, by implication, “sense of place” and what it meant to respondents. While these values and priorities were certainly mentioned, they were not the major focus of responses, perhaps because in both hypothetical vignettes, need factors were perceived as very important, and predisposing factors were considered to be of less importance. Values related to home and neighbourhood may be more effectively studied in the context of a more discretionary hypothetical move, for example from home to an independent unit in a retirement village.

Similarly, the project’s findings, the research literature, and the main theories in the area all suggest that individual differences in appraisal factors (such as family strain, sense of belonging at home, quality of life at home, and psychosocial functioning) may mediate between the three major Andersen factors (need, enabling and predisposing factors) and long-term care decisions. It has not yet been established whether these vary reliably between groups of individuals, for example between cultures or genders or between people who have and have not had previous experience of long-term care. Larger future studies could usefully focus on these appraisal variables in more detail, and extend their scope to include consideration of the safety and autonomy of family members as well as elderly people.

Methodologically, for reasons of time, this project did not include focus groups, or analysis of spoken discourse or published text, all of which may be useful techniques for examining values and priorities in this type of decision-making. Future research in this area could expand its range by using these techniques. In particular, it might be interesting to compare the public and private discourses about long-term care decision-

making with discourses about other difficult decisions, and specifically those decisions that could also be seen to reflect a socially or psychologically unacceptable abandonment of familial responsibilities. Some examples are decisions about institutional child care and respite care, and about end-of-life (Do Not Resuscitate) instructions, abortion, and divorce. It is possible that these decisions may be denied, deferred, defused, legitimised or excused in similar ways to long-term care decisions, and that similar typologies of decision-maker and decision could be identified.

8.8 Summary of conclusions

In summary, the goal of the research program was achieved. The values held by elderly people, their younger relatives, and health professionals, regarding decisions about residential care for frail elderly people, were examined prospectively. The retrospective findings of McCullough et al. (1993) were replicated. The project's strengths included its integration of mixed methods and multiple viewpoints, producing material which was rich in detail, reliable and valid. The project was also well grounded in the research literature, having integrated research and methods from a number of disciplines and literatures, and having examined the project's findings in terms of several relevant theories. The approach was innovative in that a prospective survey of community members' values has not been published, and there are few studies in this area which directly compare the responses of three groups of stakeholders.

The project findings confirmed that frail elderly medical patients in South Australia resembled those studied elsewhere in the developed world, and hence functional measures would predict their health outcomes.

With regard to application of the Andersen Behavioral Model of health service usage to use of long-term care, the project confirmed that the age and role of individuals was relevant to the priority they assigned to mediating or predisposing factors, when compared with the priority assigned to need factors.

The project findings were consistent with the ecological theory of ageing (ETA), which asserts that individuals will respond differently, at different times, to the same level of environmental press. Hence, need for placement must be assessed individually, and an individual's preferences and competencies will be predictive of subsequent adaptation and psychological adjustment. The MacArthur Model of Successful Aging, well known in the developmental literature, appeared to embody some useful concepts that are considered by stakeholders, and it also appeared to have some application to the prediction of outcomes after medical rehabilitation.

Within the general community, the priorities of elderly people were found to differ from those of younger people. Elderly people placed less emphasis on physical health and safety, and more on 'mediating', appraisal, or psychosocial priorities. Interviews with stakeholders revealed that the values they expressed, and the practical suggestions they made, differed with their age and their role in the decision.

For stakeholders, prospectively held values resembled the retrospectively described values of actual participants in long-term care decisions. Hence, the retrospective literature was found to be a useful guide to prospectively held values and priorities. It follows that policy and community education could usefully describe long-term-care planning in terms of control, choice and timing, rather than dependency, safety and need.

The values and priorities expressed by elderly stakeholders appeared to operate differently when they were thinking generally (and perhaps about themselves), and when they were asked to make practical suggestions / hypothetical decisions as a proxy for another (less successfully ageing) person. Thus, it was concluded that research using hypothetical vignettes must deal with the methodological issues of the 'third person' and the issue of proxy decision-making, by asking people to consider the decision as if it was for them.

Further mixed methods research is indicated, and some interesting and potentially productive research directions have been developed.

Appendices

Appendix A Predictors of mortality (summary of the review of the literature)

PREDICTOR	REFERENCE
Age	Campbell et al. (2004) review
Gender	Campbell et al. (2004) review
Baseline ADL	Francis & Kapoor (1992), Incalzi et al. (1992), Alarcon et al. (1999), Campbell et al. (2004) review.
ADL decline in hospital	Sager & Franke (1996)
IADL	Inouye, Peduzzi et al. (1998)
Baseline cognition	Francis & Kapoor (1992), Inouye, Peduzzi et al. (1998), Campbell et al. (2004) review.
Depression	Inouye, Peduzzi et al. (1998)
Polypharmacy	Incalzi et al. (1992), Campbell et al. (2004) review.
Severe specific medical diagnosis	Francis & Kapoor (1992), Incalzi et al. (1992).
Medical burden/ comorbidity	Desai (2002), Campbell et al. (2004) review.
Malnutrition	Incalzi et al. (1997)
Low white cell count	Incalzi et al. (1997)

Appendix B Predictors of discharge destination (from the literature)

PREDICTOR	REFERENCE
Age	Campbell et al. (2004) review
NOT age	Lysack (2001, 2003)
Gender	Challiner et al. (2003)
Baseline ADL	Alarcon et al. (1999), Rudberg et al. (1996), Sager & Franke (1996), Challiner et al. (2003), Campbell et al. (2004) review.
ADL decline in hospital	Sager & Franke (1996)
NOT IADL	Rudberg et al. (1996)
Cognition	Dunstan et al. (1996), MacNeill & Lichtenberg (1997), Alarcon et al. (1999), MacNeill et al. (2000), Lysack (2001, 2003), Challiner et al. (2003), Campbell et al. (2004) review.
Delirium / confusion	Inouye, Rushing et al. (1998), Aditya et al. (2003)
NOT depression	Lichtenberg et al. (2000), Lysack (2001, 2003)
Visual impairment	Aditya et al. (2003)
Mobility & gait	Dunstan et al. (1996), Lichtenberg et al. (2000), Lysack (2001, 2003), Aditya et al. (2003).
Falls	Aditya et al. (2003)
Incontinence	Aditya et al. (2003)
Tranquilliser use	Aditya et al. (2003)
Severe specific medical diagnosis	Campbell et al. (2004) review
Medical burden	Lysack (2001, 2003), Lichtenberg et al. (2000), Campbell et al. (2004) review.

*Appendix C Predictors of health / medical outcome after discharge**(from the literature)*

PREDICTOR	REFERENCE
Baseline ADL	Dunham & Sager (1994)
Baseline IADL	Dunham & Sager (1994)
Depression	Dunham & Sager (1994)

Appendix D Predictors of ADL decline after discharge (from the literature)

PREDICTOR	REFERENCE
Age	Sager & Franke (1996)
Gender	Sager & Franke (1996)
ADL decline in hospital	Sager & Franke (1996)
Cognition	Hansen et al. (1999), Landi et al. (2002). Sands et al. (2003).
Delirium	Inouye, Rushing et al. (1998)
Mobility	Hansen et al. (1999)
Severe specific medical diagnosis	Sager & Franke (1996)
Length of index hospital admission	Sager & Rudberg (1996)
Re-admission to hospital	Sager & Franke (1996)

Appendix E Survey items (pilot study)

Interviewer states:

“Some elderly people have dementia, which can lead to confusion and severe memory problems.

In deciding whether or not an elderly person with confusion and severe memory problems should go into residential care (to live in a nursing home or hostel): which three of these factors do you consider to be the most important?”

Interviewer shows large print card listing the following 6 numbered options

1. Physical safety / risk at home
2. Right to decide for himself or herself
3. Medical and health care needs
4. Wish to continue living at home
5. Mental capacity to make his or her own decisions
6. Amount of help available from family, neighbours or community

Appendix F Survey items (final)

Interviewer states:

“Some elderly people have dementia, which can lead to confusion and severe memory problems.

In deciding whether or not an elderly person with confusion and severe memory problems needs to go into residential care (to live in a nursing home or hostel), which three of these factors do you consider to be the most important?”

Interviewer shows large print card listing the following 8 numbered options

1. Physical safety / risk at home
2. Right to decide for himself or herself
3. Medical and health care needs
4. Wish to continue living at home
5. Mental capacity to make his or her own decisions
6. Amount of help available from family, neighbours or community
7. Burden to caregiver(s)
8. Behaviour detrimental to themselves and / or others

*Appendix G Association between carer status and five demographic variables
controlling for age cohort effect. Adjustment of p-values using the Holm method.*

P_i	p-value	$\alpha/(n-i+1)$	Significant?
P_1	.007	.05/25= 0.002	No
P_2	.011	.05/24= 0.0021	No
P_3	.018	.05/23= 0.0022	No
P_4	.022	.05/22= 0.0023	No
P_5	.035	.05/21= 0.0024	No
P_6	.041	.05/20= 0.0025	No
P_7	.058	.05/19= 0.00263	No
P_8	.133	.05/18= 0.00278	No
P_9	.214	.05/17= 0.00294	No
P_{10}	.252	.05/16= 0.00312	No
P_{11}	.285	.05/15= 0.00333	No
P_{12}	.375	.05/14= 0.00357	No
P_{13}	.376	.05/13= 0.00384	No
P_{14}	.407	.05/12= 0.00417	No
P_{15}	.434	.05/11= 0.00454	No
P_{16}	.451	.05/10= 0.005	No
P_{17}	.482	.05/ 9= 0.00556	No
P_{18}	.533	.05/ 8= 0.00625	No
P_{19}	.697	.05/ 7= 0.00714	No
P_{20}	.734	.05/ 6= 0.00833	No
P_{21}	.747	.05/ 5= 0.01	No
P_{22}	.805	.05/.4= 0.0125	No
P_{23}	.911	.05/ 3= 0.0167	No
P_{24}	.929	.05/ 2= 0.025	No
P_{25}	1.0	.05/ 1= 0.05	No

NB: $\alpha = 0.05$. $n=35$ (no. of comparisons). p_i is significant if $p_i < \alpha/(n-i+1)$ or $p_i = \alpha/(n-i+1)$

Appendix H Selection of priorities by decade of respondent age

Decade of age (n):	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85-94	95+	Whole Sample
% of respondents selecting priority	(494)	(511)	(572)	(529)	(365)	(281)	(211)	(50)	(2)	(3,015)
Physical safety / risk	77.7	82.5	86.7	80.6	77.4	64.1	52.2	58.1	51.0	77.3
Med / health needs	66.0	62.4	59.7	52.0	60.3	49.5	44.5	43.0	0.0	57.6
Mental capacity	40.3	44.2	41.7	43.8	41.1	35.9	31.4	29.6	51.0	40.7
Behaviour detrimental	31.9	44.4	44.7	44.5	40.1	38.4	34.8	34.2	0.0	40.5
Help available	36.8	31.7	31.5	34.3	31.4	38.6	34.6	29.1	25.5	33.7
Right to decide	22.1	15.3	12.4	14.2	12.9	19.3	19.5	26.4	25.5	16.2
Burden to caregiver(s).	5.5	5.7	7.9	11.2	11.0	17.4	20.9	12.0	51.0	10.0
Wish to stay home	6.9	7.7	6.2	8.8	7.9	16.4	18.1	24.2	25.5	9.3
Other/don't know	3.1	2.3	1.7	1.9	2.1	3.5	8.1	9.6	23.5	2.8

Appendix I Association between gender and selection of priorities, controlling for age cohort effect. Adjustment of p-values using the Holm method.

P_i	p-value	$\alpha/(n-i+1)$	Significance
P_1	.009	.05/40= 0.00125	no
P_2	.009	.05/39= 0.00128	no
P_3	.013	.05/38= 0.00132	no
P_4	.038	.05/37= 0.00135	no
P_5	.042	.05/36= 0.00139	no
P_6	.050	.05/35= 0.00143	no
P_7	.050	.0534= 0.00147	no
P_8	.051	.05/33= 0.00151	no
P_9	.071	.05/32= 0.00156	no
P_{10}	.078	.05/31= 0.00161	no
P_{11}	.080	.05/30= 0.00167	no
P_{12}	.107	.05/29= 0.00172	no
P_{13}	.115	.05/28= 0.00179	no
P_{14}	.139	.05/27= 0.00185	no
P_{15}	.152	.05/26= 0.00192	no
P_{16}	.155	.05/25= 0.002	no
P_{17}	.202	.05/24= 0.0021	no
P_{18}	.220	.05/23= 0.0022	no
P_{19}	.234	.05/22= 0.0023	no
P_{20}	.249	.05/21= 0.0024	no
P_{21}	.297	.05/20= 0.0025	no
P_{22}	.313	.05/19= 0.00263	no
P_{23}	.334	.05/18= 0.00278	no
P_{24}	.378	.05/17= 0.00294	no
P_{25}	.380	.05/16= 0.00312	no
P_{26}	.384	.05/15= 0.00333	no
P_{27}	.462	.05/14= 0.00357	no
P_{28}	.500	.05/13= 0.00384	no
P_{29}	.508	.05/12= 0.00417	no

P ₃₀	.609	.05/11= 0.00454	no
P ₃₁	.629	.05/10= 0.005	no
P ₃₂	.662	.05/ 9= 0.00556	no
P ₃₃	.673	.05/ 8= 0.00625	no
P ₃₄	.843	.05/ 7= 0.00714	no
P ₃₅	.863	.05/ 6= 0.00833	no
P ₃₆	.880	.05/ 5= 0.01	no
P ₃₇	.943	.05/.4= 0.0125	no
P ₃₈	1.0	.05/ 3= 0.0167	no
P ₃₉	1.0	.05/ 2= 0.025	no
P ₄₀	1.0	.05/ 1= 0.05	no

Notes: $\alpha = 0.05$. $n=35$ (number of comparisons in Table). p_i is significant if $p_i < \alpha/(n-i+1)$ or $p_i = \alpha/(n-i+1)$.

(Aickin & Gensler, 1996).

Appendix J Association between carer status and selection of priorities, controlling for age cohort effect. Adjustment of p-values using the Holm method.

P_i	p-value	$\alpha/(n-i+1)$	Significance
P_1	.032	.05/40= 0.00125	no
P_2	.088	.05/39= 0.00128	no
P_3	.097	.05/38= 0.00132	no
P_4	.100	.05/37= 0.00135	no
P_5	.105	.05/36= 0.00139	no
P_6	.137	.05/35= 0.00143	no
P_7	.160	.0534= 0.00147	no
P_8	.175	.05/33= 0.00151	no
P_9	.211	.05/32= 0.00156	no
P_{10}	.231	.05/31= 0.00161	no
P_{11}	.238	.05/30= 0.00167	no
P_{12}	.273	.05/29= 0.00172	no
P_{13}	.325	.05/28= 0.00179	no
P_{14}	.341	.05/27= 0.00185	no
P_{15}	.347	.05/26= 0.00192	no
P_{16}	.358	.05/25= 0.002	no
P_{17}	.390	.05/24= 0.0021	no
P_{18}	.422	.05/23= 0.0022	no
P_{19}	.451	.05/22= 0.0023	no
P_{20}	.535	.05/21= 0.0024	no
P_{21}	.540	.05/20= 0.0025	no
P_{22}	.554	.05/19= 0.00263	no
P_{23}	.554	.05/18= 0.00278	no
P_{24}	.599	.05/17= 0.00294	no
P_{25}	.635	.05/16= 0.00312	no
P_{26}	.656	.05/15= 0.00333	no
P_{27}	.699	.05/14= 0.00357	no

P ₂₈	.771	.05/13= 0.00384	no
P ₂₉	.778	.05/12= 0.00417	no
P ₃₀	.781	.05/11= 0.00454	no
P ₃₁	.781	.05/10= 0.005	no
P ₃₂	.825	.05/ 9= 0.00556	no
P ₃₃	.840	.05/ 8= 0.00625	no
P ₃₄	.897	.05/ 7= 0.00714	no
P ₃₅	1.0	.05/ 6= 0.00833	no
P ₃₆	1.0	.05/ 5= 0.01	no
P ₃₇	1.0	.05/4= 0.0125	no
P ₃₈	1.0	.05/ 3= 0.0167	no
P ₃₉	1.0	.05/ 2= 0.025	no
P ₄₀	1.0	.05/ 1= 0.05	no

Notes: $\alpha = 0.05$. $n=35$ (number of comparisons in Table). p_i is significant if $p_i < \alpha/(n-i+1)$ or $p_i = \alpha/(n-i+1)$

(Aickin & Gensler, 1996).

Appendix K Hypothetical vignette used in the interview study

Mrs Smith is 76 and she has been widowed for 10 years. She lives alone in the family home. Her only son rings her regularly and tries to help when he can, but he lives and works interstate. Her niece, who lives across town and has a job and a family, visits most nights after work and does Mrs Smith's shopping.

After her last operation Mrs Smith was offered help from Meals on Wheels and the district nurse, but she wouldn't let them into her home. At present she isn't receiving any help from community agencies.

Mrs Smith has a number of medical problems, including high blood pressure, diabetes and heart trouble. Her local doctor has noticed that she is losing weight, and her short-term memory has been deteriorating for at least 6 months.

A month ago, Mrs Smith's neighbours found her lying on the floor after a collapse. They rang an ambulance and Mrs Smith was admitted to hospital. She is now feeling better, and she is able to walk with a frame.

However the occupational therapist and social worker have visited Mrs Smith's home with her. They report that the house and garden need a major clean up. The council building inspector says that expensive repairs are required. Also, the steps up to the front door are dangerous.

Appendix L Codebook for interview study

(1) INTRODUCTION (FOR SECOND CODER)

The aim of the study was to document the values and priorities expressed when considering whether a frail elderly person should move into a residential aged care facility at a particular point in time.

It was hypothesised that these values might differ, or operate differently, between elderly people living in the community, the younger adult relatives of such elderly people, and health professionals involved in discharge planning and residential placement for the elderly.

The study followed the schema of beliefs, attitudes and values adopted by Forbes and Hoffart (1998) in their study of older people's decision-making about long-term care. This had been based on the findings of the ground-breaking study by McCullough et al. (1993) which directly compared the values of older people, with those of their relatives and the health professionals involved in their long-term-care decisions. McCullough et al. had defined values as "standards by which human beings judge the worth or importance of themselves, other human beings and things" (McCullough et al., 1993, pg. 325).

Forbes and Hoffart defined a belief as "a predisposition to action that contains a cognitive component and an evaluative component" whereas "attitudes are comprised of two or more underlying beliefs" (Forbes & Hoffart, 1998, pg. 737).

Forbes and Hoffart stated that adults have many attitudes and even more beliefs, but relatively few values, adding that:

Once a value is internalised, it guides (consciously or unconsciously) action, decision-making, moral judgment, and maintaining or changing attitudes. A value is more global than are attitudes and transcendentally guides actions and judgments across situations beyond the immediate to more focussed end states of existence. (p.737).

Method

Ten elderly people living in the community, eight adult relatives of such elderly people, and eighteen health professionals (from five disciplines: medicine, nursing, occupational therapy, psychology

and social work) involved in discharge planning for the elderly, all underwent the same structured interview. Each was presented with a hypothetical vignette and asked for general comments on the situation. They were then asked four questions, in order:

What should happen when Mrs Smith leaves hospital?

Who should decide?

What would make a difference?

What are the arguments for and against Mrs Smith's returning home?

Finally they were asked if they wished to make any other comments.

Interview responses were transcribed and examined for values expressed when considering the option of residential placement (nursing home or hostel care) versus more independent living options (returning to one's own home, or moving to a smaller house or unit, or a retirement village)

Some values mentioned by elderly people, family members and professionals appeared to be super-ordinate in that they could be seen to include several other value categories. For example, 'independence' was identified as an over-arching value category which might be used to describe one or more of the following value categories: autonomy, decisional capacity, identity, physical capabilities and work ethic. Similarly 'quality of life' could include many value categories, including autonomy, environment quality, health, identity, privacy, psychological well-being and respect. In each instance these value categories were coded at the lowest (most specific) level possible.

Planning, timing and balance had been identified as 'meta-concepts' which might determine the relative priority of competing or conflicting values. These were coded separately.

Inevitably values were expressed concerning matters other than the decision for or against residential placement, such as who has the right to make such placement decisions, and the extent of community responsibility for funding aged care. These were not coded.

(2) NOTES FOR CODEBOOK

(a) A value may be expressed in its *positive* form, as defined above, or as its *negative* or opposite
eg. Filial responsibility: “My adult children should take care of me”

code as *Filial responsibility*: (12)

The negative: “I don’t believe my children are obliged to care for me” – code as *Filial Responsibility*: (12-)

eg. Social contact (desirable) “ She could make some new friendships if she went into care” code as (27) but “ She prefers her own company, she would hate living in a group” code as (27-)

(b) Activities of daily living (ADLs) are the most basic self-care activities. ADL measures usually include dressing, bathing, feeding oneself, toileting, mobility in bed, transferring into and out of a bed and a chair, and walking across the room or outside the home.

IADLs are more complex activities, such as using the telephone, shopping, meal preparation, light and heavy housework, taking medications, using transport, and managing one’s own finances (Dunkle et al., 1994).

(c)* Originally derived from (McCullough et al., 1993)

** Originally derived from (Forbes & Hoffart, 1998)

(3) SUMMARY OF CODES FOR VALUES AND META-CONCEPTS

(1) META-CONSTRUCTS A-C

- A. Planning ahead
- B. Balance of competing priorities, duties, obligations
- C. Timing

(2) VALUE CATEGORIES 1-28

- | | |
|--|---|
| 1 Acceptance / Stoicism ** | 15 Identity of Elderly Person* |
| 2 Autonomy Or Independence (Elderly Person) | 16 Institutional Care |
| 3 Best Interests of the Elderly Person (Beneficence) | 17 Logic/ Pragmatism |
| 4 Care (Personal Care) * | 18 Mental Abilities (Elderly Person) |
| 5 Caregiver Autonomy | 19 Neighbourhood |
| 6 Caregiver Benefits * | 20 Physical Abilities |
| 7 Caregiver Burden * | 21 Privacy ** |
| 8 Decision-Making Capacity (Elderly Person) | 22 Professional Care |
| 9 Decision-Making Process * | 23 Professional Opinion |
| 10 Environment (Quality)* | 24 Psychological Wellbeing (Elderly Person) * |
| 11 Filial Responsibility * | 25 Relationship * |
| 12 Finances * | 26 Safety / Security * |
| 13 Health * | 27 Social Contact (desirable) |
| 14a Home – Valued / Unspecified | 28 Work Ethic / Self-Responsibility ** |
| 14b Home – Function Better There | |

2 AUTONOMY OR INDEPENDENCE (ELDERLY PERSON)

Definition Elderly person has the right to decide

Indicators/ Flags Rights, control, self-determination.

Independence in decision-making

Independence (mentioned but not explained further)

Right to make decisions about their own life / priorities

Qualifications /Exclusions

Older person should decide, if they are mentally capable, but not otherwise

- code as *Decision-making capacity*

Physical independence, ability to carry out one's decisions

- code as *Physical / ADL capacities of elderly person*

3 BEST INTERESTS OF THE ELDERLY PERSON / BENEFICENCE

Definition What is in their best interest (as distinct from anyone's wishes)

Indicators/ Flags Duty of care (for professionals)

Qualifications /Exclusions

4 CARE (PERSONAL CARE) *

Definition Personal care is available for the elderly person

Personal care includes (if required) meals, housekeeping, help with ADLs

and IADLs, available within a short enough time.

Indicators/ Flags

Qualifications /Exclusions:

Help in an emergency – code as *Safety /security*

Monitoring of person's wellbeing – code as *Safety /security*

Institutional care – code as *Institutional care*

Professional/ medical /nursing care – code as *Professional care*

5 CAREGIVER AUTONOMY

Definition Caregiver's right to make decisions about their own life / priorities

Indicators/ Flags

Qualifications /Exclusions

6 CAREGIVER BENEFITS *

Definition Caregiver wellbeing

Indicators/ Flags To feel good about older person's situation
To be able to work (financial gain, job satisfaction)

Qualifications /Exclusions

Caregiver privacy, freedom, lifestyle – code as *Caregiver Burden*

Caregiver's right to make decisions about their own life / priorities
– code as *Caregiver Autonomy*

7 CAREGIVER BURDEN *

Definition To avoid a caregiver being burdened

Indicators/ Flags Minimise physical / health /emotional burden of care and/or responsibility.
Elderly person's behaviour detrimental to others
Minimise caregiver's conflicts with other responsibilities eg. job, family
Maintain caregiver lifestyle, privacy.

Qualifications /Exclusions

Caregiver's right to make decisions about their own life / priorities –
- code as *Caregiver Autonomy*

Reduce financial strain – code as *Finances*

To be able to work (financial gain, job satisfaction) - – code as *Caregiver*

Benefits

8 DECISION-MAKING CAPACITY (ELDERLY PERSON)

Definition Elderly person should make their own decisions if mentally capable
(and otherwise not)

Indicators/ Flags

Qualifications /Exclusions

Right to decide – code as *Autonomy (Elderly person)*

Mental ability to execute decisions, carry out ADL, IADL – code as
Mental abilities

9 DECISION-MAKING PROCESS *

Definition Decision-making process meets ethical standards

Indicators/ Flags Elderly person is involved in the decision
Elderly person is fully informed about care options
Family is fully informed about care options
Communication is open, with full disclosure
Elderly person understands /accepts the decision
Family is involved in the decision
Correctly determine who should decide
Do what is feasible
Do what is professionally satisfying / correct role
Activate agency /community help for older person

Qualifications /Exclusions

Autonomy – code as *Autonomy (Elderly person)* or *Caregiver autonomy*

Right to decide – code as *Autonomy (Elderly person)*

10 ENVIRONMENT (QUALITY)*

Definition Living environment is of good quality

Indicators/ Flags Environment is adequately comfortable, spacious, homelike.
Environment provides adequate stimulation, mobility, convenient services.

Qualifications /Exclusions

Environment is own home, known, or familiar – code as *Home*

Environment is own neighbourhood – code as *Neighbourhood*

Institutional care is better – code as *Institutional care*

Personal care is available – code as *Care*

Professional care is available – code as *Professional care*

Privacy – code as *Privacy*

Social contact is available in environment – code as *Social contact*

11 FILIAL RESPONSIBILITY *

Definition Child has an obligation to provide care to parent or parent-in-law.

Indicators/ Flags

Qualifications /Exclusions

12 FINANCES *

Definition Elderly person to be financially secure /independent / able to afford expenses
Caregiver not experiencing financial strain in paying for elderly person's needs

Indicators/ Flags

Qualifications /Exclusions

Caregiver able to work – code as *Caregiver Benefit*

13 HEALTH *

Definition To be healthy, to have needs for health care met.

Indicators/ Flags

Qualifications /Exclusions

Physical capacity /independence – code as *Physical Abilities*.

Mental /decision-making capacity – code as *Decision-making Capacity*

Professional care is available – code as *Professional care*

Elderly person's health and/or safety are monitored – code as *Safety*

14a HOME (Valued or Unspecified)

Definition One's own home is the best place to live

Indicators/ Flags Home is familiar, known, holds memories

Qualifications /Exclusions

Able to function better in one's own home – code as

14b Home – function better

Living environment is of good quality, homelike – code as *Environment*

Allows continuity of local friendships – code as *Relationship*

Own neighbourhood or area – code as *Neighbourhood*

Privacy - code as *Privacy*

14b HOME (Able to function better there)

Definition Able to function better in one's own home

Indicators/ Flags

Qualifications /Exclusions

Home is familiar, known, holds memories code as

14a Home – valued /unspecified

Living environment is of good quality, homelike – code as *Environment*

15 IDENTITY OF ELDERLY PERSON*

Definition To maintain sense of self, self-image, sense of personal continuity.

Indicators/ Flags

Qualifications /Exclusions

To make own decisions, be in control – code as *Autonomy*

To be treated with respect – code as *Relationship*

Privacy – code as *Privacy*

16 INSTITUTIONAL CARE

Definition Institutional care/living is better, more appropriate, more likely to succeed

Indicators/ Flags

Qualifications /Exclusions

Personal care needs met – code as *Personal care*

Professional/ medical /nursing care is better – code as *Professional care*

Positive Examples At that age a nursing home is the best place for her

Negative Examples Some nursing homes aren't too good.

Living in a nursing home – if you call that living.

17 LOGIC/ PRAGMATISM

Definition Logic should be followed when making decisions, rather than emotion

Indicators/ Flags Facing facts and/or taking a practical approach is best

Qualifications /Exclusions

One should accept the inevitable, make the best of things – code as *Acceptance*

18 MENTAL ABILITIES (ELDERLY PERSON)

Definition Mental ability to carry out everyday activities such as ADL, IADL
Mental ability to carry out decisions, put decisions into practice.

Indicators/ Flags

Qualifications /Exclusions

Competence to make decisions – code as *Decision-making Capacity*

Right to decide – code as *Autonomy (Elderly person)*

Physical ability to carry out tasks – code as *Physical abilities*

19 NEIGHBOURHOOD

Definition Own neighbourhood or community is best

Qualifications /Exclusions

Own home or place is best – code as *Home*

Relationships with neighbours / friends living nearby – code as *Relationship*

20 PHYSICAL ABILITIES

Definition Able to cope or manage adequately at home, (possibly with supports).
Able to carry out Activities of Daily Living (ADLs) and/or
Independent Activities of Daily Living (IADLs).

Indicators/ Flags Independent at home.
Able to manage at home with current/planned levels of support
Able to look after self

(see next page)

Qualifications /Exclusions

Health / medical condition – code as *Health*

Independence of decision-making - code as *Autonomy*

Elderly person should make their own decisions if mentally capable
– code as *Decision-making Capacity*

Mental ability to carry out everyday activities – code as *Mental abilities*

Mental ability to carry out one’s decisions– code as *Mental abilities*

Belief in looking after oneself – code as *Work ethic*

21 PRIVACY

Definition Privacy of elderly person

Indicators/ Flags

Qualifications /Exclusions

22 PROFESSIONAL CARE

Definition Professional care is necessary, or better than informal care

Indicators/ Flags Medical / nursing / trained care

Qualifications /Exclusions

Institutional care is better – code as *Institutional care*

Personal care is provided – code as *Care*

23 PROFESSIONAL OPINION

Definition Professional opinion/ recommendations should be followed

Indicators/ Flags Medical / nursing / health professionals’ advice

Qualifications /Exclusions

Institutional care is better – code as *Institutional care*

Professional care – code as *Professional Care*

24 PSYCHOLOGICAL WELLBEING (ELDERLY PERSON) *

<i>Definition</i>	Psychological well-being of the elderly person
<i>Indicators/ Flags</i>	Emotional and mental health are preserved / facilitated Emotional support is available Happiness Reduction /avoidance of distress
<i>Qualifications /Exclusions</i>	Relationship issues – code as <i>Relationship</i> Social contact – code as <i>Social contact</i>

25 RELATIONSHIP *

<i>Definition</i>	Relationships should be protected / developed Conflict should be minimised /avoided / resolved
<i>Indicators/ Flags</i>	Minimising conflict between elderly person , family and others Minimising conflict within family Preserving marital relationship Staying near family and friends Trust Respect Reciprocity or give-and-take as the basis of a relationship Having others' support for decisions
<i>Qualifications /Exclusions</i>	Duty to parent or parent-in-law - code as <i>Filial responsibility</i> Respect older person's choices/decisions about placement - code as <i>Autonomy (Elderly person)</i> Identity of older person should be acknowledged – code as <i>Identity</i>

26 SAFETY / SECURITY *

Definition Elderly person is safe from injury, abuse.

Indicators/ Flags Elderly person should not be at risk

Elderly person's health / safety /basic well-being is monitored

Qualifications /Exclusions

Elderly person's health is maintained – code as *Health*

Elderly person should not be neglected – code as *Care (personal)*

Health care / professional monitoring is received

– code as *Professional care*

Positive Examples “You know someone is keeping an eye on him”

Negative Examples Elderly person is at risk of injury or abuse

27 SOCIAL CONTACT (Desirable) **

Definition Elderly person should have the opportunity for social activities
and companionship

Elderly person should not be isolated.

Elderly person should be among pleasant people

Indicators/ Flags

Qualifications /Exclusions

Existing personal relationships – code as *Relationship*

Positive Examples “In a nursing home she would have more company”

Negative Examples “She may prefer her own company, the other residents could drive her mad”

28 *WORK ETHIC / SELF-RESPONSIBILITY* **

Definition One should continue doing as much as one is able to do
 One should be responsible for one's own needs, not be a burden.
 One should not rely on, or impose on, others.

Indicators/ Flags Perseverance in existing situation despite difficulties
 Independence explained in terms of reluctance to accept help

Qualifications /Exclusions
 Independence (not further explained) – code as *Autonomy*

Appendix M List of meta-concepts and values, with examples

Meta-Concepts

A Planning ahead

“It makes you think she should have been thinking about doing something, moving somewhere more suitable... Do it while you’ve got your wits about you”. (OP03, L13)

B Balance of competing values, priorities, duties, obligations.

“Well that’s reasonable for the niece to go, but she goes most nights. She can’t go every night, but she goes most nights which is reasonable.” (OP02, L12)

C: Timing.

“So she might have some years if she lived at home, rather than just a few weeks. Of course the other side of that is, it is also going to be easier to move her into a new environment at this time and not later, and it is always tricky that one.” (HP03, L95)

Values

1 Acceptance / Stoicism

“At a certain time of your life I think you just have to say right well I’m going to put up with this. That’s going to be it.” (OP03, L70)

“When you get to this stage you do need some level of intrusion and you need to accept that.”(HP08, L84)

2 Autonomy / Independence (Elderly Person)

“I still go with the theory people can decide for themselves.” (OP03, L40)

“You have to respect Mrs Smith’s right to stay in her home.” (REL06, L10)

“The person in the centre should decide.” (HP04, L10)

“Mrs Smith’s probably not going to have a lot of say in it. And I think it would be right that she wouldn’t have a lot of say in it because she obviously is not going to look...she’s probably not going to feel that it’s in her best interests whatever decision other people make. But she is going to have to be convinced that it is for her own good and well being.” (REL08, L17, coded negative)

3 Best Interests Of The Elderly Person/Beneficence

“Someone should step in and do what’s best for her.” (OP08, L10)

“The son and niece, even if there is a friend who visits, does it mention a friend, have got to encourage her for her own good, for everybody else’s peace of mind as well.” (REL01, L33)

4 Care (Personal Care)

“She must have a carer, or someone who can look after her properly.” (OP02, L26)

“The best outcome might be, if she could stay, with a carer that’s there quite a bit, or pops in and looks after meals and that sort of thing.”(REL09, L23)

5 Caregiver Autonomy

“Because what happens is that son or daughter is limited, becomes limited in their responses, becomes limited in time, in... .freedom is limited anyway... Nursing home... is a wonderful institution that gives a chance to old person to be free, and for the family to be free.” (OP06, L399)

6 Caregiver Benefits * Not mentioned by any participant.

7 Caregiver Burden *

“I know how frustrating the distance can be, especially if the phone’s out of order, or off the hook” (REL10, L97)

“The feelings of the son, how he feels about her being on her own.” (REL01, L46)

“It’s of course very distressing for all the family. Mrs Smith of course, and her son, the niece is obviously closely involved. It has ripples in a lot of ways, and in a sense it doesn’t count for very

much in terms of the finances and the mix of care for older people and so on. But it matters enormously in people's lives." (REL02, L136)

"It's a worry for the family, the neighbours see her as being at risk. A strain for the family and an uphill battle for service providers." (HP04, L18)

"The niece lives across town, so that's a long way away, has a job and a family, and visits after work, and does the shopping. So that's an enormous burden." (HP18, L117)

8 Decision-Making Capacity (Elderly Person)

"If it has been found that she has a mental incapacity to make the decisions, because the health workers have to decide, to provide duty of care, couldn't just send her home." (HP05, L13)

9 Decision-Making Process *

"Usually in these cases, I like to have a family meeting. I think that's what we usually do. Sometimes it's been worthwhile having the patient there as well, sometimes it's not...depends. I like to have them, I don't see why that they shouldn't be there. I think that they should be there, I don't think things should be hidden from them just to protect them in a way." (HP05, L64)

10 Environment (Quality)*

"Just being somewhere where she's getting regular meals and some social company... a better environment might physically improve her." (HP03, L114)

11 Filial Responsibility *

"This is what worries me about Mrs Smith, and my parents, if Mum or Dad dies I know the other one's not going to cope very well and be left up to me and my brother, my brother and I, to worry about, or do something with them. If they don't want to budge and stay, which I'm pretty sure they won't, it's going to mean a lot of our time and effort. Geez. And may even come to a point when they've got to live with us. Which is traditional in their society. And maybe kind of expect from them. That's going to be hard." (REL09, L314)

12 Finances *

“How much money am I going to spend for the future. Even though I’ve got a condition that is going to probably lead to institutional care at some time in the future. Is it better to go through institutional care now and not worry about going, bypass the home, what’s the value of, to her, of still being in a home that she knows well... It’s a very hard judgment to make”. (HP03, L36)

13 Health *

“It all depends on what state her health etc is.” (OP10, L134)

“Well, again, it’s not in her interests in terms of her health.” (REL03, L53)

14a Home – Personal value of living there / Unspecified.

“But whether I’d be like that when I’m 76 or something who knows. I might think I want my dining-room table, I want my house I’ve lived in all this time.” (REL03, L34).

14b Home –The elderly person might function better there.

“Everything is there, everything she knows, everything she had done is always there. Her memory would revert back to that all the time. Whereas something strange she would have to wander around and ask for help all the time.” (OP02, L107)

15 Identity Of Elderly Person*

“She’d be able to maintain her independence and her dignity too.” (HP13, L57)

16 Institutional Care

“One of the other advantages of hostel living is the fairly strict routine to the day, which helps people with cognitive impairment.” (HP03, L109)

“If she went into the right home. I mean there are some homes that are not too good.” (OP02, L99, coded negative)

17 Logic/ Pragmatism

“I’ve always said I’ll go out feet first with a label on my big toe! Probably not practical though is it?” (OP09, L77)

18 Mental Abilities (Elderly Person)

“Her short-term memory, she’ll forget important things, like the bills.” (REL10, L47)

“And I guess the extent of her short term memory losses as well, if it’s just, you know, she’s getting a bit forgetful, but she can generally function okay, then that’s okay, you know with a bit of support. But if it’s to really putting herself at risk especially if she lives alone, then obviously the extent of that will make a difference as well.” (HP06, L50)

19 Neighbourhood

“She has some contact with the neighbours, as it’s a bit unclear again as to what, but I mean I presume she’s in a community and in an environment that is familiar to her. So if she had to move from there we have all the difficulties with her losing that community network. Just little things like knowing where the local shop is, to looking down the street and knowing who lives five houses down. All those sorts of losses that could confront Mrs Smith.” (HP10, L80)

20 Physical Abilities

“She’s not able to look after herself or do things.” (REL10, L43)

21 Privacy **

“Maintaining her privacy and dignity and well-being”. (HP12, L59)

22 Professional Care.

“If there was someone there that was really well trained, possibly they could do something to help her. But they would need to be, I would say just about a professional nurse or something.”

(OP09, L8)

“And let’s face it we’re not experts either. This is new to us and the rest of the family. Whereas if Mrs Smith or (elderly relative) goes into a proper home, they’ll have experts looking after her.”

(REL08, L105)

23 Professional Opinion

“I think the decision should be with the doctor.” (OP05, L128)

24 Psychological Wellbeing (Elderly Person)

“She would live much better, she would be happier.” (OP02, L92)

“She’s happy. She’s familiar with the environment, it might delay her deterioration if she’s in a familiar place.” (REL01, L41)

“Maybe she might actually live longer being in her own home in terms of being happier there or whatever. And she might just give up if she goes into a nursing home.” (REL03, L76)

“I can imagine just how devastating and depressing it would be to an elderly person, to leave their own home.” (REL08, L46).

“If we were able to institute reasonable supports and she was able to stay at home, there’s some sense of self attainment, or self achievement for actually working through a situation and staying in her own environment, not having to move out. That could be important in terms of her self esteem as well.” (HP10, L86).

25 Relationship *

“She may not be able to be placed into the sort of residential placement that would allow the niece to visit as often and probably Mrs Smith values her niece’s contact. It doesn’t say anything about neighbours or anything else. Can’t tell whether that’s a factor. It doesn’t say anything about pets, but of course they would be a very important consideration if they’re in here.” (REL02, L71)

26 Safety / Security *

“Because what we try to determine is if she is medically at risk. A danger to herself and others. And someone senior should be deciding that.” (HP02, L60)

“She could be at risk of serious injury or calamity, there’s a need to reduce the risk.” (HP04, L22)

27 Social Contact

“Going into care, well she would be with other people and I think that’s nice. She’d have company.” (OP05, L149)

“Probably in her mind that she feels more comfortable alone. Without people. She’s probably got....been widowed....she probably got used to being alone hasn’t she?” (OP05, L145, coded negative)

28 Work Ethic / Self-Responsibility **

“And if anything drastic happened, I wouldn’t have to call on the kids to come and rescue me. I’d make my own plans.” (OP03, L60)

“I wouldn’t want to be dependent on my family that much.” (REL03, L22)

Appendix N Three examples of transcripts

1 **Transcript OP04: Elderly person**

2

3 L = Linley

4 P = Participant

5 Starts with general chat

6 L What I'm going to do is show you my case study with a hypothetical lady and ask you first for
7 your general comments.

8 P Could you hand me my glasses please.

9 L Certainly. And then ask you some more particular questions. Even though I'm taping I'll take
10 some notes as well.

11 Long pause

12 P Just the first half? Or do you want me to.....

13 L No, just the questions. Just this half. So what are your thoughts generally on that situation?

14 P Well, I tend to think that having lived in a retirement village for many years, people want to stay
15 on in their own home. But in one way I think it's rather selfish. Because it puts on the onus on friends,
16 relatives. And I got inveigled into helping out many times.

17 L Because it puts the onus on others.

18 P Yes it does. And I mean they often are too far gone to realise this.

19 L What do you think should happen? She's in hospital now, and they are trying to sort out what
20 should happen when she leaves hospital. What do you think?

21 P Well, I think to me, probably secure hostel accommodation. I know at the Lutheran Homes they
22 had a special wing for people, called 'secure'. Once they got in and settled down they were quite happy.

23 L I think that's a very reasonable answer. And why do you feel she should go in that direction?

24 P Well really I don't think she has much choice. I mean you can have Meals-on-Wheels, they
25 deliver them. You can have carers come in in the morning and shower you, come in at night and.....I've
26 seen it...I've lived in this situation.

27 L You certainly have.

- 28 P And they give you the tablets and one thing and another. But invariably if they get into trouble
29 it's in the middle of the night. We used to be in this 'constant care' thing', and there I was the one they
30 would ring in the middle of the night, because I was *there*.
- 31 L Oh no
- 32 P As I say I've probably got very strong views on that. *Laughs*
- 33 L Well informed views
- 34 P Yes, I think she needs care. And I mean her son's interstate and a worry for him is tremendous.
- 35 L yes, yes
- 36 P And I don't think he'd be being unkind if he said, "yes she needs some care".
- 37 L Yes, indeed.
- 38 P Even taking the medication. Having high blood pressure, and diabetes myself I know what it's
39 like. *Laughs*
- 40 L Oh right. You know a lot about this. Okay. That's a lot to look after.
- 41 P Oh yes. You take the wrong pills and put them in little boxes in safely, this one there and this
42 one there, but they don't even remember where they are or what they've taken. It's really quite
43 dangerous.
- 44 L Who do you think should make the decision?
- 45 P Well if...it probably has to be a round table discussion. The son, the carers, the doctor. Whether
46 she can probably come into it, but I know they invariably say No. They've only got one way 'I'm staying
47 here'. They don't realise they are doing it for her own good.
- 48 L We know that sometimes people do say No.
- 49 P Oh yes, I've seen them saying No.
- 50 L So what should happen then?
- 51 P I tend to think they should be over ruled. The consensus of opinion is that it's required, I think
52 she should be over ruled.
- 53 L Thanks for that. That's good. What I'm...as you can imagine, getting a lot of views, and a lot
54 that feel the same that the lady's got to be placed and some that feel should have another try at home, and

- 55 some then feel it's No. Can you tell me what are the arguments for and against, her going back to her
56 own home? As you see it, it's *your* opinion I'm interested in.
- 57 P Yes, I realise that. Back to her own home she's got to rely on other people, she's certainly not
58 self-reliant. And I mean is this fair?
- 59 L Yes. So that's one fact against her going home, that it isn't fair.
- 60 P Yes. As I say she had....she's already had a collapse. Now she could collapse again and she
61 could lie there for sometime and die. So I think it's for her own good. I mean it's not doing anybody else
62 any good, just herself. At 76 she could live another 14 years, with care. If you call that *living!* *laughs*
- 63 L Well that's the other thing. That's right. So what you just said then, could live another 14 years
64 with care, if you call it living. And do you think from that point of view, where would she be better off?
65 Or would it be the same either way?
- 66 P Well the thing is if she stays in her own.....it's hard....I mean if she stays in her own home she
67 could die anytime virtually. She still could in care, but at least she has a far better chance of surviving.
- 68 L Yes. Better chance of surviving. Thanks. That's lovely. So they're the arguments for against
69 going home. Are there any for going home or is it more.....
- 70 P I think it's a reverse of *against*, isn't it?
- 71 L Reverse of against. So that if she did go home she could have a collapse.
- 72 P This is true and as I say, surely her niece and her son and that, would be much happier knowing
73 that she was being cared for. It's a constant worry. Day to day, hour to hour virtually.
- 74 L That's right. It is.
- 75 P The other thing are there always places available for them?
- 76 L That's the next one isn't it?
- 77 P There often isn't a choice. That's what's sad.
- 78 L You mean there isn't a choice of which place to go, or.....
- 79 P Of any place to go. As I say, having lived in a retirement village and people got to this stage and
80 they were keeping them in hospital and doing all sorts of things. Because they couldn't get them in
81 anywhere.

- 82 L Yes. We certainly see that at the hospital where I'm working at. Used to more, but we still see it
- 83 *pause* Thanks for that. The next question, I'm going to cheat and look at the cheat sheet.
- 84 *Laughter*
- 85 L There we go. What would make a difference to Mrs Smith's situation or your views about her?
- 86 P If she had a live in help. Qualified or at least very experienced live in help.
- 87 L So, not someone.....
- 88 P Oh no, they could do more harm than good actually. *Laughs*. You know what I mean, they've
- 89 got good intentions but you know they want to go out and play the pokies for half and hour, and people
- 90 when they get old like that, particularly as a far as money is concerned, they've got some weird ideas and
- 91 think everybody's out to take their money. Whereas in an institution, they are quite secure. Think people
- 92 are stealing things, following them.
- 93 L Yes
- 94 P She'd be very very fortunate to get the right person.
- 95 L Yes
- 96 P Because of the dedication.
- 97 L Yes, yes
- 98 P I know my father used to get up in the middle of the night and wander around and really didn't
- 99 know you. Very hard to deal with.
- 100 L Very, very distressing.
- 101 P Very distressing yes. He thought, who did he think I was, the woman who made the porridge.
- 102 *Laughs* Sometimes he thought he was in a hotel.
- 103 L Yes my dad did too at the end. He told me it was a very bad hotel. *Laughs*
- 104 P This is it.
- 105 L And then he was looking for his daughter.
- 106 P Yes. My parents had a hotel and I did work with them at one stage. And he said to me one night,
- 107 "you know we had a hotel" and I said "yes I know I worked for you", "did you?" No it's not an easy
- 108 situation. They really do need professional care. *Inaudible*.
- 109 L Yes

- 110 P And I don't mean strapped in a chair somewhere all day, or strapped into bed, to sit there and
111 just gaze at the windows or ceiling. Professional care and understanding.
- 112 L Yes
- 113 P *inaudible. Laughs.*
- 114 L I think that's the thing that started me interested.....and my research, and others who do similar
115 work. We feel that that people with the experience and knowledge should be consulted, it's not enough to
116 do a course at university.
- 117 P Oh no, it's technical knowledge and none of the experience.
- 118 L That's right and you can't enrol for experience.
- 119 P No. Personally I think that's what's wrong with nursing today. They go to university to get a
120 degree, but whereas I did a three or four year course in the hospital and starting at the bottom, I think they
121 come out far better qualified. But that's to do with....again that's my personal opinion.
- 122 L And I've certainly heard it said. And that's where trying to consult is important... Professional
123 care and understanding. So with understanding it's to do with, like not just strapped somewhere,
124 stored....
- 125 P No, realising what's happening to the person and that they can't help their reactions.
- 126 L Yes, that's right. Yes, exactly. Okay. Thank you. Any other comments on this situation. Some
127 of your own experience and perspective, that's what I'm after. As well as any other knowledge you have.
- 128 P No, as I say. Having seen this, and not only with my father, having lived in a retirement village
129 where people generally are old and *are* deteriorating. You can see what their needs are. And it's amazing
130 how quickly sometimes they do deteriorate. And some have husbands or wives that are with them and
131 try to look after them for a while, but they really *battle* to stay with them and look after them. But in the
132 end I think invariably they have to give in and realise that it's beyond them.
- 133 L Yes, yes. Thanks for that, some very helpful comments.

1 **Transcript REL008 (Relative of an elderly person).**

2 L= Linley

3 I = Interviewee

4 I Ok so what do you want from me?

5 L Your general thoughts on this type of situation? And I'll ask you some set questions after that.

6 I Well it's....I imagine a fairly common situation. It's got similarities to my mother-in-law. I
7 really don't know what else you want me to say about it. At the moment.

8 L That's okay. What do you think should happen? She's medically well now, she's recovered
9 from her fall and so on. She is ready to leave the hospital. What should happen?

10

11 I She obviously needs...

12 LNot the rights and wrongs, just what you think.

13 I She obviously can't live on her own. She needs care. She's now feeling better and going to be
14 able to walk with a frame. She's loosing her memory. So obviously things are going to get worse before
15 they get better. Well they probably won't get better. Things are going to deteriorate. Family or friends are
16 going to have to take action. Going to have to investigate what help is available and then investigate the
17 options and make a decision which is probably going to be hard for some and not so hard for others. Mrs
18 Smith's probably not going to have a lot of say in it. And I think it would be right that she wouldn't have
19 a lot say in it because she obviously is not going to look...she's probably not going to feel that it's in her
20 best interests whatever decision other people make. But she is going to have to be convinced that it is for
21 her own good and well being.

22 L Who should make the decisions?

23 I Her immediate family would have to do that. She got, she's as you say she lives alone, an only
24 son and a niece. Her only son would be the first one, would be the one who would have to make a
25 decision. And if he's not prepared to, then her niece. Who I presume is her next closest relative. If she's
26 not prepared to, then somebody, her a neighbour or somebody's going to have to take matters in their own
27 hands and go and see the proper authorities.

28 L What do you think are the arguments or the reasons for and against for her returning to her own
29 home? What's for and what's against?

30 I Well, if she's obviously, I think... it would be best for her to stay in familiar surroundings, I
31 know if it was *me* and I had to leave my familiar home and all the things and people that I love, I
32 probably would be devastated. So in an ideal world, ideally it would be nice and perfect if she could stay
33 in her own home. Or have somebody who lives, a live in carer. That's of course, it's usually not a very
34 practical solution because it costs money. I suppose with the number of people who need care there
35 wouldn't be enough carers to go around either.

36 L So it would be good for her to stay home because it's her familiar surroundings and the place she
37 loves.

38 I Well I think, particularly as you get older, you get more *attached*. If you were in your twenties
39 you haven't got the roots, but if you are an elderly person, you've lived in one place for a long time you
40 get very much attached to it. And you get used to familiar surroundings and it's you know.....and if you
41 have to go into unfamiliar surroundings, it's a bit (*inaudible*). When I left my home
42 country, I was a lot younger. But even when I left (home country) and came out to Australia, it was a hell
43 of a decision, it was very difficult for me to leave there, and about half way....the other side of the world,
44 a new country and new culture. I sometimes.....when I arrived here I was very, very homesick. My
45 wife caught me crying one minute. A couple of nights, missing so many things. I can relate. And as I
46 said, I was a lot younger then. And I can imagine just how devastating and depressing it would be to an
47 elderly person, to leave their own home. So you think about C's mother and she's got somebody who
48 loves her, people, family who love her and want to do the best thing for her and her husband B, and you
49 split them up, it's going to affect both of them badly. Even the fact that A's got Alzheimer's and she
50 forgets things, there are still things in here, in the mind, 'B's my husband'. The other day we had a
51 meeting here, I was the one sitting with her, and the fact that B was over here, only for an hour or so, she
52 was getting more and more agitated the longer he was away from her.

53 L Yes, C was saying about that.

54 I Yes, so it's... you just think... obviously it would be perfect if we could keep them both
55 together. But being a layman, and not being in the care industry, and never having to care for somebody

56 before, it's all new. The only other alternative that I can see is, and this would apply to Mrs Smith is that
57 she would have to go I think, into a home. Which is the way we are thinking with A. Ideally of course
58 with B nearby. But how our biggest concern at the moment is with B, because he's an old man, he's
59 finding it very very difficult to cope with her. He needs respite, he needs to get away. He needs time to
60 himself, to get away from her because she's just driving him crazy.

61

62 L 24 hours, you need a 36 hour day.

63 I Yes. I suppose in the case of Mrs Smith, she's a widow, she doesn't have a husband to have in
64 the calculations.

65 L In a way that makes it look (*inaudible*)

66 I Yes, it think it probably would. So I think she would have to have care obviously. With her
67 situation she wouldn't need.....she wouldn't need a lot of care initially. But she would just have to
68 have somewhere where an eye could be kept on her, she could be looked at, looked over. Because
69 obviously eventually she would become more dependent. Dependent on care.

70 L So for her at the moment one of the main reasons why going into care might be a good idea
71 because that way there would be someone keeping an eye on her safety or on her.

72 I Exactly yes. If she's left on her own in her own house. Even if you say, get her son or her niece
73 or whatever to pop in every day, that's only going to be for an hour or two. They're probably not going
74 to be able, they've got their own lives to lead.

75

76 L It's easy to say

77 I Yes. That's right. The niece is the closest one to her and she's probably got her own family,
78 although it doesn't say if she's got a family. (L: She does) She's got her own life to lead and she's only
79 going to be able to spend so much time with her aunt. So I think, (*tape stops and re-starts*)

80 *Long pause* family members are not going really be a lot of help. It's the same as our
81 case, we've got our own busy lives. C and I try to help as much as we can. But if you could say, C can
82 give up her job, her part-time job and go and look after her mother permanently. We couldn't afford that.

83 I don't think C could stand it.

- 84 L That's the other thing.
- 85 I Yes. A short time I was around with her yesterday. I was happy when it was over, when it was
86 finished. She was getting more and more agitated.
- 87 L It's too much.
- 88 I Kept asking me the same questions came over and over every five minutes. Where's B, why
89 didn't he tell me he was going. And you have to think of an answer and you have to keep it simple. I
90 keep saying he did tell you Mum and he was going out. Where's he gone then? Then you say He's gone
91 shopping with C. Why's he gone shopping for? Wasn't it your wedding anniversary the other day? Did
92 he get you a present? No. He's probably gone to buy you one! Over and over again the same
93 conversation. Same thing 5 minutes later. After a while, it starts to get wearing for me. You can't get
94 anxious, you have to try and keep calm and give calm answers otherwise she'll get more agitated. So
95 you've got to keep calm and keep the answer soft and short and simple. I could have juts put a tape-
96 recorder on and replayed the same conversation over and over again. After a while, as I said I was only
97 there for an hour, *inaudible* with her. I could *really* see what B has to put up with 24 hours a day seven
98 days a week. I'm 20 odd years younger than B, more to the point he was 20 odd years older than me,
99 having to put up with that. With his own problems. Mentally he's good, physically, he's got his knees
100 and other things that *inaudible*. His not a young fit healthy man. I can't ... our main concern is him.
101
- 102 L It sounds like what you are saying, it's too much for any one person, even two or three people.
- 103 I Yes. And let's face it we're not experts either. This is new to us and the rest of the family.
104 Whereas Mrs Smith or A. or whoever, goes into a proper home they'll have experts looking after her.
- 105 L People who are used to knowing how to.
- 106 I They know how to deal with it. They mostly know how. They are people who are not doing it
107 24 hours a day either.
- 108 L And it's not their Mum.
- 109 L Yes that's right. They have *respite* from it. They change shifts.
- 110 L They go home.

111 I Yes. Somebody else comes on duty and looks after them. People who can go home, can switch
112 off. The family member can't do that.

113 L No. It sounds like your father-in-law's done a fantastic job.

114 I Yes he has. It's time I think, to come to an end, that job for him. Let's face it, he hasn't got a
115 lot of years left. And we don't want to spend it in misery, or for it to be shortened unnecessarily, which it
116 could, it could drive him to the grave. So Mrs Smith and the relatives (?) all those cases are very similar.

117 L The last questions on Mrs Smith, and you may have answered this one. What would make a
118 difference on the way you think about what should happen? It's pretty clear as the situation is, what
119 should happen? What if anything would make a difference to that?

120 I To the end?

121 L Your decision on the overall view of what should happen here. It's all hypothetical. Do you
122 find yourself thinking, if only such and such, or *that's* a problem?

123 I Well, I don't want to sound callous but if she died that would solve everybody's problem
124 wouldn't it? But you wouldn't wish that on anybody. If anything could change a decision.....I suppose
125 if her condition didn't deteriorate any further, at this stage that she is in this hypothetical situation, from
126 what I gather from the nature of the Alzheimer's it's not like say a cancer that sometimes goes into
127 remission I don't think. I'm not an expert.

128 L No, I think you are right.

129 I And I think Alzheimer's a progressive disease and it gets worse and worse. I think to hope for a
130 halt to her deterioration would be asking too much. So you would have to assume her situation will
131 deteriorate. And I can't see that *any* circumstances, any other circumstances would change what her
132 decision would be.

133 L That's fine. Any other thoughts, any other comments on that situation. You've been very helpful
134 on what you've said, you've covered a lot of issues.

135 I No I can't think of anything else to add. I don't think so. So what's next..

1

1 **Transcript HP05 (health professional involved in discharge planning)**

2 L = Linley

3 P = Participant

4

5 P Right, what do you want me to do, just answer each question. Or....

6 L Yes

7 P First up

8 L Yes, whichever suits you, I'd make some general comments in this kind of situation.

9 P Sounds very familiar. What should happen and why? Thinking about the patient I've got at the
10 moment. Just because of the short term memories and deteriorating really for about six months. I'd
11 probably consider any Guardianship Board thing with the social worker there. But first before the
12 Guardianship Board we need **you** to do the Dementia screen, just to prove that they haven't got the
13 mental capacity to make those decisions. So I guess, who should decide and why. If it has been found
14 that she has a mental incapacity to make the decisions, because the health workers have to decide, to
15 provide duty of care, couldn't just send her home.

16 *Long pause.* I guess... and also, if she is reluctant to receive services as well, it makes it hard for
17 us to send her home. She wouldn't accept any support she obviously needs, just to be safe.

18 *Long pause.* I can only think of a thing **for** her going home, except for the whole thing
19 about...it's not really maintaining her independence, because the way she is at home, she's not really
20 independent, **safely**.

21 *Long pause.* I guess I think she shouldn't go home just because of her deteriorating mental state,
22 memory. And that she has been found lying on the floor after a collapse at home. And the neighbours
23 found her, so she obviously wasn't able to contact the ambulance, or get up off the floor, to get the phone.
24 And also, just her family support, so though they are there to see her once a night, or to help with
25 shopping, it's still not enough during the day and also overnight as well, would be of a concern for me.

26 *Long Pause.* There's not really enough supports for her to go home.

27 *Long Pause.* It's a dangerous home environment as well. What would make a difference...that
28 means?

29 L Sometimes there are ifs and buts, if this was the case, if that was the case, that would make a
30 difference. What do you think would make a difference in her case?

31 P I think the difference would be if she was willing to receive services at home and supports. And
32 I guess also able to fund the extensive repairs and things that are required. And also the family supports,
33 if they were increased. That would probably make a bit of difference.

34 *Long pause.* Also, I guess the main point there would be her deteriorating, short term memory
35 thing. If that wasn't a factor, it would probably make a difference.

36 L That's fine. *Inaudible.* I've been fortunate to be able to interview people here and elsewhere and
37 I've got a lot of different opinions. **In** on this one, and these are the points they make. Do you have some
38 general comments on this kind of situation and what the issues are? For a professional kind of situation?

39 P Well for me, I find it....because I am only quite new. I find it hard having to make that
40 decision. And then to actually decide, yes I think this should go the Guardianship Board, or...I don't like
41 having to hand someone's...is it handing over their power in a way. I find it quite difficult and I can see
42 if that's going to happen I think Oh...I don't want to have to do that. But then the social workers always
43 emphasise it is our duty of care, and we can't just send someone home because you don't want to take
44 away their independence and things.

45 L Yes, that's absolutely....for those of us, I think the things that concerns is trying to work out....

46 P Yes. It's not so bad when they are actually aware of it, and they know that they need to. When
47 they are not aware, and they think they are coping quite fine at home, and things. And get quite upset by
48 the fact that they might not go home.

49 L Yes. Yes I think it's tough. It's really hard. The fact that, you know, it really brings you up
50 against it in a lot of ways.

51 P Yes. I've found it hard just *inaudible*, first few weeks, I had quite a few guardianship things and
52 I thought Oh what is this. They didn't tell you about it before hand that this is what people always chose
53 to, and that if they didn't want to they didn't have to go.

54 L Yes, I was much the same way. I remember by first Guardianship case very clearly.

55 P At least I don't have to make the final decision regarding their mental capacity.

56 L Yes that's right. And certainly other people have said this too that, if the issue of the duty of
57 care and the independence.....

58 P That's right. We'd get in big trouble if you sent somebody home and then something happens.
59 The hospital wouldn't be.....*laughs* so thankful, I don't think. Especially with all this public liability and
60 things happening at the moment.

61 L Yes that's right. Thanks for that. That's very helpful. Very helpful comments. Have you ever
62 thought about the case in general, the options you would be weighing up, or the way you go about
63 weighing them up?

64 P Usually in these cases, I like to have a family meeting. I think that's what we usually do.
65 Sometimes it's been worthwhile having the patient there as well, sometimes it's not...depends. I like to
66 have them, I don't see why that they shouldn't be there. I think that they should be there, I don't think
67 things should be hidden from them just to protect them in a way. But I guess sometimes...if they haven't
68 come to me. I guess, really...I like to have a family meeting and then kind of go from there, get an idea
69 of what other family members feel. Although usually they agree with the health worker. I probably
70 wouldn't be really looking at nursing for them as of yet. But that would be the ACAT assessment
71 anyway.

72 L She might be more of a hostel person...

73 P I think so.. Well she's mobile with a frame. I would assume if she was mobile, she would be
74 independent or of little assistance in ADLs.

75 *Long pause*

76 L Thanks for that

Appendix O Information sheet and consent forms for interviews (font reduced)

**ROYAL ADELAIDE HOSPITAL
& THE UNIVERSITY OF ADELAIDE
PSYCHOLOGY DEPARTMENTS
Information Sheet**

Research Project: Elderly people's, their relatives' and staff attitudes to the residential placement of elderly people in hostels or nursing homes.

Investigators: Ms Linley Denson, Ms Maree Farley, Dr Robert Penhall & Dr Helen Winefield.

In this research project we are asking elderly people, their relatives, and staff members for their opinions and views about the residential placement of elderly people in nursing homes. It is hoped that the research project will help health professionals to better understand the issues involved in residential placement.

Participation in the study involves being interviewed on your views about residential placement for about one hour in an office at the RAH (or elsewhere if that is more convenient for you). You will be asked your opinion on the situation of a "hypothetical" elderly person described in a case study. It is not likely that this will cause you any distress. You will not be asked about your own or your relatives' situations.

Your interview will be audio-tape-recorded, to ensure accuracy. The interview tapes will be kept in a locked filing cabinet, and destroyed after the study is completed.

The project is supported by the Directors of the Royal Adelaide Hospital Internal Medicine Service, the Department of Geriatrics and Rehabilitation Medicine, and the Nursing and Patient Care Service. The research has been approved by the Research Ethics Committees of the Royal Adelaide Hospital and the University of Adelaide Psychology Department.

This is a voluntary research project and you do not have to be involved.

If you do not wish to participate, this will not affect your situation in any way.

You are free to withdraw from the study at any time if you wish to do so.

Any information you provide will remain strictly confidential.

In order to ensure staff and patient privacy, information may be collected in more than one health unit.

Your participation would be much appreciated.

If you have any questions about the study, please contact Ms Linley Denson (8222.4770, office hours, or pager 8273.2822, any time) or Dr Helen Winefield (8222.5153, office hours).

If you would like to discuss the study with someone not directly involved, please contact Dr Michael James, the Chairman of the RAH Research Ethics Committee (8222.4139, office hours) or Dr Eric Rump, the Chairman of the University of Adelaide Psychology Department Ethics Committee (8303.5737, office hours)

**ROYAL ADELAIDE HOSPITAL
& THE UNIVERSITY OF ADELAIDE
PSYCHOLOGY DEPARTMENTS**

Elderly person’s consent form

Research Project: Elderly people’s, their relatives’ and staff attitudes to residential placement of elderly people in hostels or nursing homes.

Investigators: Ms Linley Denson, Ms Marie Farley, Dr Robert Penhall & Dr Helen Winefield.

Participant’s Name:

1. I consent to participate in the above study. The nature and purpose of the study, including the interview procedure, has been explained to me and is summarised on the information sheet I have been given. I understand it and I agree to take part.

I authorise the investigator to use this interview procedure with me.

I understand that my interview will remain confidential, and it will not be discussed with my family members, other patients or hospital staff.

I understand that my interview will be tape-recorded, to ensure accuracy. The interview tapes will be kept in a locked filing cabinet, and destroyed after the study is completed.

I understand that:

(a) I will not benefit directly from taking part in the study.

The study is for the purposes of research only.

I can withdraw from the study at any time and this will not affect me or my treatment, now or in the future.

While the results of the research may be published and presented, I will not be identified. Any personal or identifying information will remain confidential.

(e) There are no known adverse effects of this interview procedure.

I have had the opportunity to discuss taking part in this study with a relative, a friend or a member of staff not involved with the study.

Signature of Participant: (date)

I have explained the study to the interviewee and I consider that the interviewee understands what is involved.

Signature of Investigator: (date)

**ROYAL ADELAIDE HOSPITAL
& THE UNIVERSITY OF ADELAIDE
PSYCHOLOGY DEPARTMENTS
Relative's Consent Form**

Research Project: Elderly people's, their relatives' and staff attitudes to residential placement of elderly people in hostels or nursing homes.

Investigators: Ms Linley Denson, Ms Marie Farley, Dr Robert Penhall & Dr Helen Winefield.

Participant's (Relative's)Name:

Relationship to Older Person

1. I consent to participate in the above study. The nature and purpose of the study, including the interview procedure, has been explained to me and is summarised on the information sheet I have been given. I understand it and I agree to take part. I authorise the investigator to use this interview procedure with me.

I understand that my interview will remain confidential, and it will not be discussed with the patient, other family members or hospital staff.

I understand that my interview will be tape-recorded, to ensure accuracy. The interview tapes will be kept in a locked filing cabinet, and destroyed after the study is completed.

I understand that:

(a) Neither my relative nor I will benefit directly from taking part in the study.

The study is for the purposes of research only.

I can withdraw from the study at any time and this will not affect my relative's treatment, now or in the future.

While the results of the research may be published or presented, neither my relative nor I will be identified. Any personal or identifying information will remain confidential.

(e) There are no known adverse effects of this interview procedure.

6. I have had the opportunity to discuss taking part in this study with a relative, a friend, or a member of staff not involved with the study.

Signature of Participant: (date)

I have explained the study to the interviewee and I consider that the interviewee understands what is involved.

Signature of Investigator: (date)

**ROYAL ADELAIDE HOSPITAL
& THE UNIVERSITY OF ADELAIDE
PSYCHOLOGY DEPARTMENTS
Health Professional's Consent Form**

Research Project: Elderly people's, their relatives' and staff attitudes to residential placement of elderly people in hostels or nursing homes.

Investigators: Ms Linley Denson, Ms Marie Farley, Dr Robert Penhall & Dr Helen Winefield.

Staff Member's Name:

Profession:

1. I consent to participate in the above study. The nature and purpose of the study, including the interview procedure, has been explained to me and is summarised on the information sheet I have been given. I understand it and I agree to take part.

I authorise the investigator to use this interview procedure with me.

I understand that my participation in the study and my interview will remain confidential, and they will not be discussed with patients or with other members of staff.

I understand that my interview will remain confidential, and it will not be discussed with the patient, other family members or hospital staff.

5 I understand that my interview will be tape-recorded, to ensure accuracy. The interview tapes will be kept in a locked filing cabinet, and destroyed after the study is completed.

6. I understand that:

(a) I will not benefit directly from taking part in the study.

(b) The study is for the purposes of research only.

(c) I can withdraw from the study at any time and this will not affect me in any way, now or in the future.

(d) While the results of the research may be published, I will not be identified.

Any personal or identifying information will remain confidential.

(e) There are no known adverse effects of this interview procedure.

7. I have had the opportunity to discuss taking part in this study with a relative, a friend, or a colleague not involved with the study.

Signature of Participant: (date)

I have explained the study to the interviewee and I consider that the interviewee understands what is involved.

Signature of Investigator: (date)

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