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Christine Toye
Edith Cowan University

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**Perceived Social Support of Family Members of Aged Care Facility Residents
and its Relationship with Family Members' Well-Being and their Support of
Relatives in Residential Care**

A thesis submitted in fulfilment of the requirements for the award of
Doctor of Philosophy (Nursing)
Faculty of Communications, Health and Science,
Edith Cowan University, Western Australia

Christine Toye, B Nursing (Hons)

March 2nd 2000

ABSTRACT

When elderly people are cared for in Aged Care Facilities (ACFs) it is known that their family members frequently suffer negative effects. These effects may be alleviated by social support and, because they feel better, family members may then offer more support to residents. In this study, the researcher tested a model with a sample of 213 family members of ACF residents. Predictive relationships were hypothesised among incentives for family members to support residents, stress related factors, the perceived formal and informal support of family members, their psychological well-being, and the support they offered to residents. The researcher also developed the Relatives' of Aged Care Residents Assessment of Staff Support Tool (RACRASST) to measure family members' perceptions of support from the staff.

The researcher developed the RACRASST from data obtained at interviews with family members of ACF residents and ACF staff, and from a review of the literature. The instrument underwent testing and refinement procedures, including a factor analysis. The test-retest reliability co-efficient for the scale was found to be 0.99 over 2-3 days. As used in the study, the RACRASST was a 29-item unidimensional scale. Response options ranged from Strongly Disagree to Strongly Agree. A not applicable option was retained to identify items needing review. Items referred to staff/family member communication, staff care activities, staff use of the environment, and family members' perceptions of a reliable alliance between themselves and the staff. The instrument was re-examined during the study and two items were deleted because of a high percentage of missing/not applicable responses. Cronbach's alpha co-efficient for the 27-item RACRASST was 0.96.

Findings of model testing confirmed hypothesised positive predictive relationships between residents' family members' well-being (the dependent variable) and both family members' perceptions of the residents' adjustment and the length of stay. Pressures related to the placement were confirmed as negatively predicting well-being in family members, and the degree to which family members felt attached to residents was confirmed as positively predicting their self-reported support of residents. The familial relationship between the family member and the resident was also confirmed as predicting family members' well-being. Support from ACF staff was not a significant predictor of family members' well-being, and well-being failed to predict family members' support for residents.

An empirical model was also developed. This model accounted for 47% of the variance in family members' well-being and 23% of the variance in family members' self-reported support for residents. Family members' perceptions of their informal support were found to account for 7% of the variance in support for residents and 5% of the variance in pressures experienced because of the placement. Pressures in family members negatively predicted their health and well-being, and being a residents' daughter was a positive predictor of pressures.

The main conclusion is that informal support is potentially highly beneficial to residents' family members. Accordingly, it is recommended that ACF staff facilitate supportive relationships among family members and residents. Further research to develop and test the RACRASST and to test the empirical model is also recommended.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;
- (ii) contain any material previously published or written by another person except where due reference is made in the text; or
- (iii) contain any defamatory material.

Signature

Date 23 October 2020

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The researcher wishes to acknowledge, with heartfelt thanks, the contribution to this research provided by a number of people and organisations.

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Secondly, supervision of the work was provided initially by Dr Richard Hugman and Dr Patricia Percival, and then by Professor Linda Kristjanson and Associate Professor Ed Helmes. The patience and carefully considered advice offered by my supervisors allowed me to negotiate the many steps of the project with the help that was needed.

Thirdly, advisers came to my assistance when requested. Professor Pender Pedler, Dr David Roberts, Clinical Nurse Specialist Sue Dicker, and the University's team of statistical advisers gave freely of their time and expertise, also offering much appreciated encouragement.

Fourthly, this project would not have come to fruition without the participation of the family members of Australia's aged care facility residents. These very special people were the inspiration for the work undertaken.

The final and greatest debt of gratitude is owed to my family. My husband has been a source of enormous support throughout the project, often taking over the household duties without complaint. Jennifer, Benjamin, Amy, and Kieran have all also contributed in their own ways, recognising that it was important to their mother to complete the project that so often kept her away from them.

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CHAPTER I

Introduction

Nurses caring for elderly residents in long term care settings are required to be both specialists in gerontological care and workers in settings that are unique, fitting neither the acute care model nor that of community care. The needs of elderly people must be met in surroundings that are shared with many others, but that are also their permanent homes.

In a person's home, there is an expectation that family members and friends will be welcome visitors. It is both desirable and likely, therefore, that nurses and other staff in Aged Care Facilities (ACFs), will have frequent contact with residents' "significant others". Relationships among the triad of residents, staff, and residents' family members were the main foci of the study documented here. This chapter outlines the background to the study and explains the purpose and significance of the work.

Background to the Study

The care of elderly people is becoming an issue of widespread concern. This is because the proportion of the population that is elderly, aged 65 years or older, is increasing in many countries, including those as diverse as China, Japan, Italy, Sweden, Australia, the United States of America (USA), and the United Kingdom (UK). Additionally, it is generally the proportion of the very old, aged 80 years or older, that is rising most quickly, whilst greater age in adults is associated with poorer health. Australian data illustrate these changes. Here, the annual rate of increase in the elderly population as a whole, from 1995 to 2005, is predicted to be 1.8%. This increase is expected to be 3.9% in the case of the very old. Additionally, data from 1993 show that 8.4% of women between 65 and 69 years of age and 6.2% of men in

the same age group had a severe or profound handicap. These percentages increased to 59.1% and 50.8% respectively in those aged 85 years and older (Australian Institute of Health and Welfare [AIHW] & Commonwealth Department of Health and Family Services [CDHFS], 1997).

Any increase in the proportion of the disabled elderly population means that a greater number of dependent elderly people rely upon proportionately fewer younger family members and friends for their care. Also, when this increase occurs in the very elderly, more of the caregivers are elderly themselves and more likely to be frail. Therefore, the need for professional care that is either residential or community based is increasing. The social acceptability and affordability of such care are issues meriting urgent consideration.

Professional care provided in a community setting is likely to be more socially acceptable than residential care since it addresses the maintenance of the family unit. The aim of this care is often to support and assist informal caregivers so they may continue in their caregiving roles without incurring adverse effects on their own health (Twigg, 1989). Additionally, informal caregivers who suffer financial privations, such as loss of income from paid employment, may sometimes be offered monetary assistance (Askham, 1998). Although the provision of professional care in the community is costly, it is frequently more financially viable than the provision of residential care. However, when the care recipient is very heavily dependent, and/or a home caregiver is absent or debilitated, the costs of providing adequate care in the community may become prohibitive. Residential care is essential, but frequently socially unacceptable. It may remove the infirm elderly from a home that is familiar and dear to them and separate family members who have lived together for many

years. Elderly people entering ACFs may feel abandoned or ostracised, and their family members may believe they have failed to fulfil their obligations (Braithwaite, 1990). The admission of an elderly person into an ACF may contribute to great distress within the family unit.

The distress that may be brought about by ACF placements is well documented. Although residents' family members are relieved of the necessity of performing caregiving tasks, they may experience feelings such as guilt and sadness or grief (Kellett, 1996; Matthiesen, 1989), anger (Rosenthal & Dawson, 1991), and uncertainty or confusion (Dellasega & Mastrian, 1995; Johnson, Morton, & Knox, 1992). At the same time, residents need to undergo an adjustment process so profound that it has been called a "status passage" (Chenitz, 1986, p. 215), a process that may not be finite (Brooke, 1989).

Social support theory indicates mechanisms by which the distress suffered by ACF residents and their family members may be alleviated. This theory proposes that the adverse effects of stress may be relieved by social support, the support people have from others (Cohen & Wills, 1985). It follows, therefore, that residents' family members who are supported may suffer fewer adverse effects from an ACF placement than those who lack support. Additionally, when family members are less distressed and, consequently, more able to support their loved ones in the ACFs, residents, too, should find the placement less traumatic.

Within the ACF, the main opportunities for supportive exchanges occur in interactions among staff, residents, and residents' family members. However, supportive interactions outside the ACF are also relevant, mainly to residents' family members.

The study reported here involved the development and testing of a model of family-resident support that was anchored in some of the tenets of social support theory. These tenets are detailed in the next chapter of the thesis, and relevant definitions are to be found in Appendix A. The model proposed relationships among (a) the perceived formal support of residents' family members (from ACF staff); (b) their perceived informal support (from family and friends); (c) contextual variables relating to the placement, as identified from the literature; (d) family members' psychological well-being; and (e) the support these family members report providing to their institutionalised relatives. This model suggested that the perceived support of family members might influence family members' well-being, and, via well-being, predict family members' support of their relatives in the ACFs. Well-being was viewed as likely to be related to the ability to offer support because it is a concept that embraces energy levels and perceptions of health (Dupuy, cited in McDowell & Newell, 1996). Contextual variables were seen as influencing family members' support of their institutionalised relatives directly and/or via family members' well-being. The model is illustrated and described in more detail at the conclusion of the literature review.

To test the model, the researcher developed and refined an instrument to measure family members' perceived support from the staff. The psychometric properties of this scale were also tested. The researcher measured perceived support from the staff as a separate entity, not as part of one incorporating informal support, so that a specific knowledge base for those working in ACFs might become accessible. A new instrument was developed because an extensive review of the literature discovered no existing instrument specific to this construct. Data used to develop the instrument were collected in a qualitative investigation of family members' perceptions of their

support from ACF staff. Family members' input continued during refinement and testing procedures.

The researcher selected an existing instrument to measure family members' perceptions of the support they provided to residents. It would have been preferable to measure ACF *residents'* perceptions of the support received from their family members because perceptions of received support have most often been associated with decreases in the adverse effects of stress (Cohen, 1992; Turner, 1992). However, a high degree of cognitive and communicative disability is often seen in the population of ACF residents so the selected instrument was used as a proxy.

In summary, there exists a widespread problem of an aging population needing care from an increasingly smaller proportion of younger, fitter people. This problem requires socially acceptable and economically viable solutions. Residential care for the disabled elderly, sometimes the only economically viable solution, may be more or less socially acceptable depending upon the effectiveness of the potentially supportive relationships that exist. Social support theory suggests that the perceived support of residents' family members will be a predictor of their well-being. In turn, family members' well-being may be related to family members' support for their relatives in the ACFs. These possible relationships were examined in the study using a model testing approach. Given the lack of appropriate assessment tools, the researcher developed an instrument to measure family members' perceptions of their support from the staff prior to this investigation.

Purposes of the Study

This study was conducted for two main purposes:

1. The methodological purpose was to develop and test an instrument to measure the perceived social support of family members of residents in Aged Care Facilities from the staff.
2. The clinical and theoretical purpose was to test a model of family-resident support. This model purported to predict Aged Care Facility residents' family members' self-reported resident support from family members' perceived support, and from contextual variables. These predictive relationships were postulated to be mainly indirect, occurring via family member well-being. However, direct predictive relationships, not mediated by family members' well-being, between some variables and family members' support for residents, were also suggested by the model.

Significance of the Study

The study was conducted against a backdrop of widespread concern about the future of elderly people in countries with aging populations. Study findings have significance for government and ACF policies, for nursing practice and research, and for the practice and research of members of other disciplines.

Governments may be responsible for health care funding, and/or for the guidelines under which ACFs operate. To be aware of possible outcomes of exercising these responsibilities in particular ways, they require information about the degree to which ACF staff can influence the well-being of family members and the degree to which

these family members support residents. For example, government provision of funding and/or guidelines to encourage staff support of residents' relatives might ensure a diminished demand for health care from relatives and improved support for residents. Findings of this study give preliminary indications about the extent to which this is true.

In the ACFs, decisions need to be made about the foci of staff education and practice within the funding constraints that exist. The findings of this study provide information about staff behaviours that are perceived as supportive by family members and any benefits that might flow from these. Results also offer information about how staff support should be channelled to particular groups of family members who may require more or less support.

Findings of this study are also highly significant to nursing practice and research. Nurses working in ACFs have frequent contact with visiting family members and have many opportunities to help them. Nurses also supervise other staff with similar opportunities. They are committed to providing high quality care to residents, and caring for the family unit has long been in keeping with the philosophical stance of the nursing profession (Gillis, 1989). Although nurses might sympathise with family members and attempt to help them, there was no way of measuring whether or not their initiatives were perceived as supportive prior to this study. Findings from the study provide empirical information about nurses' family member support practices. Additionally, the study has produced an Instrument with respectable psychometric properties that may be useful in subsequent research. Recommendations for future nursing research are also provided.

Finally, members of other disciplines working in ACFs may also benefit from this study. For example, social workers, psychologists, and medical practitioners working in the area may choose to use the new instrument to assess changes, brought about by their initiatives, in perceived support in family members.

CHAPTER II

Review of the Literature and Conceptual Framework

Introduction

This chapter examines literature related to the need for support of ACF residents and their family members, and to some of the salient supportive relationships that exist. Six major themes emerged from this literature: (a) the impact of a residential care arrangement on the psychological well-being of residents and their family members, (b) social support theory as it relates to that impact, (c) the support directed towards residents' family members by ACF staff, (d) the support directed towards residents' family members by their families and friends, (e) the support directed towards ACF residents by their family members, and (f) contextual factors surrounding the placement that have been found to influence the well-being or support status of residents or their family members. This literature provides theoretical and empirical rationale for the model underpinning the study. The chapter concludes with a discussion of the model.

Residential Care for the Elderly and the Psychological Well-Being of Residents and their Family Members

Because the term "psychological well-being" is used in diverse ways in an immense body of literature, the reviewer initially conducted an examination of examples of this literature to decide upon a definition of the term for this study. Following this, documented studies were examined that assessed the impact on residents' psychological well-being of life in an ACF, and the impact on family members' psychological well-being of having a relative living in an ACF.

The Definition of Psychological Well-Being

In the literature concerning psychological well-being, the reviewer discovered no consistent definition of the construct. Disagreement amongst authors primarily related to the breadth of definition.

Langford, Bowsher, Maloney, and Lillis (1997) discussed an exceptionally broad view of psychological well-being. These authors, reviewing 85 articles to analyse the concept of social support, found well-being to be one of the positive health states defined as a consequence of social support. However, they went on to note an hypothesis, developed by Langford and Bowsher (as cited in Langford et al.), stating that social support increases psychological well-being by increasing control. According to Langford and associates, if the hypothesis is supported by future research, psychological well-being may be shown to be the overall outcome of social support. The many previously identified outcomes, including depression, anxiety, self-esteem, positive affect, personal competence, health maintenance behaviours, and a sense of stability, would all then be viewed as components of well-being.

Many researchers, however, take a much narrower view of psychological well-being. This view suggests that the construct relates only to the degree of negative symptoms or feelings experienced, or only to the degree of positive symptoms or feelings experienced. Illustrating the former point, Cox, Thirlaway, Gotts, and Cox (1983) tentatively interpreted a model of well-being as including two (negative) factors. One was based on symptoms of fatigue, emotional fragility, and confusion; the other was based on symptoms of tension, agitation, and anxiety. Findings of a study describing the construction of the Mental Health Inventory illustrate the latter point. These findings indicated psychological well-being included only general positive affect and

emotional ties. Mental health was described as the broader, "umbrella" construct that incorporated a negative component, psychological distress, and a positive component, psychological well-being (Veit & Ware, 1983).

Finally, some researchers conceptualise psychological well-being as a balance between positive and negative symptoms or feelings (McDowell & Newell, 1996), although not defining it as the overall outcome of social support. Symptoms/feelings include, for example, vitality, energy, anxiety, and depression. This is the conceptualisation adhered to in this thesis. The investigator considered it essential to include both positive and negative dimensions of the construct to allow for adequate exploration of relationships between variables. However, the broader conceptualisation, suggested by Langford and associates (1997), was speculative, and it may prove difficult to measure in a single study without overburdening participants.

The Impact on Residents' Well-Being of Living in Aged Care Facilities

Three qualitative studies have helped define the experience of entering and adjusting to life in an ACF. Brooke (1989) conducted out a longitudinal participant/observer study with 42 subjects, Chenitz (1986) used the grounded theory method with a sample of 30 participants, and Porter and Clinton (1992) asked open-ended questions of 243 people.

Findings of these three studies complement each other. Brooke (1989) identified four phases in post-ACF-admission adjustment: disorganisation, reorganisation, relationship building, and stabilisation. She found 39 people in her sample progressed through these phases within 8 months, although others remained in "disorganisation". The latter group of residents reported feeling displaced, vulnerable, and abandoned.

Chenitz's (1986) findings help to explain why some people fail to adjust. She selected her sample from people admitted between 6 and 9 months before the study. This author discovered that, although all new residents experienced stress, acceptance of the placement was dependent upon the admission process and residents' coping abilities.

Finally, Porter and Clinton (1992) identified ways in which residents of at least 6 months were adjusting. These authors discovered that keeping quiet, obeying, and confronting change were adjustment approaches. Those confronting change were found to experience emotions ranging from depression to happiness, and to endure fear and feeling trapped. Porter and Clinton also identified two adjustment influences. These influences were circumstances associated with the transfer and the degree to which admission was seen as the only option. This finding tends to confirm Chenitz's (1986) findings that the admission process influences adjustment. Porter and Clinton also identified residents' life histories and social resources as relevant to adjustment.

The Impact of an Aged Care Facility Placement on Residents' Family Members

Salient literature referring to the impact on the well-being of residents' family members of having a relative in an ACF was categorised into two types: studies that used a (mainly) qualitative methodology (see Table 1), and those that used a (mainly) quantitative methodology (see Table 2). These studies are reviewed in that order.

Table 1**Studies Discovering Feelings of Family Members of Aged Care Facility Residents (mainly qualitative methodology)**

Author	Date	Methodology	Relevant Findings	Limitations
Matthiesen	1989	Grounded theory. Interviews with 32 daughters. USA.	A lack of knowledge about the situation. Unresolved guilt and grief.	<ul style="list-style-type: none"> • Only daughters.
Johnson	1990	Case study. USA. Interviews with 16 daughters. Seven nursing homes. Each daughter interviewed 3 times during 60-70 days after admission.	The decision to institutionalise out of respondents' control. Facing dilemmas, such as trying to keep all the family happy.	<ul style="list-style-type: none"> • Only daughters.
Wiener & Kayser-Jones	1990	Grounded theory, observational, and survey. Part of a 3-year study in 3 nursing homes. At least 100 interviews with family members. USA.	Family member grievances: poor nursing care, poor food and inadequate feeding arrangements, property losses, depressing environment, poor communication with staff, a lack of knowledge about how the system operated, financial suffering, a lack of alternatives.	<ul style="list-style-type: none"> • Data reported only from two private nursing homes.
Kaplan & Ade-Ridder	1991	Case study. Three women with husbands in one nursing home. USA.	Changes experienced since admission: expressions of love and physical affection, support systems, activities, needs, expectations. Feelings: sadness, loneliness, frustration, relief, comfort, depression, burden, the spouse no longer a husband.	<ul style="list-style-type: none"> • Only wives. • A single setting.

Author	Date	Methodology	Relevant Findings	Limitations
Rosenthal, & Dawson	1991	Five interviews with each of 69 wives of patients in an extended care department. During 18 months after admission. Article reports on early findings. Canada.	In the first few weeks after admission: poor health, low morale, and high levels of depression. Relief, guilt, anger, sadness, resentment, and loneliness.	<ul style="list-style-type: none"> • Only wives. • A single setting. • Results only from early months after admission.
Johnson et al.	1992	Twenty-two family members of 10 residents in four nursing homes interviewed three times over 6 post-admission months. Content analysis. USA.	Two categories of perceptions: Uncertainties, as to resident progress, the health care system, and the resident's current status. Conflicts, between family values and the existing situation, the goals of the institution and those of the family, the needs of other family members and of the resident.	None noted.
Wells	1993	Grounded theory. Canada. Interviews with 10 spouses of residents in one ACF.	A need to divide thoughts, energies, and presences between life in the ACF and life outside it.	<ul style="list-style-type: none"> • Only spouses. • A single setting.
Bartlett	1994	Semi-structured questionnaire administered to 24 residents' wives at interview. Depression scale too. Four facilities. USA.	Role ambiguity, finality, sense of freedom, relief of burden, financial concerns, loss of reciprocity in marriage, loss of other relationships, coping with new responsibilities, depression. Effective copers developed interests outside the facility. Poor copers visited daily, over 50% had health problems. Religion practiced by 16 wives - a coping strategy.	<ul style="list-style-type: none"> • Wives only.
Fleming	1994	Grounded theory. Eight carers. Preliminary findings. Australia.	All maintained significant contact. Experiencing sadness, lacking support from health professionals, attributing special meaning to caregiving activities. Role changes.	<ul style="list-style-type: none"> • Only preliminary findings.

Author	Date	Methodology	Relevant Findings	Limitations
Tilse	1994	Interviews with 18 people with partners in 6 ACFs. Interviews with 72 staff, direct observations, and examination of information given to families. Australia.	Placement brought about loneliness, sadness, and financial worry. Placement changed perceptions of identity and security, and made partners feel they had failed in obligations. Visits met some needs.	<ul style="list-style-type: none"> Partners only.
Dellasega & Mastrian	1995	Interviews with 7 relatives. Placements in two ACFs up to 6 weeks before. USA.	Relief, emotional turmoil, ambivalence, uncertainty about the placement, a wish to redefine roles.	<ul style="list-style-type: none"> Contextual factors not investigated (Weinert, 1995).
Bonnel	1996	Case study. USA. A 79 year old man with a wife in a nursing home interviewed three times.	Sadness, guilt, frustration. Lack of positive affirmation from staff. A wish to talk about issues such as the death that was to occur, but nothing to contribute to case conferences. A need to withdraw, but a wish for permission to do this.	<ul style="list-style-type: none"> Single setting. Husband only.
Kellett	1996	Phenomenological. Eight family caregivers of residents in Australian ACF interviewed and observed.	Guilt, sadness, loss, self-doubt, anxiety. Experiencing role loss, being out of control, not being heard. A need to adjust, use expertise in loved ones' care, maintain relationships with residents.	<ul style="list-style-type: none"> Single setting.
Nay	1996 and 1997	Phenomenological. Interviews with 19 relatives. Australia.	Guilt, anger, sadness, frustration and confusion. "Feeling central to care, and, feeling marginalised" (p. 25). Coping tactics: developing outside interests, staying away.	None noted.

Qualitative studies. Many researchers have used a (mainly) qualitative methodology to investigate how family members react to the institutionalisation of a loved one. Studies have most often been conducted in North America. In keeping with the fact that the generalisability of findings is not usually an aim of qualitative research (Patton, 1990), researchers have tended to use small samples from one, two, or three settings, including particular types of family members (e.g. adult children or spouses). However, the reviewer found a tendency in these published studies for only limited details to be provided about the sample, setting, and/or methodology, making judgements about the applicability of findings outside of the study setting problematic. Nevertheless, the cumulative and consistent findings of the studies warrant attention. Findings common to a variety of family members are noted in the following paragraphs. Feelings/experiences only reported by particular types of family members (e.g. spouses) are discussed in the section of the review that concerns contextual factors.

Family members of ACF residents included in qualitative studies have reported two main, positive impacts on their well-being following the placements. These impacts include the feelings of relief and/or freedom reported by wives participating in two studies (Bartlett, 1994; Kaplan & Ade-Ridder, 1991) and by a variety of family members participating in a third study (Dellasega & Mastrian, 1995). They also include a belief that family members remain central to care, as reported by members of a sample of diverse family members (Nay, 1996, 1997). However, evidence of negative impacts is overwhelming and far outweighs the published benefits.

Firstly, there is a great deal of evidence that guilt and sadness or grief are experienced by ACF residents' family members. This evidence has been found in samples of diverse

family members (Kellett, 1996; Nay, 1996, 1997), wives (Rosenthal & Dawson, 1991), daughters (Matthiesen, 1989), and a single husband (Bonnel, 1996). Additionally, residents' partners (Tilse, 1994), wives (Kaplan & Ade-Ridder, 1991), and carers (Fleming, 1994) have reported feelings of sadness, but not of guilt.

The list of negative impacts on family members' well-being of the ACF placement of a loved one is further augmented by reports of feelings of frustration in spouses (Bonnel, 1996; Kaplan & Ade-Ridder, 1991) and in a more diverse sample of family members (Nay, 1996, 1997). Additionally, feelings of conflict engendered by discrepancies between placement situations and family members' expectations have been reported by a variety of family members (Johnson et al., 1992), including daughters (Johnson, 1990). Furthermore, in at least one study, participants reported that there were no alternatives to the unsatisfactory situation (Wiener & Kayser-Jones, 1990).

Finally, family members of ACF residents may also experience uncertainty and confusion (Dellasega & Mastrian, 1995; Johnson et al., 1992; Nay, 1996, 1997). Feelings such as these may arise from a lack of knowledge about the system. This lack was reported by daughters in Matthiesen's (1989) study and confirmed in a large, longitudinal study of family members (Wiener & Kayser-Jones, 1990). Feelings of uncertainty and confusion may also be related to problems associated with role change, strain, and ambiguity reported in numerous studies (Bartlett, 1994; Dellasega & Mastrian; Fleming, 1994; Kaplan & Ade-Ridder, 1991; Kellett, 1996; Nay; Tilse, 1994; Wells, 1993).

Table 2

Studies Discovering Feelings of Family Members of Aged Care Facility Residents (mainly quantitative methodology)

Author	Date	Methodology	Instrumentation	Relevant Findings	Limitations
Townsend	1990	Two longitudinal panel surveys. Over 5 years, 538 families followed, each including an elderly person. Impact on the family of the 81 admissions into ACFs reported. USA.	Details of instrumentation not included.	Relatives reported distress, guilt, relief. Physical/temporal well-being maintained or improved. Perceptions of quality of care related to satisfaction with the care arrangement and to guilt. Spouses reported greater emotional upset, less positive affect, poorer mental health, more depression. Dimensions of stressors in adult children: resident's mental state and adjustment; respondent's adjustment, other obligations, and perceptions of the institution; facility's proximity; family strain; family visiting patterns.	<ul style="list-style-type: none"> • Details of instrumentation undocumented.
Harper & Lund	1992	Sample: 482 caregivers of dementia sufferers. Three groups: Nursing home group - 91. Examination of 18 variables using multiple regression. USA.	Life satisfaction scale - LSI-Z (Wood et al., 1969). Established properties. Burden Index (Zarit et al., 1980). Established properties. Informal support: number of people; ease, frequency of contact; perceived satisfaction with support.	Nursing home group: high guilt scores. Much time visiting. Predictors of burden - wives: 25% explained by social support. Degree/type of dementia and life satisfaction also implicated. Husbands: hours spent caring, degree/type of dementia - 68%. Daughters: social support, degree/type of dementia, length of time caregiving - 51%.	<ul style="list-style-type: none"> • Sons too small a group to examine. • Small sub-groups overall.

Author	Date	Methodology	Instrumentation	Relevant Findings	Limitations
Zarit & Whitlatch also Aneshensel et al.	1992 and 1993 1995	Longitudinal survey of caregivers of demented relatives. At Time 1: 555 people. Comparisons made over time and between those who placed their relatives and those who did not. Post-placement interviews with 185 people. USA.	Measures: (Pearlin et al., 1990). Previously tested for caregiver use (alpha 0.73 - 0.86). 1. Primary caregiving effects: overload, tension, feeling trapped. 2. Role evaluation: loss of self, caregiving competence, personal gain. 3. Well-being: affect, depression, anxiety, anger.	About 50% of those placing a relative had high levels of mental health problems. Factors the same in both groups: loss of intimate exchange; financial, family, and work strain; feelings of competency, personal gains, and loss of self; self-efficacy; and depression. Role overload, role captivity, anxiety, and anger less in those who had institutionalised the care recipient, but guilt increased.	<ul style="list-style-type: none"> • Sample: those who had pre-placement involvement with demented relatives. • Too few sons included for their data to be meaningfully analysed.
Grau et al.	1993	Survey of 422 family caregivers of residents in two nursing homes. USA.	Demoralisation: adaptation of a scale examining anxiety, self-esteem, hopelessness/ helplessness, sadness (Link & Dohrenwend, 1980). Perceptions of caregiving burden: Items of Burden Interview (Zarit et al., 1980).	Spouses the most demoralised, then daughters, lastly, sons. Similar pattern of guilt, worry, caregiver burden. Spouses had poorest health. Ill health, guilt, worry, burden and lack of social support were significant predictors of demoralisation.	<ul style="list-style-type: none"> • Some small sub-groups. • Sample 49% Jewish.

Quantitative studies. There are large numbers of quantitative studies in which the impact on a family member's well-being of the ACF placement of a relative has been assessed. Many of these studies were also conducted in North America (see Table 2). Generalisability of findings varies widely across the studies; therefore, this review has concentrated on studies using large samples.

Findings of the study documented by Townsend (1990) are generalisable to the wider population of ACF residents' family members. The researcher used a longitudinal design over 5 years, involving panel surveys with a sample of 538 families. Family members of the 81 elderly people institutionalised during that time reported distress, guilt, and/or relief; although their physical and temporal well-being remained the same or increased. Family members' perceptions of the quality of care were related to their satisfaction with care, and, inversely, to guilt. Details of instrumentation were not reported.

Grau, Teresi, and Chandler (1993) selected 422 family caregivers of residents of two nursing homes to discover predictors of demoralisation in residents' family members after the placement. Ill health, guilt, worry, and burden were all found to play a part. These authors utilised a cross sectional methodology. Almost half the sample reported their religious affiliation to be Jewish, a factor that lessened the generalisability of findings. However, the use of a large sample and validated instruments produced useful data.

Authors of quantitative studies in ACFs that include only family members whose relatives have AD tend to use comparative designs. Comparisons are made between pre and post-placement status in a single sample, or between community and

institutional caregiver status in two sub-samples. The study examined here (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Zarit & Whitlatch, 1992, 1993) included both types of comparisons. Using previously tested instruments with acceptable reported reliability estimates, the researchers followed an initial sample of 555 community caregivers over 3 years. During the study, 243 people each institutionalised a relative. The researchers identified similarities in experiences between community and institutional caregivers. These similarities were in the areas of the loss of intimate exchange; financial, family, and work strain; feelings of competency, personal gain, and loss of self; and levels of self-efficacy and depression. However, those who institutionalised the care recipient reported lower levels of role overload, role captivity, anxiety, and anger than the community caregivers, and higher levels of guilt. Approximately 50% of those whose relatives had been placed in ACFs reported high levels of mental health problems. Within the year following placement, a positive impact on emotional well-being was found to be more frequent as time went by. A positive impact on emotional well-being was also found to be more likely in those whose feelings of role captivity and role overload were reduced by the placement, and less likely in those who reported increased mastery after the placement. After the first year of residential care, those at risk of poor adjustment included family members who were providing high levels of physical care to their loved ones and those who were experiencing a loss of their sense of identity.

Finally, Harper and Lund (1990) examined data collected from 34 wives, 32 daughters, and 25 husbands of nursing home residents. Although the study was limited by small sub-group sizes, reputable instruments were used. Harper and Lund found participants in all sub-groups to experience high levels of guilt and spend a great deal of time

visiting. A predictor of burden in caregivers common to each of the three sub-groups was the degree of disability produced by the dementing process.

Section Summary (Well-Being in Residents and Family Members)

In summary, literature related to the construct of well-being reveals disparate views of the construct. In this study, psychological well-being is viewed as a balance between positive feelings/symptoms and negative feelings/symptoms.

Researchers have found that new ACF residents tend to go through a period of readjustment after the stressful time of relocation, but, for some, negative well-being is long term. Residents' coping abilities, life histories, circumstances surrounding the placement, and social resources have all been related to their readjustment. Since residents' social resources are likely to include their family members, family members' support is likely to influence residents' adjustment to life in an ACF.

In the case of residents' family members, feelings of relief, freedom, and being central to care have all been reported in qualitative studies. However, negative impacts on family members' well-being have been found to include experiencing guilt, sadness, grief, conflict, frustration, uncertainty, confusion, a lack of knowledge about the system, and a lack of known alternatives. Role changes, strain, and ambiguity are also documented as occurring in these family members.

Findings of quantitative studies tend to confirm that family members of those in ACFs experience a number of negative feelings as well as some that are positive. In the case of those with institutionalised relatives with AD, negative effects of caregiving appear to be altered by an ACF placement, but not necessarily diminished. Over the first year

after the placement, a positive impact has been shown to become more likely, but the degree of dementia-related disability is also known to be relevant.

Although social resources and/or social support have not been specifically identified as helping family members in the studies reviewed here, some formal support needs have been identified by omission, for example, a need for information about the system.

Social Support and the Negative Effects of Psychological Stress

Psychological stress, as defined by Lazarus and Folkman (1984), is a "relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her [positive] well-being" (p. 21). When elderly people have to live in an ACF, their positive well-being, and that of their family members, is known to be at risk (see the previous section). Residents and their loved ones commonly experience psychological stress.

Many authors have examined relationships between psychological stress and social support. Stewart (1993) defines social support as "interactions with family members, friends, peers, and health care providers that communicate information, esteem, aid, and reliable alliance" (p. 7). In this section of the thesis, the reviewer examines the most relevant literature concerning possible benefits of social support for those experiencing psychological stress, especially those in ACFs.

More than a decade ago, Cohen and Wills (1985) summarised the benefits of social support to health (citing authors such as Caplan, 1974; Cobb, 1976; Gottlieb, 1981). They reviewed studies of informal support (that received from relatives, friends, and peers) to determine whether these benefits occurred because social support protects

(buffers) people from the negative effects of stress, or because social support is beneficial in all circumstances (the main effect). When the social support available was specific to needs felt because of stressful events, the authors found there was evidence of a buffering effect. When social support was measured as integration into society, they found there was evidence of a main effect. Additionally, when Kessler and McLeod (1985) reviewed 23 surveys considering support in relation to stressful experiences, they found strong evidence of a buffering effect.

Barrera (1986) further explicated relationships between social support and stress. He identified the key dimensions of (a) social embeddedness, the connections that people have to their significant others; (b) perceived social support, the "cognitive appraisal of being reliably connected to others" (p. 416); and (c) enacted support, the actions performed to help another person. He also established that enacted support was positively linked to stressful events, and to distress, and that perceived support was negatively correlated with stress and distress.

The buffering effect of social support on the negative effects of stress is a tenet of social support theory. Discussion continues about whether this buffering effect occurs because social support affects stress appraisal (Cohen, 1992), or because it forms part of the coping process (Folkman et al., 1991). However, there is now consensus that perceived social support, not social embeddedness or the receipt of enacted support, is the support variable of interest in the buffering effect. This is because perceived support takes into consideration the costs of social support (Turner, 1992).

Costs of social support occur either because support is expected to be reciprocated, or because stress results from the context of the relationship within which support is

provided or the way in which the exchange takes place (Tilden & Galyen, 1987).

Tilden's (1985) proposition, that the reciprocity associated with formal (professional) support is likely to be different to the reciprocity associated with informal support, is highly relevant to the current study. Money or professional status is seen as likely to be the main recompense for formal support. Informal support may be reciprocated in a variety of ways.

In a recent update, Langford and associates (1997) reviewed 85 articles and summarised existing empirical knowledge about social support and stress. They compiled a list of known antecedents of social support: social network, social embeddedness, and social climate. They also noted the continued relevance of four long-standing, attributes of social support: informational, emotional, instrumental, and appraisal support (citing Barrera, 1986; House, 1981; Tilden & Weinert, 1987).

Informational support is defined as information provided by another person during a stressful period. Emotional support is hypothesised to be related to caring, valuing, and trusting. Instrumental support is tangible aid, and appraisal support is support providing the information needed for self-appraisal.

Social support is relevant to nursing practice (Stewart, 1993). Reviewing existing evidence, Stewart calls for improved measures of social support and conceptual clarity. She urges nurses to explicate relationships among stress, coping, support, and health; to clarify the negative features of relationships and interactions; and to conduct cost-benefit analyses when interventions are evaluated.

Stewart (1993) also laments the lack of social support instruments nurses have developed that have demonstrated satisfactory reliability and validity estimates. She

cites only three adequate scales: the Interpersonal Relationship Inventory (IRI) (Tilden, Nelson, & May, 1990), the Personal Resources Questionnaire (PRQ) (Brandt & Weiner, 1981), and the Norbeck Social Support Questionnaire (NSSQ) (Norbeck, Lindsey, & Carrieri, 1981). Langford and associates (1997) also review these scales, describing them as all measuring emotional, instrumental, and appraisal support. However, the reviewers note, only the IRI indexes informational support.

As yet, few authors have examined stress/social support relationships, per se, in the population of family members of those in ACFs, or in community caregivers of the aged. Two North American studies are particularly relevant. In the first, Neary (1993) utilised a sample of 168 family members of nursing home residents. This researcher discovered that perceived satisfaction with social support had a main effect on depression, as did having children aged younger than 17 years. In the second, Bass, Tausig, and Noelker (1988) tested an interactive buffering hypothesis in 87 community caregivers of the elderly. These authors found that greater instrumental support (tangible help) interacted with cognitive impairment in care recipients to buffer the negative effects of caregiving in family members.

Section Summary (Social Support and the Negative Effects of Stress)

Many authors have examined the complexity of relationships between stress and social support. Evidence exists that perceived social support is a potential buffer of the negative effects of stress. This may be because social support aids coping in stressful situations or because it influences stress appraisal. Evidence also exists that social integration into society can be beneficial at all times. Nurses have been urged to add to the body of knowledge in this area, but have been cautioned to exercise conceptual clarity and to use valid and reliable instrumentation. There has been little investigation

of relationships between social support and the negative effects of psychological stress within ACFs, but it seems likely social support could buffer the negative effects of an ACF placement in both the residents and the family members.

Staff Support Directed at Aged Care Facility Residents' Family Members

Literature reviewed first in this section addresses the theoretical and empirical rationale for ACF staff support for the family members of residents. Reference is then made to studies that have identified needs for specific kinds of family member support from staff. Finally, the reviewer examines studies formally evaluating staff support strategies aimed at family members.

The Rationale for Staff Support for Residents' Family Members

There is a growing body of literature in the area of family nursing that documents the importance of considering the care of an individual from a family perspective (e.g. Friedman, 1992; Leavitt, 1982). The rationale for family nursing is based in both theory and research, as discussed below.

Family nursing has its origins in family systems theory, the history of which was examined by Broderick (1993). This author explained that open, living systems were first differentiated from closed, mechanical systems by Bertalanffy; that social systems were then differentiated from biological systems by Buckley; and that other theorists, including Kantor and Lehr, went on to examine the unique qualities of the family system. This literature provides theoretical support for the notion that a change in one family member sends reverberations throughout the family unit. More recently, Robinson (1995) has noted four ways in which family systems theory may be interpreted when used in nursing: in the first, the client is the individual, viewed as a

member of a family; in the second, clients are two or more people within the context of the family; in the third, the whole family unit is the focus of care; and, in the fourth, the individual is considered simultaneously with the family.

Authors have also documented examples of family nursing. In one such example, Kupferschmid, Briones, Dawson, and Drongowski (1991) provided a case study analysis of staff support for family members of a patient in a critical care setting. Staff were mobilised to support family members by observing how the critical illness of the patient affected those other members. They supported the patient's wife while she stayed by the bedside and participated in care until the death of her spouse. The implication exists that she would not have been able to provide this care without staff support. Similarly, the admission of a person into an ACF is likely to affect his or her family members, and staff support of these members is likely, ultimately, to affect the resident.

Needs for Specific Kinds of Staff Support for Family Members

Few authors have investigated family members' needs for specific kinds of support in an ACF setting. Findings of five studies are considered to be relevant to this issue. With the exception of Kellett's (1996) Australian study, all are North American.

Authors of four studies discovered that ACF residents' family members had a need for some kind of affirmation. Firstly, Bonnel (1996) conducted a single case study analysis illuminating a husband's experience. This family member needed to withdraw, but with staff permission. He also wanted positive affirmation from the staff of the role he had played. Kellett's (1996) sample of eight family members also wanted affirmation, but of a continuing role in which they could use their caregiving expertise. Similarly, Campbell

and Linc (1996), obtaining answers to questionnaires from 102 residents' relatives, found that family members wanted to be taught skills they could use to comfort and support their loved ones in the ACF, and to receive positive reinforcement for their input from the staff. Finally, Morgan and Zimmerman (1990), who targeted 10 AD sufferers' wives, discovered a need in them for an authority figure to affirm their decisions to institutionalise their loved ones. In the latter two studies, the researchers also discovered a need in respondents for emotional support. Additionally, control over the situation was a helpful factor for the wives included in Morgan and Zimmerman's study.

Johnson and associates (1992) conducted the fifth study. These researchers found information needs to be identified implicitly in their sample of 22 residents' family members. This was because family members spoke of uncertainties about residents' progress, the health care system, and the resident's current status. (For the studies of Bonnel, 1996; Johnson et al.; and Kellett, 1996, see Table 1).

Evidence that Staff Support has Helped Residents' Family Members

In this section, the reviewer examines four rigorously evaluated programs involving the provision of staff support for family members of ACF residents.

The first two programs were examined by social workers. Monohan's (1995) evaluation took place in a 45-bed dementia unit that was part of an ACF. This researcher found that family members' burden levels were negatively predicted by their participation in support groups, but positively predicted by their participation in workshops. The cross-sectional design leaves the interpretation of these findings open to some doubt, but the researcher suggests they show benefits for support group members, and may

indicate that those experiencing high levels of burden are the most likely to attend workshops. In the second study, Dziegielewski (1991) used a pre-test, post-test, control group design to examine effects on family members' attitudes to residents with AD of three interventions. Ten people received education, 10 support, 10 a combination of support and education, while the final 10 people continued as before. Significant improvements in attitude were found in all three experimental groups when compared to the control group. No single intervention was found to be more or less beneficial than the others.

A research team examined the effect on family members' satisfaction with the care arrangement of including family members in care, using a quasi-experimental design in an ACF (Buckwalter, Cusack, Kruckeberg, & Shoemaker, 1991; Buckwalter, Cusack, Sidles, Wadle, & Beaver, 1989). This team included family members of 23 brain-damaged residents, none having AD, in a speech pathology intervention with residents. Experimental group members became significantly more satisfied with the care arrangement, felt they were more involved in the care process, and perceived nursing staff to be more concerned about the residents than those in the control group.

Findings of a nursing study by Toye, Percival, and Blackmore (1996) were far less conclusive than those described in the previous paragraph, although the study design was similar. In a pre-test-post-test control group design, 15 experimental group members, family members of ACF residents, were offered extra involvement in their loved ones' care and assigned a contact person. However, only four people chose to increase their caregiving involvement. The 16 control group members continued as before for the 6 weeks of the study. Participants were relatives of residents with

various disabilities in a single setting. The intervention was not found to have a significant effect on satisfaction with the care arrangement.

The sample sizes in the two latter studies (Buckwalter et al., 1989, 1991; Toye et al., 1996) were small, and their sampling frames were not the same. However, the conflicting findings suggest a need to discover ways in which participants in Buckwalter and associate's study had been helped. The offer of inclusion in care, showing that family members' input was valued, may not have been the variable that led to increased satisfaction. Instead, perhaps staff provided other forms of support for family members during the intervention, such as information or emotional support. Alternatively, perhaps finding a useful role prompted family members to view the placement more favourably.

Section Summary (Staff Support Directed at Family Members)

In summary, there is sound theoretical rationale for the use of nursing interventions to address the support of ACF residents' family members. There is also some evidence that family members of ACF residents may need appraisal support in the form of affirmation; emotional support; control over the situation; and informational support. Study findings suggests that support groups and/or educational sessions for family members of ACF residents with AD are beneficial to participants, and may positively affect their attitudes to their loved ones in the ACFs. The evidence concerning benefits to family members of their inclusion in care is less clear. Studies show, therefore, that some kinds of staff support have the potential to improve the well-being of ACF residents' family members.

Informal Support Directed Towards Aged Care Facility Residents' Family

Members

Informal support of family members of ACF residents has rarely been designated as a sole topic of research projects. However, indications that informal support is relevant to the well-being of these family members are embedded in the findings of a number of studies, four of which are examined here.

Findings of the first two studies have limited generalisability as they utilised small samples of specific groups of family members. Firstly, McCarty (1996) used a grounded theory methodology when interviewing 17 caregiving daughters and daughters-in-law, seven of whom were caring for parents in ACFs. All the parents had AD. This researcher found that a sense of a lack of support from significant others worsened the stress reactions of respondents. Specifically, support from siblings and spouses was found to aid in coping, whilst needing to make caregiving decisions unilaterally was seen to be a source of stress.

Using a quantitative approach, some confirmation of the importance of informal social support was obtained in the findings of a study conducted by Almberg, Grafstrom, and Winblad (1997). These authors examined burden and burnout experiences in 52 family community and ACF caregivers of those with AD. Social life limitation was found to be one of the most important variables explaining burnout in this sample.

The two relevant studies using samples of family members related to ACF residents with a variety of disabilities have been described previously. Neary's (1993) study examined stress buffering. The finding that having children aged younger than 17 years had a buffering effect on depression in a sample of 168 family members of ACF

residents is pertinent. This effect may have occurred because children supported their parents, but it may have other explanations instead. For example, guilt may have been alleviated because children provided a justification for their parents not providing home care for elderly relatives. However, Grau and associates (1993) (see Table 2) found that a lack of social support was a significant predictor of demoralisation in ACF residents' family members.

Finally, a cautionary note is found in the writings of Phillips (1990), discussing the complexity of elder/family caregiver relationships in the community with reference to previous research and theoretical knowledge. Phillips indicated that family members tend to "elect" a caregiver and designate different responsibilities to others in the family (p. 802). However, the result of this election is not always considered satisfactory by those affected, and can lead to conflict. As is indicated by Tilden and Galyen (1985), there are costs as well as benefits associated with social support.

Section Summary (Residents' Family Members' Informal Support)

There are indications in the literature that informal support sometimes does help the family members of ACF residents. However, there are also indications that the dynamics and effects of informal support are extremely complex and not always beneficial for the well-being of family members. This tends to confirm that researchers should concentrate on an examination of support perceptions in this population to gain maximum insight into any relationship between support and well-being.

Family Members' Support Directed Towards Aged Care Facility Residents

The topic of family members' support for ACF residents began to be a focus of empirical work approximately 20 years ago. In addition, many authors have discussed the topic, and more have described related initiatives, sometimes including informal evaluations of their effects. Empirical work only is included in this review, with the exception of two salient papers (i.e. Brody, 1985; Tiise, 1997) that will be discussed at the appropriate junctures.

Studies investigating aspects of family members' support for ACF residents have been categorised into those examining (a) perceptions of family members and/or staff (see Table 3), (b) residents' or observers' perceptions (see Table 4), and (c) outcomes (see Table 5).

Particular care is needed when interpreting the findings of some of these studies because they included samples of residents. The fact that these residents possessed cognitive and/or communicative abilities sufficient to answer study questions means they are probably not representative of the general population of ACF residents, and study findings must be read with this in mind. However, investigating support from a provider's (family member's) perspective is not ideal either, because family members may not be accurate proxies for residents.

Table 3**Studies Examining Staff and Family Members' Perceptions of Family Members' Care for Aged Care Facility Residents**

Author	Year	Methodology	Findings	Limitations
Shutdesworth et al.	1982	Rated 100 tasks in a survey of 166 administrators and family members in 33 homes, according to who was believed to be responsible for carrying them out. USA.	Agreement between groups in the case of 61 tasks. Both groups saw most tasks as the nursing home's responsibility. Family members claimed more responsibility for non-technical tasks than administrators believed was the case.	<ul style="list-style-type: none">• Convenience sampling.
Rubin & Shuttlesworth	1983	Inventory administered to 64 staff and 137 family members of residents in two ACFs. Tasks marked as either being primarily a family, staff, or joint responsibility. USA.	Little disagreement in the case of 60 items: 54 were either allocated to staff or regarded as a joint responsibility, 6 were seen to be family responsibilities. Most of the disagreement from overlapping claims.	<ul style="list-style-type: none">• Only two settings, both promoting family members' involvement.
Bowers	1988	Grounded dimensional analysis: 28 relatives of residents of one ACF. USA.	Relatives felt staff were responsible for most care, but monitored and evaluated that care, teaching staff and helping preserve the residents' identities.	<ul style="list-style-type: none">• Single setting.
Schwartz & Vogel	1990	Inventory of 100 care tasks rated by 142 staff and 144 residents' family members in 11 nursing homes as the responsibility of staff, of family members, or both. USA.	Staff/relative agreement for 69 tasks: 36 designated to staff, 7 to relatives, 26 to both. Disagreement mainly in personal care/activities, staff rating their responsibility as more than that indicated by family.	<ul style="list-style-type: none">• Non-random sample.

Author	Year	Methodology	Findings	Limitations
Dempsey & Pruchno	1993	Interviews with 424 ACF residents' sons and daughters. USA.	<p>Predictors of adult children carrying out non-technical tasks: more frequent visits, being a daughter, more illnesses in the parent.</p> <p>Predictors of adult children carrying out technical tasks: more frequent visits, more illnesses in the parent, an older parent, more technical care given by the staff.</p>	<ul style="list-style-type: none"> • Adult children only.
Duncan & Morgan	1994	Investigated relationships between family caregivers and staff in dementia-care. Sample: 77 community caregivers of those with AD and 102 family members of AD sufferers in long term care. Data obtained from focus group discussions and individual interviews. USA.	Family members monitored staff behaviour towards residents, trying to teach staff to treat their loved ones as people, and to use their relationships with staff to raise the standard of care. Care was judged against home care. Conflict was reported between organisational goals and those of family members.	<ul style="list-style-type: none"> • Family members of those with AD.
Fleming	1998	Investigated meaning, in 14 ACF residents' family members, of their involvement in care. Residents all had dementia. A grounded theory methodology. Australia.	Family members felt they provided a "lifeline of special care" (p.141). Purposes of care were preservative and protective, but the provision of care was also meaningful to, and rewarding for, the caregiver.	<ul style="list-style-type: none"> • Family members of those with AD only.

Table 4**Studies Examining Residents' and Observers' Perceptions of Family Members' Support for Aged Care Facility Residents**

Author	Year	Methodology	Findings	Limitations
Litwak	1985	Tested a theory suggesting formal and informal support would complement each other. Questionnaires completed during interviews with 399 ACF residents. USA.	Theory generally confirmed.	<ul style="list-style-type: none"> • Staff nominated residents. • Informal supports excluded spouses.
High & Rowles Rowles & High	1995 1996	Anthropological study of family involvement in ACF decision making, over 3 years. Participant observation, interviews, and event analysis. Four diverse homes included, and relatives of 61 residents. Typology of ways in which family involvement individualises care developed. USA.	Highest involvement in financial and crisis decisions, lowest in social environment and transfer. High level for 4 years. Typology: personalising, mediating, comforting residents, sustaining links with former lives, educating staff, controlling.	<ul style="list-style-type: none"> • None noted.
Patterson	1995	Twelve ACF residents in a single setting interviewed about what they perceived as supportive/non-supportive. Participant-observation also. Half of the sample newly admitted relatives, the other half residents of <a year. Data validated using feedback. USA.	Family members most often linked with financial/material help, socialisation. Supportive behaviours: emotional support, practical help, material aid, socialisation. Advice desired.	<ul style="list-style-type: none"> • Single setting.
Tickle & Hull	1995	A 3-month study using participant-observation in a 300-bed long-term care facility to discover family members' roles and reasons for them. USA.	Three themes: frequency of visits, degree of regularity, commitment. Functions: feeding, assisting with ambulation, and assisting with/monitoring elimination.	<ul style="list-style-type: none"> • Single setting.

Table 5**Studies Examining Outcomes of Family Members' Support for Aged Care Facility Residents**

Author	Year	Methodology	Instruments	Findings	Limitations
Harel & Noelker	1982	Investigated effects of factors on well-being of (USA) residents. One factor was social integration. From 14 ACFs, 125 residents interviewed. Stepwise regression.	Measured social resources, help given/received, visitors, someone to talk to, close outsiders and insiders, frequency of participation. Life satisfaction and satisfaction with treatment self-rated. Morale: Philadelphia Geriatric Center's Morale Scale (Lawton, 1972).	Number of preferred visitors predicted life satisfaction. Number of preferred visitors and having close person outside ACF predicted morale. Preferred visitors, close outsider, and number of visitors accounted for 13% variance in satisfaction with treatment.	<ul style="list-style-type: none"> • Non-representative sample.
Nelson	1989	Correlational. Investigated relationships among social support, self esteem, and depression in 26 residents. USA.	Norbeck Social Support Questionnaire (Norbeck, Lindsay, & Carrier, 1981). Geriatric Depression Scale (Brink et al., 1982). Rosenberg Self-Esteem Scale (Hunter, Linn, & Harris, 1981).	Significant negative correlations between functional properties of the social network and depression, between the strength of the network and depression, and between self esteem and depression.	<ul style="list-style-type: none"> • Very small, non-representative sample. • Two settings only.
Porter & Clinton	1992	Data from interviews with 243 (USA) residents. Question: "How did you handle the change when you first came to this nursing home?" (p. 466).	N/A	Adjustment approaches: mostly reframing. Influences on adjustment: transfer circumstances, life history, person-environment mesh, and belief in the only option.	<ul style="list-style-type: none"> • Non-representative sample. • Small data sets.
Shaw	1992	Path analysis of model of coping effectiveness. Cluster sample: 100 (USA) residents, 10 ACFs. Respondents assisted in completing questionnaires.	<ul style="list-style-type: none"> * Importance, Locus, and range of Activities Checklist * Jalowiec Coping Scale * Self-anchoring ladders (coping effectiveness). 	Two variables had positive influences on coping effectiveness in residents: perceived health and secondary control. Latter included getting help from family.	<ul style="list-style-type: none"> • Scales not ideal for population. • Sample non-representative.

Perceptions of Staff and Family Members

In six helpful North American studies, researchers have investigated perceptions of family members' support responsibilities for ACF residents. A seventh study, from Australia, has sought to explicate the meaning to family members of involvement in care. The first four studies reviewed emphasised a division between technical and non-technical care. Three of these projects examined perceptions of staff and family members using a similar, quantitative methodology (Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth, Rubin, & Duffy, 1982). In the other, researchers collected data from residents' sons and daughters to discover predictors of the kinds of caregiving tasks with which they became involved (Dempsey & Pruchno, 1993). The final three studies reviewed were quite different. These examined the perspectives of family members using qualitative methodologies (Bowers, 1988; Duncan & Morgan, 1994; Fleming, 1998).

The three, quantitative studies examining perceptions of staff and a variety of family members all used large samples. Rubin and Shuttlesworth (1983) collected data at two sites, Schwartz and Vogel (1990) at 11, and Shuttlesworth and associates (1982) at 33. In all studies, an inventory of 100 nursing home care tasks was given to participants so that they could indicate whether staff or family members should carry them out. In the two later studies, an alternative of joint responsibility was also offered. Agreement between staff and family members ranged from 60% to 70%. In all three studies, overlapping claims produced most of the disagreement, and there was only general agreement that family members were solely responsible in the case of a few tasks. Staff believed that family member responsibilities were more limited than the family members believed them to be. Non-technical care was the source of

most overlapping claims in the first study, and personal care and activities in the most recent, with areas of overlap being scattered in the second.

Dempsey and Pruchno (1993) interviewed 424 adult children of ACF residents. Respondents were again asked to classify care tasks. Twenty-eight tasks were classified as to who was carrying them out and who should be doing this (staff or family members). There was a high level of congruence between expectations and experiences. Using logistic regression analyses, predictions were made as to the characteristics of family members carrying out technical tasks and non-technical tasks. Significant predictors of non-technical tasks being carried out by respondents included more frequent visits, the respondent being female, and more illnesses being suffered by the parent. Significant predictors of technical tasks being done by respondents included more frequent visits, more parent illnesses, an older parent, and more technical care given by staff.

Bowers' (1988) study does not refer to a division between technical and non-technical tasks. In this study, 28 family members interviewed in one nursing home indicated they felt their responsibilities were to monitor/evaluate care, teach staff how to care, and help to preserve the identity of the resident (i.e. to provide preservative care). Duncan and Morgan's (1994) findings extended those of Bowers. Participants in their study described the duties they undertook in order to fulfil their self-perceived support responsibilities. Interview and discussion group data were obtained from 102 institutionalised AD sufferers' family members. Family members reported using relationships with staff to raise standards of care. They also spoke of monitoring staff behaviours, trying to teach staff to treat residents as people, and helping to ensure that technical care incorporated sensitivity to personhood.

Finally, Fleming (1998) discussed his findings in terms of a "lifeline of special care" (p.141). He found that 14 family members providing care to dementia sufferers in ACFs saw themselves as providing special care that addressed the quality of life of their loved ones, and that showed love. Staff were viewed as providing maintenance care. Residents' family members, far from finding their input into care to be a burden, discovered meaning for their own lives in providing protective and/or preservative care to their loved ones.

Perceptions of Residents and/or Observers

Studies reviewed in this section include four studies using samples of residents and/or observational methods. All were conducted in the United States. Two of the qualitative studies used methodological triangulation (High & Rowles, 1995; Patterson, 1995; Rowles & High, 1996), providing evidence of the trustworthiness of results. One quantitative study was conducted at randomly selected settings, increasing the generalisability of findings (Litwak, 1985).

Patterson (1995) used participant observation in a single ACF and interviewed 12 residents. This researcher identified the support needs of residents to be for socialisation, emotional support, financial/material help, practical assistance, and advice/guidance. The latter need was found to be unmet; but staff, residents, family members, and friends were all seen to be meeting the other needs. Family members were most often linked with socialisation and financial/material help. Residents who had been recently admitted referred to their families most during interviews.

To an extent, Litwak's (1985) study findings support those of Patterson's (1995) work. Litwak interviewed 399 ACF residents. Findings suggest that formal and informal support in ACFs are complementary. The formal support of residents met needs where standardised and funded actions were required, such as needs for assistance with hygiene and mobility. Residents' informal support met their remaining needs (or they remained unmet). However, Tickle and Hull (1995) conducted a three month long participant-observation study in a single setting 10 years later, and reported findings that conflict with those of Litwak. These researchers observed family members feeding residents; helping them with ambulation; assisting them with, or monitoring, their elimination processes; and sharing their activities. Most needs met by these family members could have been classified as standardised/funded actions.

One type of family members' support for ACF residents is their involvement in decision making. High and Rowles (1995) and Rowles and High (1996) used participant observation, interviews with 61 relatives, and event analysis, in a three year long anthropological study in four ACFs to examine this topic. Family members' involvement in decision making was found to remain at a high level for the four years after admission, and it included mainly financial and crisis decision making. There was little input into decisions about transfers or the social environment.

Tilse (1997) discussed a similar area, that of family members' advocacy, with reference to the findings of an Australian study (Tilse, 1994, see Table 1). Tilse noted that family members had little power because they lacked knowledge of the system and a collective identity. She also identified spouses as being inhibited in their advocacy initiatives. This was because they felt such initiatives might be detrimental to their relationships with staff, and because they were aware of heavy staff workloads.

Brody (1985) also discussed family members' involvement in decision making and advocacy, seeing these as areas rife with ambiguity and possible family member/staff conflict. Citing Harel and Noelker (1978), and Kleban, Brody, and Lawton (1971), Brody stated that family members are known to provide food, clothes, money, flowers, birthday visits, outings, financial management, laundry and domestic assistance, in addition to emotional and socialisation support. Alternatively, she noted that residents sometimes emotionally support their family members. This author advocated research into family members' roles within the ACF. She reasoned that family members who know their loved ones are well cared for, and whose well-being is enhanced because they have roles to play within the ACFs, are more likely, in turn, to enhance the well-being of their institutionalised relatives. This rationale underpinned the development of the model tested in the current study.

Outcomes of Family Members' Support for Residents

Studies obtaining information about outcomes of family members' support for ACF residents include those of Harel and Noelker (1982), Nelson (1989), Porter and Clinton (1992), and Shaw (1992). These researchers all used samples of ACF residents in the USA.

Harel and Noelker (1982) interviewed 125 respondents in 14 ACFs. The researchers used 10 measures of social integration and found some of these to be related to aspects of residents' well-being. Having preferred visitors was a significant predictor of self-rated life satisfaction and morale (measured by a validated instrument). Having a close person outside the ACF also predicted higher morale. Having preferred

visitors, a greater number of visitors, and a close person outside the facility accounted for 13% of the variance in self-rated satisfaction with treatment in the facility.

Nelson (1989) employed validated instruments with a sample of 26 residents at a single site. This researcher found a negative correlation between functional properties of the social network (the amount of affect, affirmation, and aid it provided) and depression, and between strength of the social network (the number, duration, and frequency of contacts) and depression. However, given the very small sample, these findings should be viewed with caution.

Porter and Clinton (1992) investigated adjustment approaches in a large sample of 243 ACF residents. The study, described as phenomenological, produced short answers (under six sentences in length) to the question "How did you handle the change when you came to this nursing home?" (p. 466). Approximately one third of participants mentioned influences on their adjustment that fell into four categories (described earlier in this review). One category was that of person-environment mesh, social embeddedness, and included informal support. Informal support was found to aid the adjustment process in these people.

Finally, Shaw (1992) tested a model of coping effectiveness with a sample of 100 ACF residents. The cluster sampling method used in 10 ACFs increased the generalisability of the findings. Additionally, instruments used were mainly tried and tested. Shaw found that secondary control, including family help, influenced coping effectiveness.

Section Summary (Family Members' Support for Residents)

In summary, study findings suggest that staff see family members as having limited responsibilities for resident support. However, the supportive role that family members do provide is described as wide-ranging and rewarding, and it may include monitoring and/or correcting the care practices of staff. Residents have been found to be in need of social integration, emotional support, financial/material help, practical assistance, and advice/guidance. Family members have been found to assist with all of these needs except the last. They are also involved with staff in financial and crisis decision making, but it is apparent that they are not well prepared to become residents' advocates. The evidence suggests that residents with family members' support tend to adjust more easily to institutional life, to have higher morale and satisfaction ratings, and to be less likely to become depressed. Clarifying roles of family members within ACFs has been suggested as a strategy that could promote their positive well-being and that of the residents. This suggestion is consistent with the hypothesis that providing more formal support for family members will indirectly lead to the provision of more family members' support for residents.

The Context of the Residential Aged Care Facility Placement

As a final step in the literature review process, the reviewer examined empirical work for evidence of the influence of the context of ACF placements on the well-being of residents' family members, on the support of family members for residents, and/or on the well-being of residents. In this thesis, "context" is defined as that which precedes and follows an occurrence and illuminates its meaning (*Pocket Oxford Dictionary, 1969*). References to four relevant contextual factors were found in the literature:

- I. Familial relationships between residents and their family members.
- II. The cognitive health status of residents (i.e. whether or not residents were suffering from dementia).
- III. Pressures on family members.
- IV. The quality of relationships between residents and their family members.

Literature related to these four contextual factors was reviewed. However, many of the studies mentioned here have also been referred to in earlier sections of the review and will not be re-examined in detail again. Those that are mentioned here for the first time will be discussed more thoroughly.

I. Familial Relationships Between Residents and Relatives

There is considerable evidence in the literature that people experience the impact of a relative's ACF placement differently according to their familial relationship with that relative. This evidence is examined first. Additionally, indications exist that support directed towards residents varies according to the familial relationship between the resident and the support provider. These indications are examined next.

Experiencing the ACF placement of a relative as a son, daughter, husband or wife. Adult children of ACF residents have been the population of interest in a number of relevant investigations. In Townsend's (1990) study (see Table 2), stressors of adult children were found to include lack of adjustment in residents and negative family members' perceptions of the Institution. In Brody, Dempsey, and Pruchno's (1990)

study, predictors of negative emotional effects from the placement in 331 sons and daughters included negative perceptions of staff, greater youth, and upsetting visits. Instruments used in this study had established psychometric properties (Cronbach's alpha coefficients ranging from 0.85 to 0.91).

Brody and associates (1990) also discovered that daughters were more likely to experience negative effects than sons. Grau and associates (1993) (see Table 2) confirmed these findings. They found residents' daughters more likely to be demoralised, feel guilty, worry, and experience caregiver burden than sons. Additionally, in two qualitative studies where daughters were specifically selected (Johnson, 1990; Matthiesen, 1989) (see Table 1), Matthiesen found that daughters' emotional effects were unremitting, and Johnson's respondents spoke of facing dilemmas, such as trying to keep the family happy.

A more diverse sample was chosen by Harper and Lund (1992) (see Table 2). These authors made comparisons amongst husbands, daughters, and wives visiting dementia sufferers in ACFs. Greater social support was found to predict lower levels of burden in wives and daughters. Life satisfaction had a similar effect in wives, as did the pre-existing length of time spent caregiving in daughters. Finally, more current hours spent caregiving significantly predicted greater burden in husbands.

Townsend (1990), Grau and associates (1993), and Bidewell, Ledwidge, Blanch, and Johnson (1999) examined the effect on residents' spouses of the ACF placement. The first two of these studies made comparisons with effects in other family members. Townsend found spouses to be the most upset; the most likely to be sick, to feel guilty, and to worry; and the most likely to experience burden. Grau and associates

found this group to be the most demoralised by the placement, and at the greatest risk of poor mental health. Bidewell and associates, however, reported little evidence that ACF placements lead to negative effects in spouses. These authors conducted interviews with 22 wives and 18 husbands of residents in Australian ACFs. Respondents were asked to make pre/post-placement comparisons in physical functioning, time management, interpersonal relationships, affective well-being, and financial issues. Almost no changes were significant. The authors explained this fact by stating that reported changes were rarely in a uniform direction.

Experiences of spouses have been further investigated in several qualitative studies, and findings confirm that ACF placements are likely to be traumatic for residents' spouses. Tilse (1994) found that spouses/partners of those in ACFs endured the change as the end of an epoch. They experienced loneliness, feelings of failure, and of financial and emotional insecurity. However, they still recognised bonds with their partners, and a need to remain loyal. Wives, in particular, reported changes in their expressions of intimacy and overall communication with their husbands. One of Kaplan and Ade-Ridder's (1991) respondents believed this phase of her life would prove harder to bear than widowhood. Additionally, wives in Rosenthal and Dawson's (1991) study reported experiencing resentment and poor health. (For the last three studies see Table 1).

Support for ACF residents from sons, daughters, or wives. Only a few studies have examined family members' support practices with reference to familial relationships. Four relevant findings have been found. These refer to support provided by sons, daughters, and wives.

Kammer (1994) surveyed 100 family members of residents of two ACFs in the USA. This researcher found that daughters were the most frequent visitors to ACFs and that the younger adult children were the most likely to withdraw. Dempsey and Pruchno (1992) (see Table 3) found that daughters were more likely than sons to carry out non-technical care tasks in ACFs, but Brody and associates (1990) (see Table 2) found that adult children tended to be helped by providing physical care.

Finally, an interesting perspective on the support roles of wives was addressed by Bartlett (1994) (see Table 1). This author found that wives believed their roles provided "the extra emotional and tactile stimulation through meaningful touch, which could not be expected from the nursing home staff" (p. 97).

Sub-summary. The literature demonstrates, therefore, that sons and daughters of ACF residents are influenced negatively by a lack of adjustment in residents, negative perceptions of staff and/or the institution, greater youth, and upsetting visits. Moreover, daughters are more likely to suffer negative effects than sons, but may be helped by having spent time caregiving before the admission and by social support, which also tends to help residents' wives. Despite some conflicting findings, spouses seem to suffer the most from the institutionalisation of a loved one. There are also indications that the support family members provide for residents varies according to the familial relationship, but this area has not yet been explored in any depth.

II. The Cognitive Health Status of Residents

In this section, relevant studies again concern the well-being and support practices of ACF residents' family members. Two authors (Neary, 1993; Townsend, 1990) compared the well-being of family members of ACF residents with dementia with that

of family members of cognitively intact residents. Other authors (Aneshensel et al., 1995; Fleming, 1994; McCarty, 1996) restricted their samples to family members of residents suffering from dementia and examined their support practices. The reviewer has not found the post-admission support of family members for cognitively intact residents to be well documented in the literature.

Experiencing the ACF placement of a cognitively impaired or cognitively intact relative. The two studies investigating well-being in family members of ACF residents with and without dementia have produced findings that are not entirely compatible. In one, Neary (1993) made comparisons between 95 caregivers of cognitively intact relatives and 18 caregivers of relatives with cognitive impairments, within 6 months of the placement. Neary used instruments with established acceptable psychometric properties to examine burden and depression in participants, who also reported details of their physical health. No significant differences were detected between the groups. However, Townsend (1990) (see Table 2), using a larger sample, and investigating many aspects of ACF placements, found that poor mental health in the institutionalised aged was a stressor for their adult children.

Support for cognitively impaired ACF residents from their family members.

There is more concordance across three studies of support practices of family members of Institutionalised dementia sufferers. Aneshensel et al. (1995) (see Table 2) found that the sample of 185 caregivers generally remained involved in care, and fewer than 10% failed to at least visit regularly. Fleming's (1994) findings (see Table 1) tend to confirm that family members offer strong support as the 8 ACF based participants maintained regular contact after the admission. However, a specific aspect of the dementing process may make a difference to daughters' commitment to

caregiving, as reported by McCarty (1996). In this study, using a grounded theory methodology, McCarty interviewed 17 caregiving daughters and daughters-in-law of community dwelling or institutionalised people with AD. A key finding was that the perception that a parent was finally unable to recognise his/her daughter signalled the withdrawal of that daughter.

Sub-summary. It is unclear, from the literature, whether or not the cognitive status of the ACF resident influences the well-being of his/her family members. It is also unclear whether or not this cognitive status influences the support that family members provide for residents. However, family members' support for residents with dementia has been shown to be of a generally high level.

III. Pressures on Family Members

Researchers have identified several factors that may exert pressure on family members of those in ACFs and affect their well-being. Some of these factors have also been related to the support family members provide for ACF residents. Additionally, Schneewind (1990) and Phillips (1990) have produced significant discussion papers based on empirical work that are relevant to this section of the review.

Pressures affecting the well-being of ACF residents' family members. Firstly, poor physical health has been associated with the well-being of family members of ACF residents. In one study, researchers found that poor health predicted adverse emotional effects of the placement and depression in adult children (Brody et al., 1990). In another, researchers found that poor health predicted demoralisation in a heterogeneous sample of family caregivers (Grau et al., 1993). In the latter study,

demoralisation was defined as including anxiety, negative self-esteem, hopelessness/helplessness, and sadness.

Secondly, Townsend (1990) found responsibilities away from the ACF and a lack of proximity to the Institution to be stressors in a heterogeneous sample of residents' family members. Brody and associates (1990) also found that conflicting responsibilities were predictors of negative emotional effects in sons and daughters, and of depression in daughters.

Thirdly, Waltrowicz, Ames, McKenzie, and Flicker (1996), in an Australian study, examined burden in 41 informal carers of those in ACFs with dementia. They found burden to be significantly greater in those carers from a non-English speaking background. Although the authors recommend further studies to clarify the reason for this finding, they also state that many of these participants were members of cultural groups wherein home care of the disabled elderly might be considered to be the norm.

Schneewind's (1990) discussion paper is of particular relevance to Waltrowicz and associates' (1996) findings, as this author argues that societal/cultural/familial expectations are, indeed, pressures with the potential to impact upon the well-being of family members of ACF residents. Schneewind suggests that the placement decision may be viewed as an admission of failure when societal expectations are that families will nurture their frailer members. She also points out that, although spouses may generally be expected to show more commitment to care than sons or daughters, individual families develop their own rules. Family members who break these rules or flout the expectations of society generally experience feelings of guilt, even though the actions perceived as transgressions may have been unavoidable.

Pressures affecting the support practices of ACF residents' family members.

Firstly, responsibilities away from the ACF have also been related to the support family members provide for ACF residents. Kammer (1994) found that daughters visited most often when they had fewer children living at home. Additionally, in community studies the proximity of the family member to the resident has been identified as relevant to family member support (Given & Given, 1991). This may apply in the case of ACFs as well.

Secondly, Phillips (1990) discusses obligations that may act as pressures on the family members of elderly people with reference to the quality of community care that ensues. She points out that family members' provision of care is related to their perceptions of correct role behaviours, feelings of filial obligation, and debts of obligations to the care recipients. Extrapolations may be made to the population of family members of ACF residents. For example, ACF residents' family members may visit frequently when they believe it is their duty to do this or when they feel they owe this to their loved ones.

Sub-summary. Poor health, additional responsibilities, a lack of proximity to the ACF, a non-English speaking background, and societal/cultural/family expectations have all been found to be pressures influencing the well-being of family members of ACF residents. Moreover, pressures including additional responsibilities, a lack of proximity to the institution, and perceived obligations have been found to influence the support family members provide for their loved ones in the ACFs.

IV. The Quality of Relationships Between Residents and Family Members

Very little literature is available concerning the influence of the quality of pre-existing family relationships on the well-being of ACF residents and their family members. Two studies are relevant, McCarty's (1996) study of family members' well-being, and Dunkle, Haug, Coulton, and Formosa's (1995) research related to residents' well-being. McCarty's study and Phillip's (1990) work are both relevant to the impact of the quality of family member/resident relationships on family members' support for residents.

The influence on family members' well-being of the quality of the resident/family member relationship.

McCarty (1996) used a sample of daughters and daughters-in-law of those with AD in the community and in ACFs. Respondents who perceived conflict in their previous relationships with care recipients and/or who were more ambivalent about these parents were the most vulnerable caregivers.

The influence on residents' well-being of the quality of the resident/family member relationship.

Dunkle and associates (1996) examined family and environmental influences on adjustment to life in an ACF. One hundred and eleven people were included who had been admitted into rehabilitation hospitals or nursing homes. Using path analysis, the authors found involvement of the resident in the placement decision impacted upon that resident's post-placement well-being. They also found that elders who perceived their family members to be more supportive of their independence, and/or less controlling, were most likely to experience that involvement.

The influence on family members' support for the resident of the quality of the resident/family member relationship. McCarty's (1996) study findings are also relevant to family members' support for residents. Daughters' perceptions of their previous relationships with their parents, and their pre-caregiving perceptions of those parents, affected their caregiving. These findings are congruent with Phillips' (1990) work documenting that family members have stores of experiences and memories of each other built up over many years. These stores influence ongoing interactions and, specifically, caregiving behaviours. Additionally, caregivers' feelings of attachment to the care recipient, and how well the current images they hold of the care recipient match those retained from the past, are also seen as relevant to caregiving.

Sub-summary. The literature suggests that daughters whose relationships with ACF residents are based in conflict or ambivalence may be at particular risk of negative well-being. It also suggests that residents who have been in a relationship where they are allowed little independence in decision making may be at particular risk of negative effects from an ACF placement. The pre-existing quality of the family member/resident relationship is additionally seen to be relevant to the support provided to the ACF resident by the family member.

Section Summary (Contextual Factors)

Researchers have found contextual factors associated with the placement to be relevant to the well-being of ACF residents' family members, to that of the residents themselves, and/or to the support directed by family members towards their loved ones in the ACFs. The following findings have been documented in the literature.

Firstly, sons and daughters suffer more adverse effects related to the placement if they have negative perceptions of the facility and/or the staff, they are young, they have upsetting visits, the resident fails to adjust to the placement, and/or the resident has dementia. They are also likely to be helped by participation in care, but to withdraw if they are young.

Secondly, in daughters, previous conflict in the parent/child relationship, or feeling ambivalent about the parent, may lead to decreased well-being after the placement of an AD sufferer. Moreover, daughters, whilst being the most frequent visitors to ACFs, and more likely than sons to participate in non-technical care, are also more at risk of adverse effects than sons, and find themselves facing dilemmas. Their distress may be unremitting, or even increase over time. However, they are likely to be helped by social support.

Thirdly, greater social support and life satisfaction in residents' wives have been shown to predict lower levels of burden. Wives like to incorporate touch in their care for their loved ones. However, spouses are also known to be at the greatest risk of adverse emotional effects from the placement, and, in husbands, burden may be exacerbated by ACF caregiving for a wife with dementia.

Fourthly, pressures on ACF residents' family members may include their poor health, an inability to speak the language of the country, responsibilities outside the ACF, a lack of proximity to the ACF, and societal/familial expectations/obligations. These tend to negatively impact upon their well-being. The three latter-mentioned factors are also relevant to the extent to which family members support residents.

Fifthly, the quality of relationships between family caregivers and care recipients, past and present, is important to the support practices of family members in the community, which may indicate that it is important in ACFs too. Certainly, in the ACFs it has been shown that these relationships are relevant to residents' adjustment, via input into placement decision making.

Finally, it is not known if the cognitive status of ACF residents is relevant to the support their family members provide, but it is known that dementia sufferers generally receive good support from their family members in the ACFs. However, findings of one study suggest that daughters may withdraw when the parent no longer recognises them.

Overall Summary

Psychological well-being has been defined in widely varying ways in the literature, but in this study, it is viewed as a psychological health state that is a balance between positive and negative feelings/symptoms. ACF residents and their family members have been found to experience many negative impacts on their well-being because of the placement, as well as some that are positive.

Research has demonstrated that perceived social support generally buffers the adverse effects of stress on well-being, although studies investigating this phenomenon within ACFs are rare. Social support may be from formal (professional) sources or from informal sources (family or friends).

The rationale for ACF staff supporting residents' family members is clear in the literature. There is also a little evidence that residents' family members would like

particular kinds of staff support, and that some staff support initiatives have helped family members. Additionally, researchers have found indications that informal support helps residents' family members, although evidence is scant.

Researchers have also found that family members' support for residents is helpful to those residents, and that family members tend to be willing to provide support in a variety of ways. Although it is not known whether or not particular kinds of family members (e.g. wives or daughters) provide more support to residents than others, it is known that daughters are the most frequent visitors to ACFs, and that they are more likely than sons to be involved in tasks. However, despite the fact that some researchers have concentrated on identifying care tasks undertaken by family members, findings of other studies demonstrate that these family members see residents' happiness as the overall goal and participation in care tasks as one way to work towards that goal.

Because the happiness of residents is an overall goal for family members, it is likely that the degree to which residents are happy in the ACF will influence the well-being of their family members. Researchers have also shown that family members' well-being is influenced by their familial relationships with the residents and by any pressures they experience. These pressures include poor health, additional responsibilities, an inability to speak the language of the country, a lack of proximity to the ACF, and societal/familial obligations/expectations. The latter two pressures have also been found to influence the extent to which family members support their relatives in the ACFs.

Study findings also show that AD sufferers in ACFs tend to be well supported by their family members, but that the well-being of adult children is affected by their parents' mental health. However, there is evidence that family members of those with AD are increasingly likely to experience a positive impact from the placement over time, at least during the year following the admission.

Findings of community studies suggest that another factor relevant to ACF resident support may be the quality of the relationship between the family member and the resident. Although few studies within ACFs have examined this possibility, it has been shown that the well-being of residents' daughters is influenced by conflict/ambivalence within the parent/child relationship, and that residents are probably helped most by a relationship with family members that is not controlling, at least at the time of admission.

In brief, the literature indicates that ACF residents and their family members experience threats to their well-being related to the placement and that social support may buffer adverse effects of the placement. The role of staff in the support of residents is already clear, but the literature shows that family members' support of residents is also helpful to those residents, and that staff support can help improve the well-being of family members. Additionally, contextual factors have been identified that influence mainly the well-being of residents' family members and the support of family members for residents. Although it has been speculated that family members who are supported by staff may be better able to support their relatives in the ACFs, this has not yet been reported empirically.

Methodological Review

The literature review revealed three major areas of methodological concern and/or interest. These were issues related to (a) the generalisability/applicability of findings, (b) the interpretability of findings, and (c) the selection of topics for investigation.

The generalisability of findings of many of the quantitative studies is compromised because of the use of restricted sampling frames and/or because of the sampling methodology. Firstly, although useful, the overwhelming majority of studies were conducted in the USA, making extrapolations from these findings to non-American populations uncertain given the differences in culture and health care systems. International studies are expensive and difficult to co-ordinate. However, further research, conducted in other countries and producing comparable findings would help to redress this concern. Secondly, the use of randomly selected settings within individual countries is uncommon and would ensure that findings were more generalisable within those countries. Thirdly, the use of small, non-random samples has also reduced the generalisability of some findings.

The author recognises that the use of a qualitative methodology is not intended to lead to the generalisability of findings. However, Guba and Lincoln (cited in Sandelowski, 1986) indicate that one of the criteria for the evaluation of qualitative work is that of fittingness, which is achieved when findings are applicable and meaningful outside of the study situation and are congruent with the data. Detailed descriptions of study samples, settings, and methodologies are essential to judge fittingness, and the omission of details in published accounts of qualitative studies tends to make its evaluation problematic. This is especially the case where the research has been conducted and published overseas, with an assumption that the

reader possesses underlying knowledge about settings. When only sparse details are provided, assessment of the applicability of findings outside of study settings tends to rely upon the cumulation of consistent findings, which may take many years to achieve.

Interpretation of many of the findings is limited by the use of cross-sectional designs. Longitudinal studies in ACFs, using samples of residents and/or their family members, require larger initial samples than those conducted in many other settings because of the relatively high mortality rate of the frail aged population. Additionally, the monetary costs of longitudinal studies are often high. Yet, such studies can be of great value. However, the inclusion of length of stay as a variable in cross-sectional studies is a strategy that some researchers have successfully adopted as an aid to interpretation of findings.

A topic that has already been widely investigated has been ACF residents' family members' well-being. It is probably appropriate that future studies should not concentrate on this issue, but on understanding how the identified problems may be alleviated. Relationships between perceived social support (formal and informal) and well-being have been found to be complex and are likely to be situation specific. There has been little investigation of the relationships among these variables in the context of the experiences of family members of ACF residents. Consequently, studies concentrating on this area are required. The influence of contextual variables affecting placement should be included in these investigations. Stewart's (1993) call for conceptual clarity and the use of instruments with acceptable psychometric properties should be heeded if maximum benefit is to be gained from these investigations.

Furthermore, components of the perceived support of family members of ACF residents from staff have not been substantially identified in the literature. This variable needs to be defined and measured as a separate entity from informal support if understanding of support/well-being relationships in this situation is to be thorough. The reviewer has been unable to discover an existing instrument that allows for separate measurement of formal support in such a situation. The "qualitative to quantitative" methodology of instrument development is an appropriate action to address this concern (Imle & Atwood, 1988). This methodology involves the collection of data from multiple sources, including the literature and those experiencing the phenomenon. These data are then used to define the dimensions of the domain under investigation and to form the bases for the items (Fleury, 1993). Qualitative validity is retained in the instrument during its development and testing by continuing to include those experiencing the phenomenon at each stage of the process.

The final problem is one related to the investigation of family members' support for ACF residents. To date, studies in this area have been conceptually narrow and have not examined ways in which family members may be influenced by variables such as their well-being and perceived support. The lack of investigation in this area may, in part, be due to the fact that measurement of residents' support is problematic. Only unrepresentative samples of residents are able to supply data, yet the reports of others are of their own perceptions, not of those of the residents. Use of observational methodologies has been a strategy used to rectify this problem; however, samples used in observational studies tend to be small, limiting generalisability of findings.

In conclusion, studies investigating relationships between ACF residents' family members' perceived support from formal and informal sources and family members'

well-being are needed. For these studies, samples should be large and randomly selected so that findings may be generalisable, and instruments used should possess adequate psychometric properties. Longitudinal studies or those including time as a variable are the most likely to provide findings that may be interpretable. It would also be useful to examine how family members' support for residents is influenced by their perceived support, their well-being, and other contextual variables. Two problems emerging when considering this need for additional studies are the lack of an existing instrument that specifically measures formal support, and the fact that family members' support for ACF residents in studies with large samples is probably only measurable as the perceptions of either staff or family members.

This study addressed the need for further research outlined in the previous paragraph. It tested a model, based on the literature, that posited relationships among the perceived formal and informal support of family members of ACF residents, their well-being, their self-reported enacted support for their institutionalised loved ones, and contextual variables identified from the literature. Length of stay was included as a variable. An instrument to measure the perceived formal support of ACF residents' family members from the staff was developed, utilising a "qualitative to quantitative" methodology, for use in this study. This instrument underwent testing to establish its psychometric properties prior to its use, and further information about its properties was gained during the study. Existing instruments used in the study had documented adequate psychometric properties. Family members' support for residents was measured in terms of the perceptions of those family members, as the study sample was so large that the use of observational strategies was considered to be untenable.

The Model

This model of family-resident support is anchored in the body of knowledge about social support that demonstrates a buffering effect of social support on the negative effects of stress. It shows ACF residents' family members' well-being as being negatively affected by stress related factors associated with the ACF placement but positively affected by perceived informal and formal support. Well-being is conceptualised as a balance between positive feelings/symptoms and negative feelings/symptoms. The model also shows that a more positive state of well-being in the family member will lead to that family member providing more support for the resident. This is because positive well-being is seen to encompass the vitality and energy required to provide such support.

Five constructs provide the over-arching formulation for the model tested in this study. These constructs have been operationalised by defining 10 specific concepts (see Figure 1). The basis for the selection of constructs and concepts for inclusion, and for the postulated relationships among the constructs, exists in the literature reviewed earlier in the chapter. The model is explained in the following paragraphs.

Table 6 shows details of the operationalisation of constructs, including measures.

Explication of measures and modifications made are detailed in the following chapters.

Construct Five, the support an ACF resident's family member directs towards the resident, is represented by the concept of the family member's self-reported enacted support for the resident. This is the main outcome (dependent) variable. Alternative concepts, not considered feasible for inclusion in this study, would include observations of the family member's support for the resident and the resident's perceptions of support from the family member.

Constructs

I. Incentives in the resident's family member to direct support towards the resident

II. Stress related factors in the resident's family member

III. Perceived support of the resident's family member

IV. Psychological health of the resident's family member

V. Support the resident's family member directs towards the resident

Concepts

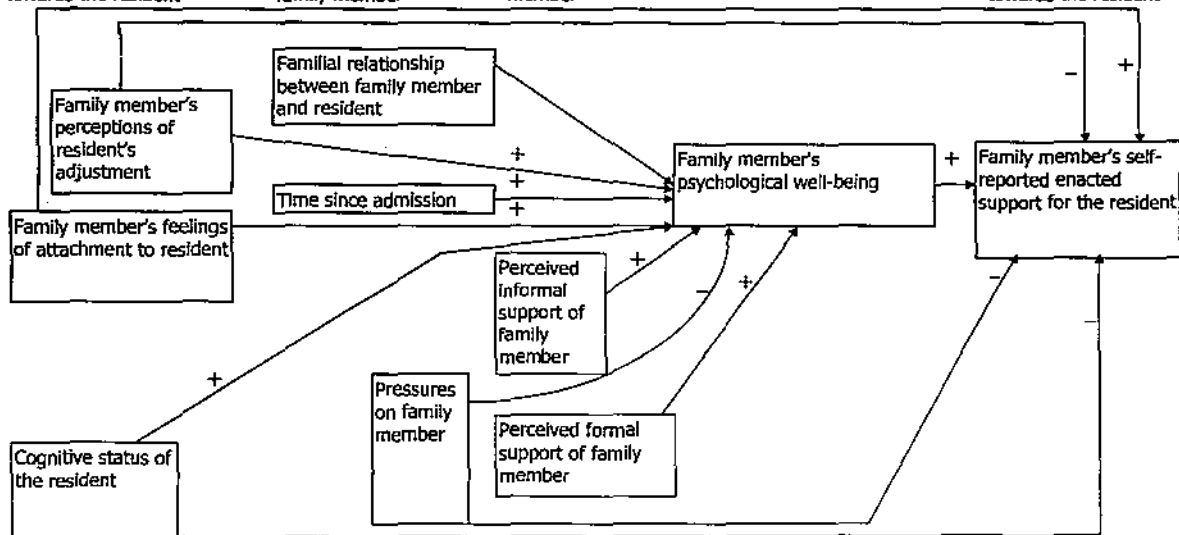


Figure 1: Postulated relationships in the Aged Care Facility resident's family member among incentives to support the resident, stress related factors, perceived social support, well-being, and support directed towards the resident.

Construct Four, the family member's psychological health, is represented by the concept of psychological well-being. This concept is seen as positively influencing the dependent variable. This is because aspects of the concept, such as energy levels and positivity/negativity, affect the ability of family members to function. Negative well-being, therefore, is seen as inhibiting the ability of a family member to support the resident.

Construct Three, the perceived support of the resident's family member, is represented by the concepts of perceived formal support and perceived informal support. These are postulated to buffer the negative effects on well-being of stress related factors via their action on well-being. In this way, they are also seen as indirectly influencing the main outcome variable. For the purposes of this study, a family member's perceived formal support is assumed to be that which emanates from ACF staff.

Construct Two, stress related factors in the resident's family member, is seen to include three concepts, all influencing that family member's well-being, and the main dependent variable via well-being. The first concept is the type of familial relationship between the family member and the resident. The literature suggests that being a resident's spouse will be associated to the greatest degree with negative well-being, and that being a daughter will be associated more strongly with negative well-being than being a son. A relationship between the type of familial relationship and the support provided by the family member to the resident is not clearly indicated in the literature so it is omitted from the model.

The second concept in Construct Two is the length of time since the resident's admission, postulated as having a positive relationship with the well-being of the

family member. The third concept is the pressures on the family member, postulated as having a negative relationship with the well-being of the family member. Pressures are also shown as having a direct and negative relationship with enacted support. Indicators of pressures, for the purpose of this study, were designated to be (a) a journey index, including perceived difficulty of the journey, time taken travelling, and the inconvenience associated with the type of transport utilised; (b) perceived (III) health; and (c) conflicting responsibilities (see Table 6).

Construct One, incentives for family members to direct support towards the resident, is shown as including three concepts. All are seen as directly and indirectly influencing the main dependent variable, and directly and positively influencing well-being. The first concept is the family member's perception of the resident's adjustment to living in the ACF. This was to be measured in terms of happiness of the resident, as reported by the family member (see Table 6). The direction of the relationship of this concept with the main dependent variable is seen to be negative. The second concept is that of feelings of attachment to the resident experienced by the family member, seen as positively influencing the main dependent variable. Indicators of this concept were to be the family member's perception of the closeness of the relationship and the frequency of pre and post-admission family member's contact with the resident (again see Table 6). The third concept is that of the cognitive status of the resident, also as reported by the family member (the use of test reports being untenable in this study). A resident with a reported main diagnosis of dementia was to be viewed as having a negative cognitive status and a resident without a reported main diagnosis of dementia was to be viewed as having a positive cognitive status. It was anticipated that asking for a report of a main diagnosis of dementia would ensure that ACF residents with only a mild degree of confusion were not designated as having a negative cognitive status.

Table 6**Details of the Operationalisation of the Constructs of the Model**

Constructs	Concepts	Indicators	Intended Measures
I. Incentives in the resident's family member to direct support towards the resident	◆ Family member's perceptions of resident's adjustment	◆ Perceptions of resident's happiness	◆ Single item: "How do you think the resident feels about living in the facility?"
	◆ Family member's feelings of attachment to resident	◆ Perceptions of closeness of relationship ◆ Frequency of pre and post - admission contact	◆ "How close do you feel....?" ◆ Pre-admission contact ◆ Current contact
	◆ Cognitive status of resident	◆ Family member's report re: dementia	◆ Single item: "... state resident's main disability/disease"
II. Stress related factors in the resident's family member	◆ Familial relationship: family member/resident	N/A	◆ Single item
	◆ Time since admission	N/A	◆ Single item

Table continues.

Constructs	Concepts	Indicators	Intended Measures
	◆ Pressures on family member	◆ Journey: perceived difficulty, length of journey time, inconvenience of transport	◆ "How difficult ...?" ◆ 'How long?' ◆ "How do you travel ...?"
		◆ Perceived (ill) health	◆ Single item: "How is your health?"
		◆ Conflicting responsibilities	◆ Two items from the "Time Pressures on the Family Member Scale" (Brody, Dempsey, & Pruchno, 1990)
III. Perceived support of the resident's family member	◆ Perceived informal support	N/A	◆ The Multidimensional Scale of Perceived Social support (Zimet, Dahlem, & Farley, 1988)
	◆ Perceived formal support	N/A	◆ The Relatives' of Aged Care Residents Assessment of Staff Support Tool (developed for this study)
IV. Psychological health of the resident's family member	◆ Family member's psychological well-being	N/A	◆ The General Well-Being Schedule (Dupuy, cited in McDowell & Newell, 1996)
V. Support family member directs towards the resident	◆ Family member's self-reported enacted support for resident	N/A	◆ The Family Help Sub-Scale of the Primary Group Helping Behaviour Scale (Rice, 1988)

Hypotheses

Most of the hypothesised relationships emanating from the model are between continuous variables. However, two variables "familial relationship between the family member and the resident" and "cognitive status of the resident" (i.e. having dementia or not having dementia) are categorical variables. Accordingly, the thirteen hypotheses tested in this study are as follows:

1. The extent to which a family member perceives that his/her relative has adjusted to living in an ACF inversely predicts the amount of enacted support the family member reports providing to that relative.
2. The extent to which a family member perceives that his/her relative has adjusted to living in an ACF positively predicts the degree of psychological well-being in the family member.
3. The extent to which an ACF resident's family member feels attached to the resident positively predicts the amount of enacted support the family member reports providing to that resident.
4. The extent to which an ACF resident's family member feels attached to the resident positively predicts the degree of psychological well-being in that family member.
5. Being the family member of an ACF resident who is cognitively intact predicts more positive levels of psychological well-being in that family member than does being the family member of a resident who is cognitively impaired (has dementia).

6. Being the family member of a resident in an ACF who is cognitively intact predicts lower levels of self-reported enacted support for that resident in the family member than does being the family member of a resident who is cognitively impaired (has dementia).
7. The extent to which an ACF resident's family member experiences pressures related to the placement inversely predicts the degree of psychological well-being in that family member.
8. The extent to which an ACF resident's family member experiences pressures related to the placement inversely predicts the amount of enacted support the family member reports providing to that resident.
9. The length of time that has passed since a family member has experienced the admission of a relative into an ACF positively predicts the degree of psychological well-being in that family member.
10. The familial relationship between a family member of an ACF resident and that resident predicts the degree of psychological well-being in the family member.
11. The perceived informal support of a family member of an ACF resident positively predicts the degree of psychological well-being in that family member.
12. The perceived formal support of a family member of an ACF resident positively predicts the degree of psychological well-being in that family member.

13. The degree of psychological well-being in a family member of an ACF resident positively predicts the amount of enacted support the family member reports providing to that relative.

CHAPTER III

Methodology

Introduction

The methodology for this study is recounted in two parts. Firstly, the initial phase of instrument development and refinement is documented. For this phase, all the details of findings are in appendices to allow easy reference to them before an examination of the next stage of the methodology. Secondly, the way in which the main study was carried out is described. Ethical considerations are addressed at the end of the chapter.

Instrument Development and Refinement

Introduction

The researcher needed to develop, test, and refine a tool to measure the perceived support of ACF residents' relatives from the staff. The processes involved, producing an instrument called the Relatives' of Aged Care Residents Assessment of Staff Support Tool (RACRASST), were carried out in the following stages: Stage One, development of the first draft; Stage Two, panel review and subsequent revision; Stage Three, revisions based on responses from a small sample; Stage Four, factor analyses with subsequent revisions; and Stage Five, test-retest reliability analysis.

At the commencement of the study, ACFs were either nursing homes, providing a high level of care, or hostels, providing a low level of care. The RACRASST was intended for use in nursing homes. However, an Australian Government initiative occurring between Stage One and Stage Two of the instrument development phase of the study required nursing homes and hostels to merge (AIHW & CDHFS, 1997). As a result, residents provided with high levels of care were sometimes cared for in the same settings as

residents receiving low levels of care. To ensure the relevance of the RACRASST to the newly defined Australian ACFs, the sampling frame was extended at that time to include family members of residents receiving low levels of care.

Stage One: Development of the First Draft of the RACRASST

Design. Development of the first draft of the RACRASST involved the clarification of a concept: ACF residents' family members' perceived support from the staff. The researcher discovered essential attributes of the concept by obtaining data from (a) a review of the relevant qualitative literature (Appendix B), (b) interviews with those working in the area (Appendix C), and (c) interviews conducted with a representative sample of family members of nursing home residents (described in this section). Quantitative items were generated from analysed qualitative data, whilst seeking to preserve the meaning of the data by involving family member respondents in the item development process. The methodology was based on that described by Fleury (1993).

Population, sample, and setting. The population targeted at this time was of family members of elderly (aged 65 or older) nursing home residents. Initially, Directors of Nursing (DONs) or Managers of 12 Western Australian nursing homes were contacted. In an attempt to include a broad range of residents' family members in the sample, the researcher approached DONs/Managers of the following: metropolitan and rural facilities, ethnically specific and ethnically diverse facilities, and large (>100 beds) and small (<100 beds) facilities. After an explanation of the study, the researcher asked DONs/Managers to either provide the current researcher with contact numbers/addresses of residents' family members, or to mail out letters from the researcher to potential respondents (Appendix D). Positive responses were obtained from six nursing homes. In three cases, DONs/Managers provided contact

numbers and/or addresses. In the other three cases, they mailed out letters for the researcher. The researcher sent a total of 210 letters to a variety of family members. Sample characteristics are shown in Appendix E.

Procedures. The researcher offered all respondents, except any outside the metropolitan area, a choice of settings in which to be interviewed.

Twenty-one respondents requested that the researcher visit them at home, eight people chose to be interviewed in a private part of the nursing home in which they were visiting, and the single, rural respondent was telephoned at home at a pre-arranged time. Interviews lasted for 30 to 60 minutes and were generally conducted individually at the request of respondents. However, in two cases, two family members were interviewed together, at their request. In the first of these cases, two nursing home placements were involved because each member of a married couple reflected upon visits to a parent. In the second case, one placement was involved as a resident's spouse and his "adult child" reflected upon their visits.

The researcher made appointments for interviews by telephone and, when they were to take place in nursing homes, organised the availability of private rooms. Prior to each interview, the researcher explained the study verbally, and answered any questions about it that were asked. Consent forms were completed (Appendix F). The researcher tape-recorded and transcribed all interviews, except for that conducted by telephone during which the researcher took notes.

During semi-structured interviews, the researcher requested that participants describe the staff actions/behaviours that they had found helpful, or would find helpful.

Participants were also asked to identify unhelpful actions/behaviours so those that

would have been helpful in the same situation could be identified. The researcher informed participants that the term "staff" was being used to refer to any employees at the nursing homes.

The first five interviews were regarded as pilot interviews, and were reviewed carefully to see if the interviewing technique should be modified. In particular, it was ensured that the researcher was not "leading" participants, but listening in a non-judgemental manner, seeking clarification where necessary. Although a decision was made to include data from the pilot interviews in the analysis because no major faults in interviewing technique were detected, one significant change was made to the procedure for the remaining interviews. The change added a statement at the beginning of the interview asking people to reflect upon the more difficult times they had experienced. This was because earlier respondents tended to concentrate on residents' care, rather than family members' care. In this way, the focus of the interview was shifted, somewhat, onto the help given to family members.

"Prompts", used to help participants consider an area they had not yet covered, were initially only taken from the review of findings of published research and the data provided by staff. However, as the process progressed, more were added from the findings of previous family members' interviews. The researcher worded these prompts tentatively, stating, for example, that some family members had found a certain kind of staff behaviour helpful. The researcher then asked how the respondent felt about that staff behaviour. The researcher ended interviews by asking participants if they would like to add anything, and thanking them for their input. Participants were also asked if the researcher might contact them later, to clarify interview material or ask

their views on identified themes. The researcher made notes after interviews to act as reminders of context, as suggested by Burnard (1991).

Data analysis plan. An initial check revealed that all the data obtained from the literature review or from staff had been confirmed as relevant by at least one family member. Data to be analysed, therefore, were exclusively contained in family members' interview transcripts.

The analysis of data from interviews with AFC residents' family members was based upon the method described by Burnard (1991):

1. The researcher became immersed in the data in order to understand the frame of reference of each participant. Transcripts were read and re-read, notes being made about the overall impression given by the interview.
2. Where the meaning of any part of a transcript was unclear, the participant was contacted and asked to clarify this.
3. Unusable material, that which was unrelated to the interview topic, was bracketed.
4. Headings were written that categorised all data that were not bracketed.
5. Categories that were similar were subsumed into broader categories with sub-headings.

6. Two colleagues generated categories independently from the researcher, each using transcripts from three different interviews chosen at random. The researcher reviewed the categories already developed based on this collegial input, with a view to eliminating researcher bias.
7. The researcher re-read the transcripts, together with the category and sub-heading lists, and made any necessary adjustments.
8. Four interviewees who had expressed willingness to be involved in the analysis process were contacted and asked to check whether or not their interview statements belonged in the categories nominated by the researcher. They were also asked to examine all the category headings/sub-headings and to comment on these. Any necessary adjustments were made, based on this feedback.

Items were developed from data according to the method described by Fleury (1993):

1. The researcher, once more, reviewed the transcripts and categories.
2. Scale items were generated from each data bit within each category, retaining the language and expression used by participants, and trying to use only language that would be easily understood by any future participants. Categories, defined as dimensions of the concept, became sub-scales.
3. The researcher compared items, combining those that were redundant.

4. The researcher reviewed items, rewording some to increase their clarity and/or brevity.
5. This collection of items formed Draft One of the RACRASST (Appendix G).
Definitions of the concept domains covered by each sub-scale were included in this draft.

At the conclusion of this stage, the researcher presented to the DON/Manager of each participating home a summary of the kinds of things family members in the sample had said they found helpful from staff. This information was not identifiable and was provided in the form of a booklet that could be utilised by staff.

Stage Two: Panel Review and Subsequent RACRASST Revision

Design. A panel of experts pilot tested Draft One of the RACRASST. These experts examined the clarity of items, and the apparent internal consistency and content validity of the sub-scales, as prescribed by Imle and Atwood (1988).

Population definition. The population of interest was now that of family members of Australian ACF residents receiving high or low levels of care.

Panel selection. Experts for the panel were required to be family members of residents in ACFs. However, it was considered preferable that these family members should also have some familiarity with research terminology. For this reason, panel members were initially recruited via an advertisement in a newsletter sent to post-graduate students and staff. Only four people were recruited in this way. The

researcher recruited the fifth person by word of mouth. This person was a final year undergraduate student with a relative in an ACF.

Procedures. The researcher made up packages (Appendix H), each containing an explanatory letter, a consent form, directions, a copy of the draft questionnaire with space beside items for panel members' comments, and a stamped envelope addressed to the researcher. Each sub-scale of the questionnaire was printed on paper of a particular colour, to avoid confusion. In each case, the researcher offered to deliver packages to panel members to explain requirements and answer questions about them. This offer was accepted in three cases. In the other two cases, packages were mailed out and correspondence by electronic mail provided clarification.

Panel members were asked to comment on the clarity of each item, on possible redundancies, on whether each item fitted the definition of the sub-scale, and on whether items of each sub-scale appeared to be consistent (apparent internal consistency). Columns beside the draft items allowed space for these comments, and direction sheets described the suggested format of these comments.

Each panel member completed the review independently, and, in all except one case, the forms were left with participants and returned by mail. The remaining panel member requested that the researcher remain present while the questionnaire was being completed. This request was complied with, but the participant completed the exercise without assistance.

Data analysis plan. In the data analysis plan, following the criteria set by Imle and Atwood (1988), the researcher required that four out of five panel members should

agree that items were clear, not redundant, and congruent with the definition of the appropriate sub-scale for them to be retained in their current form. A similar level of agreement was required when the comments on the apparent internal consistency of the sub-scales were examined. The researcher reviewed items/sub-scales for which this level of agreement was not reached. Redundant items were deleted, unclear items were clarified or deleted according to reviewers' recommendations, and items not fitting sub-scale definitions were deleted or moved according to reviewers' suggestions. Findings of these analyses are to be found in Appendix I. The researcher developed Draft Two of the RACRASST (Appendix J) based on these findings. At this stage, a four point Likert scale (Strongly Agree-Strongly Disagree) was added, together with a "Not Applicable" column as recommended by reviewers. Sub-scale definitions were replaced, on the pages of the questionnaire, with directions. Gridlines were retained to aid clarity, as shown in the appendix, and a large font was used when copies were printed for distribution during the next section of the study.

Stage Three: RACRASST Revisions from Small Sample Responses

Design. Draft Two of the RACRASST remained so lengthy that it might be burdensome for some participants to complete. Therefore, it was decided to include a phase of the study that pre-tested the scale as suggested by Waltz, Strickland, and Lenz (1991). The findings of reliability/validity analyses could then be used to select items to include in the scale, as discussed by Nunnally (1978). Preliminary psychometric properties of the instrument were also established at this stage.

Population, sample, and setting. The researcher selected the sample from the population with which the instrument was to be used to preserve the qualitative validity of the scale. Family members of ACF residents were recruited by advertising in

a local church magazine and a newspaper, tapping personal contacts, and appealing to DONs/Managers of local ACFs to advertise on the researcher's behalf. This process yielded insufficient numbers, so the researcher asked several DONs/Managers of Western Australian ACFs to forward packages to family members (Appendix K). The researcher ensured that family members of those in small and large ACFs were represented. Sample characteristics are shown in Appendix L.

Procedures. When advertisements/appeals were successful, prospective participants telephoned the researcher, who explained the study and offered to send out or deliver packages. Each of these included a letter, consent form, personal details form, directions, a copy of Draft Two of the RACRASST, and a stamped, addressed, return envelope. Each sub-scale of the draft instrument was printed on paper of a different colour. The terms "nursing home" and "hostel" were still used in this documentation as these were considered to be the most easily understood by family members. Packages to be given out by DONs/ Managers contained a letter requesting help, rather than one thanking recipients for their interest.

Family members were asked to complete the draft RACRASST at their convenience, and return it using the envelope provided. A telephone number for inquiries was included in the package.

Data Analysis Plan. The analysis plan included the following steps:

1. The researcher recorded the following statistics for each sub-scale prior to any item deletions: Cronbach's and standardised item alpha co-efficients, and the means and ranges of inter-Item correlations and Item-to-total correlations.

2. The researcher identified and deleted items lacking utility because 5 or more of the 30 responses to them were "Not Applicable", then repeating the statistical assessments detailed in the first step.
3. The researcher used additional correlational analyses to identify items that did not aid in discriminating among the domains of the concept measured by the sub-scales of the instrument. These items would threaten the discriminant validity of the instrument (Jackson, 1970). Identification was achieved by correlating scores for each item with total scores for each sub-scale, and making comparisons. Items that were more highly correlated with total scores of sub-scales in which they were *not* located than with total scores of those in which they *were* located were deleted. Following these deletions, the analyses for Step One were again repeated.
4. Percentages of participants choosing each of the possible responses were examined. If items attracted a single response from 80% or more of participants they were to be deleted because they would not be useful in discriminating among participants.
5. A list was made of items that might lack utility because they had attracted four "Not Applicable" responses.
6. The researcher calculated mean scores of items, and the standard deviations of these scores. Items attracting scores with very high or very low means, or very small standard deviations, might lack utility. These items were listed for possible deletion.

7. The researcher identified (a) items that might not fit well into the sub-scales and (b) items that might be unnecessary to the sub-scales from an examination of sub-scale inter-item correlations and item-to-total correlations. Items that might not fit were those with scores correlating poorly with scores of other items and/or with total sub-scale scores. Items that might be unnecessary were those with scores correlating very highly with the scores of the total sub-scale (Carmines & Zeller, 1979, Nunnally, 1978). All these items were listed for possible deletion. Criteria set demanded that at least 50% of retained item scores correlated with total sub-scale scores in the range 0.40 to 0.70, and that scores of retained items correlated with 50% or more of other item scores in the range 0.30 – 0.70.

8. Listed items were deleted where it was considered that, on balance, their loss would improve the instrument. The likelihood of their loss diminishing the qualitative validity of the instrument was weighed against the threat to the utility of the instrument, and against the burden on participants of using additional items. The Cronbach's alpha co-efficient for each sub-scale was referred to during the process as an indicator of the internal consistency of that sub-scale. Finally, the statistical analyses used in Step One were again repeated.

Findings of analyses are shown in Appendix M. Draft Three of the RACRASST is shown in Appendix N.

Stage Four: Factor Analysis of the RACRASST

The researcher conducted a factor analysis of the RACRASST to assess the construct validity of the scale. The researcher had hypothesised that items clustered into proposed sub-scales measured distinct dimensions of perceived staff support in family members and the factor analysis provided a means to test that hypothesis. Having established the structure of the scale in this way, it was then possible to examine its internal consistency reliability by assessing Cronbach's alpha and theta coefficients, and inter-item and item-to-total correlations. These analyses could also be used as a basis for reducing the number of items in the scale.

Design. The researcher conducted a mail-out of Draft Three of the RACRASST. For the mail-out, items were not arranged in the sub-scales shown in Draft Three in case this influenced the responses of participants. Instead, the researcher presented items in a random arrangement.

Population, sample, and setting. The sample size for a factor analysis needs to be fairly large because the correlations upon which this is based cannot be reliably interpreted in small samples. According to Tabachnick and Fidell (1996), it is "comforting" to have at least 5 cases for every variable (p. 603). The researcher obtained a large sample of 297 family members of ACF residents by asking DONs/Managers of ACFs in six Australian states to forward questionnaires to relatives of residents. However, because of "not applicable" and missing responses only 195 data sets could be included in the factor analysis. Letters were the initial means of contacting DONs/Managers, with slips to be returned in reply-paid envelopes indicating a willingness or unwillingness to assist. The researcher also placed an advertisement in a professional journal that asked DONs/Managers to participate in the study if they

were contacted. Follow-up telephone calls were made to many DONs/Managers who did not return their slips.

The researcher selected DONs/Managers of facilities that had not, previously, been involved in the study, using the *Hospitals and Health Services Yearbook* (1997) and working through the alphabetically arranged listings for each state. Roughly equivalent numbers of ACFs were included from the five larger states. Smaller numbers were included from Tasmania, where the population base is lower. This was so that responses from previously untapped Tasmanian sources could be sought in the next stage of the study. The Northern and Australian Capital Territories were not included in this stage of the study as very few ACFs exist in these areas.

Procedures. The researcher asked DONs/Managers who were prepared to assist how many packages they anticipated distributing, and whether they wished them to be supplied in envelopes or folded to go in with the accounts being mailed out from the facilities. These packages were sent as requested, each including a letter of explanation; a copy of Draft Three of the RACRASST with directions and two "personal details" questions (asking about the relationship with the resident and the length of stay); and a stamped, addressed, return envelope (Appendix D). All written material to potential participants was presented in a large font for easier reading.

Data Analysis Plan. The analysis plan used at this stage is summarised in Table 7. Principal Components Analysis was used as the goal of the analysis was to obtain a practical rather than a purely theoretical solution, "an empirical summary of the data set" as described by Tabachnick and Fidell (1996, p. 625).

Table 7**Analysis Plan: Factor Analysis of Draft Three of the RACRASST**

Step no.	Action
1.	Deletion of items with 20 (6.7%) or more "Not Applicable" or missing responses.
2.	Principal Components Analysis computed, entering six factors and viewing results of both varimax and oblique rotations.
3.	Principal Components Analysis computed, entering "factors with Eigenvalues greater than one" and viewing results of both varimax and oblique rotations.
4.	Selection of the most parsimonious and interpretable solution.
5.	Examination of properties of each newly designated sub-scale: inter-item and item-to-total correlations and Cronbach's Alpha.
6.	Computation of Cronbach's alpha and Theta co-efficient for the total scale and comparison of findings.
7.	Documentation of Draft Four of the RACRASST.

Initially, a six factor solution was requested, as six sub-scales had been designated by the researcher based on theoretical and practical knowledge. The next approach made in the analysis was to discover a possible alternate sub-scale construction. Finally, an analysis was carried out to discover whether or not the instrument should be viewed, instead, as a single scale, without sub-scales.

In addition to these analyses, two lists were made. One was of retained items that had attracted 10 or more "Not Applicable" responses. These items were examined for clarity once more and re-worded, if possible, to avoid possible future misunderstanding(s). The second list was of comments made on the questionnaire by respondents. These were examined with regard to making changes that might improve the questionnaire.

Sample characteristics and findings of analyses are shown in Appendix P. Items retained in Draft Four of the RACRASST are shown in Appendix Q.

Stage Five: Test Re-Test Reliability Analysis of the RACRASST

Design. To determine the stability of the RACRASST over time, two responses to the instrument were sought from each member of small sample. A time interval of 2-3 days was to elapse between initial and repeat responses. This time frame is substantially shorter than the two weeks suggested by Nunnally (1978). However, ACF residents' conditions were considered likely to fluctuate, possibly affecting the support of family members by staff. The use of a shorter time frame meant that that instrument stability could be assessed rather than effects of changes in support.

Population, sample, and setting. The convenience sample was selected from the population of family members of ACF residents. Seven DONs/Managers of ACFs not previously included in the study, and in a variety of states, were asked to hand out packages to family members when they visited. The purpose of the project was explained to these DONs/Managers. Twenty-nine participants were recruited in this way, but one of these failed to return the second questionnaire.

Procedures. Each package included a letter of explanation (Appendix R); two reply-paid envelopes addressed to the researcher; and two copies of the questionnaire, each contained in a separate envelope. Participants were asked to return each questionnaire as soon as it had been completed.

Data analysis plan. Scores of individual items at Time One were correlated with scores at Time Two. Finally, total scores at Time One were correlated with the total scores at Time Two. A brief summary of findings is included in Appendix R. However, summary statistics for the RACRASST, at this stage of its development, are also presented in the summary of the instrument development section of the thesis.

Summary (Instrument Development)

The Relatives' of Aged Care Residents Assessment of Staff Support Tool was developed and tested using five steps. Data for item development were gathered from ACF residents' family members, the literature, and ACF staff. A panel of experts then evaluated items and sub-scales, and this evaluation led to changes in the draft instrument. Findings from administration of the instrument to a small sample of family members led to further changes, including considerable abbreviation of the instrument. Data from 195 family members were used in a factor analysis of the instrument, a

sample size that ensured more than the requisite 5 cases per variable, and further refinement of the instrument occurred at this stage. Test-retest reliability analyses were conducted on responses to the instrument from another small sample.

Table 8 shows summary statistics for the instrument. These summary statistics were calculated using data collected for the test-retest reliability analyses, by which stage it was known that the RACRASST was a single scale with underlying dimensions but no sub-scales. Cronbach's alpha coefficient for the total instrument was 0.97 at Time 1 (T1) and 0.98 at Time 2 (T2). These high coefficients, and the fact that some of the item-to-total and inter-item correlations were also quite high when assessed after the factor analysis, suggest slight redundancy within the scale. However, in view of the immaturity of the RACRASST, all the 29 items included at the end of the factor analysis were retained. Total scores for the 29-item instrument during the test-retest reliability analysis ranged from 60 to 114 at T1 ($M = 89.15$, $SD = 16.19$) and from 60 to 116 at T2 ($M = 88.83$, $SD = 17.35$).

The RACRASST, therefore, whilst requiring further testing and refinement, has established clarity, apparent internal consistency, and content validity. The scale has been found to be unidimensional during assessment of its construct validity, and to demonstrate stability over time. Despite indications of some slight redundancy within the scale, these findings, in addition to those determined during assessment of the internal consistency reliability of the RACRASST, suggest that the instrument possesses satisfactory psychometric properties for an immature instrument. All additional details of findings related to the development of the RACRASST are in the appendices.

Table 8**Summary Statistics for RACRASST Items from Data Collected at Time 1 (T1) and Time 2 (T2) for Test-Retest Reliability Analyses**

Item	M (T1)	M (T2)	SD (T1)	SD (T2)	Correlation	N^a
1) Greet me when I visit	3.27	3.36	0.73	0.68	0.93	28
2) Keep me informed about my relative's condition	3.02	3.04	0.92	0.90	0.90	27
3) Attend to residents' needs promptly	2.95	3.04	0.84	0.84	0.89	28
4) Ensure there is somewhere family members may have private time with residents	3.12	3.20	0.73	0.71	0.96	25
5) Keep me informed about my relative's care	2.84	3.04	0.93	0.85	0.87	27
6) Can be found easily, when I want to talk to them	2.77	2.80	1.00	0.91	0.82	28
7) Seem to be working in an organised manner	3.23	3.14	0.71	0.52	0.78	28
8) Ensure the home is safe for residents ^b	3.36	3.40	0.56	0.50	0.81	28
9) Invite me to come to social events at the home	3.18	3.33	0.78	0.68	0.83	27
10) Say that my input into care helps ^b	2.83	3.00	1.03	0.77	0.86	28
11) Hold any private discussions with me in a private place	2.89	3.04	0.78	0.79	0.82	24
12) Provide "warm care" to residents ^b	3.50	3.32	0.64	0.67	0.74	28
13) Do not allow bad smells to linger	3.43	3.32	0.70	0.77	0.84	28
14) Spare the time to talk to me	3.25	3.14	0.75	0.71	0.84	28
15) Include family members in social conversations	3.18	3.22	0.73	0.67	0.96	22

Item	M (T1)	M (T2)	SD (T1)	SD (T2)	Correlation	N ^a
16) Accept responsibility for the care of my relative	3.25	3.29	0.59	0.60	0.84	28
17) Ask family members about residents' backgrounds	2.93	3.00	0.86	0.82	0.85	28
18) Allow residents to bring in their own pictures, etc.	3.68	3.43	0.48	0.50	0.60	28
19) Keep me informed about how family members may help with resident care in this home ^b	3.00	2.96	0.87	0.96	0.85	24
20) Keep me informed about how any changes in government policy will affect the home	3.22	3.11	0.64	0.75	0.83	27
21) Are regular (i.e. not agency)	3.00	3.00	0.83	0.89	0.87	26
22) Make it clear that resident care comes first	3.36	3.36	0.62	0.62	0.90	28
23) Only relocate residents from their current rooms into different rooms or areas of the home when it is in the best interests of those residents	3.21	3.22	0.83	0.74	0.86	22
24) Set aside an area where visitors and residents may mix	3.41	3.70	0.69	0.69	0.80	26
25) Sometimes use touch to show support for residents' family members who are in distress ^b	3.30	3.43	0.64	0.59	0.93	22
26) Treat my relative as an adult	3.46	3.46	0.58	0.58	1.00	28
27) Are careful with my relative's possessions	2.90	2.85	0.88	0.86	0.93	27
28) Keep my relative comfortable	3.43	3.39	0.57	0.57	0.83	28
29) Who are in management positions ("Top Staff") are friendly to me	3.44	3.56	0.75	0.78	0.97	27

Note: Stem for all items is "staff". ^aNumbers shown are those from correlational analyses, varying due to missing/not applicable data. ^bComplete item includes examples.

Main Study

Introduction

In this section of the study, the researcher used the newly developed PACRASST alongside existing instruments to test the model illustrated earlier in this thesis and develop an improved model. The study design, sampling frame and selection procedures, instrumentation, and data analysis plan are described in the following paragraphs.

Design

The main study was conducted using a cross-sectional, descriptive/predictive correlational, ex post facto design to test a model developed by the researcher and to construct an empirical model. This approach allowed the researcher to examine the strength and direction of relationships among a number of key variables relevant to ACF family-resident support.

Population, Sample, and Setting

The researcher describes the sampling frame and selection of participants here. Characteristics of participants are documented alongside findings of the study.

The sample was selected from the population of family members of Australian ACF residents aged 65 or older. One hundred and seventy DONs/Managers of ACFs in all states and territories of Australia were contacted and asked to pass on packages to potential participants. These DONs/Managers were only contacted if their facilities had not been involved in the study before. The names and addresses of facilities were accessed from the *Hospitals and Health Services Yearbook (1997)*, and they were utilised in alphabetical order. Fifty-four DONs/Managers agreed to assist, taking a total

of 890 packages. Some indicated they would put these into account envelopes, and the remainder said they would give them out to visitors. Two hundred and thirteen data sets were obtained from this "mail-out". This indicates a response rate of 24%, assuming that all packages were distributed as agreed.

Instrumentation

Here, the researcher describes the piloting of instruments to be used in the study, changes made as a result of piloting, properties of the instruments, and the final presentation of questionnaires.

The researcher utilised the following questionnaires in the main study: the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988), the "Family Help" sub-scale of the Primary Group Helping Behaviour Scale (PGHBS) (Rice, 1988), the General Well-Being Schedule (GWB) (Dupuy, 1977, cited in McDowell & Newell, 1996), the Time Pressures on the Family Member Scale (Brody et al., 1990), a modified version of a demographic questionnaire previously designed by Toye and associates (1996), and the newly developed RACRASST. The researcher decided to retain the "not applicable" response option in the RACRASST for the main study, despite the resulting potential for loss of data, so that another opportunity would be available to review items in this immature instrument that were not well-understood or were inapplicable to many participants.

Piloting. With the exception of the RACRASST and the demographic questionnaire, which the researcher had used with similar samples before, all questionnaires were pilot tested.

The researcher obtained a convenience sample of 20 family members of ACF residents. This sample was accessed via acquaintanceships with a number of DONs of ACFs. Packages distributed by these DONs included a letter of explanation; the questionnaires printed in a large font, with directions and space for comments about each item; and a stamped envelope addressed to the researcher.

Findings generally resulted in minor changes being made: the researcher simplified directions given for the PGHBS (Rice, 1988) and changed the way responses were to be marked for the last few questions of the GWB (Dupuy, cited in McDowell & Newell, 1996), replacing bars to be circled with boxes to tick. However, responses to the eight items included in the Time Pressures on the Family Member Scale (Brody et al., 1990), designed for use in North American nursing homes, were either very strongly negative or omitted, suggesting they might be offensive to respondents. In view of this, six items, listed in Table 9, were not included in the final package sent to participants. Instead, the researcher added Items 4 and 8 to the demographic questionnaire, as Items 18 and 19, after an introductory sentence. As shown with square brackets in the table, the word "parent" was replaced with "relative" throughout this questionnaire, prior to pilot testing.

All the questionnaires, as used in the main study, are documented in Appendix 5, as is permission from the author of the PGHBS to use her scale.

Table 9**Omissions from the Time Pressures on the Family Member Scale****(Brody et al., 1990)**

-
1. Because of my involvement with my parent [relative], I don't have time for myself

 2. I feel that the present situation with my parent [relative] doesn't allow me as much privacy as I'd like

 3. I feel that my social life is suffering because of my involvement with my parent [relative]

 5. I can fit in most of the things I need to do in spite of the time taken up by my parent [relative]

 6. It's hard to plan things ahead when my parent's [relative's] needs are so unpredictable

 7. My parent's [relative's] condition is interfering with my going on vacation or weekend trips
-

The Multidimensional Scale of Perceived Social Support (Zimet et al., 1988).

Informal support is defined, for the purpose of this study, as being the social support provided by family members, friends, and peers. Social support, including formal and informal support, is defined as communicating information, esteem, aid, and reliable

alliance (Stewart, 1993). Information, however, is viewed as a part of formal rather than informal support.

The MSPSS (Zimet et al., 1988) is a 12-item instrument that measures perceptions of informal social support. The items refer to all three of the dimensions of informal social support include in the definition used in this study: esteem, aid, and reliable alliance. The MSPSS utilises a 7-point, Likert-type scale, strongly disagree to strongly agree, and no items need reverse coding. The instrument consists of three sub-scales: "Family", "Friends", and "Significant Others". In testing, Cronbach's alpha for the sub-scales has varied from 0.81 to 0.98, and for the total scale it has ranged from 0.84 to 0.92 (Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Predictive validity has been established with the use of the Depression and Anxiety sub-scales of the Hopkins Symptom Checklist, and factorial validity has also been established (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974, cited in Zimet et al., 1988). The MSPSS was found to be the least burdensome measure of informal support that had adequate established psychometric properties and fitted the definition of informal support used in this study.

The Primary Group Helping Behaviour Scale (Rice, 1988). The definition of informal support is also relevant to the selection of the "Family Help" sub-scale of the PGHBS. This sub-scale was selected to measure the informal support family members reported providing to their relatives in the ACFs so it needed to measure the esteem, aid, and reliable alliance, but it also needed to be context specific. The PGHBS was designed as a 60-item measure of the help given to nursing home residents. It has established face and content validity, and preliminary construct validity. Thirty-six items form the "Family Help" sub-scale, as confirmed by factor analysis. These items measure esteem, aid, and reliable alliance in the context of an aged care setting.

Cronbach's alpha for this sub-scale is reported as being 0.94. Items have a 5-point, Likert type response scale ranging from never (1) to always (5). No items need to be reverse coded. This instrument was the only one found that measured the necessary dimensions of family members' support for ACF residents, had undergone testing for construct validity, and had established acceptable internal consistency reliability.

The General Well-Being Schedule (Dupuy, cited in McDowell & Newell,

1996). The psychological well-being of participants in this study was defined as the balance between participants' positive and negative symptoms or feelings, as described by McDowell and Newell (1996). The 18-item version of the GWB was chosen to measure psychological well-being because it measures this balance, is not unduly burdensome to respondents, and possesses acceptable established psychometric properties. The items of this instrument also appear less intrusive than some of those included in similar instruments examined by the researcher. In this version of the GWB, the first fourteen items use six-point response scales, and the final four items use ten-point response scales. Low scores reflect low well-being and high scores reflect high well-being. Therefore, responses are reverse-coded for items 1, 3, 6, 7, 9, 11, 13, 15, and 16. Fourteen is deducted from final scores to assess well-being in categories listed by the author (McDowell & Newell, 1996).

McDowell and Newell (1996) describe the GWB as having produced "outstanding reliability and validity results" (p.213). This tool has six sub-scales, confirmed by factor analysis. Sub-scales are labelled "Anxiety" (Items 2, 5, 8, and 16), "Depression" (Items 4, 12, and 18), "Positive Well-Being" (Items 1, 6, and 11), "Self Control" (Items 3, 7, and 13), "Vitality" (Items 9, 14, and 17), and "General Health" (Items 10 and 15). Internal consistency co-efficients for the sub-scales have ranged from 0.72 to 0.88. For

the total scale, reports of internal consistency co-efficients range from 0.88 to 0.95. (Edwards et al., 1978; Fazio, 1977; Himmelfarb & Murrell, 1983; Ware et al, 1979, all cited in McDowell & Newell).

Demographic Questionnaire. The Demographic Questionnaire was used to document demographic characteristics of family members (Items 2, 3, and 4), those of their relatives in ACFs (Items 5 and 6), and the type of care received by residents ("hostel type", low care; or "nursing home type", high care) (Item 9). It was also designed to document the following (as reported by family members):

1. The familial relationship existing between the family member and the resident (Item 1) The coding of this variable was as indicated on the questionnaire.
2. The main disability of the resident as an indicator of a moderate or high degree of dementia existing or not existing in the resident (Item 7). The coding of this variable was dichotomous. Only when dementia was listed as being the main disability, or, as did occur, one of several main disabilities, was the resident designated as "cognitively impaired". The researcher recognises that measuring this variable in this manner meant that residents who suffered from dementia but who had other more major problems were designated as "cognitively intact". However, given that it was necessary to obtain this information from family members, not health professionals, this seemed a reasonable strategy to ensure that only residents with moderate or severe dementia were described as cognitively impaired, not those who merely had a tendency to be forgetful and disorientated.

3. The happiness of the resident with regard to living in an ACF, as an indicator of the resident's adjustment to life in an ACF (Item 8). This item was scored using a five-point scale with an additional option, "unable to tell". Scoring is shown in Table 10.
4. The length of time since the admission, in months (Item 10).
5. The degree of pre-admission contact between the family member and the resident (Item 11), the degree of current contact between them (Item 12), and the closeness of the relationship between the members of this dyad (Item 17). All these items were viewed as indicators of the family member's feelings of attachment to the resident. Although the items of this "attachment index" that refer to contact, rather than to feelings, appear incongruous in this context, they were included in an attempt to balance the tendency that might occur to produce a socially desirable response indicating feelings of closeness. These three items were scored as is shown in Table 10 and a summated score was to be used as a measure of feelings of attachment. However, this measure was reviewed and revised when data were prepared for the initial regression analyses (see p. 116).
6. The pressures on the family member. From the literature, these pressures are known to include poor health, an inability to speak the language of the country, responsibilities outside the ACF, a lack of proximity to the ACF, and societal/familial expectations/obligations. People from non-English speaking backgrounds would, by definition, be unable to participate in this study, and measuring societal/familial expectations/obligations was beyond the scope of the study. A pressure index was therefore constructed to measure the remaining known pressures. Items 13, 14, and 15 measured problems encountered when travelling to visit the ACF and,

therefore, all associated with a lack of proximity to the ACF. Item 13 referred to the use of various modes of transport, and was scored according to the degree of inconvenience usually associated with them. Item 14 referred to the time taken on the journey, and Item 15 measured the degree of difficulty of the journey. Item 16 measured the perceived health of the family member. Items 18 and 19 (from Brody et al., 1990) measured the degree of conflict in the family member between other commitments and commitment to the resident (see Table 10 for scoring details for each item). Had the other items from Brody and associates' Time Pressures on the Family Member Scale been included, the time pressures already reflected in the items concerning conflict between commitments would have been measured in additional dimensions. A summated score of items 13, 14, 15, 16, 18, and 19 was to be calculated as a measure of pressures in the family member. However, upon review of the data prior to the first regression analyses, this index was also reviewed and refined (see again p. 116).

Presentation. Before the questionnaires were mailed out for the main study, the researcher added an example at the beginning of the RACRASST, inserted notes to assist users (e.g. "the next question is over the page"), expressed thanks to participants, and allocated a section for participants' comments. Questionnaires were presented to respondents in packages. Each package included a large font copy of a letter of explanation (Appendix T), and of a booklet comprised of the five questionnaires, plus a reply-paid envelope addressed to the researcher.

Table 10**Scoring of Variables in the Demographic Questionnaire**

No.	Item	Scoring						
		1	2	3	4	5	0	
8	Happiness of resident	very unhappy	quite unhappy	neither happy nor unhappy	quite happy	very happy	unable to tell	
11	Pre-admission contact	< monthly	monthly	fortnightly	weekly	daily		
12	Current contact	< monthly	monthly	fortnightly	weekly	daily		
13	Transport inconvenience	own car	walking	lifts	public transport	taxi		
14	Length of journey time	1-15 minutes	15-30 minutes	30-45 minutes	45-60 minutes	> 60 minutes		
15	Journey difficulties	very easy	quite easy	not too difficult	quite difficult	very difficult		
16	Health	very good	good	fair	poor	very poor		
17	Closeness of relationship	not at all close	not very close	unsure	close	very close		
18	Resident/home pressures	not at all ----->					very much so	
19	Resident/work pressures	not at all ----->					very much so	

Data Analysis Plan

The data analysis plan for main study findings included provision for the following: (a) a descriptive analysis of the characteristics of participants; (b) exploration of all other data; (c) dealing with missing data; (d) checking that data met statistical assumptions for the use of multiple regression analyses; (e) the use of hierarchical regression for the testing of hypotheses illustrated in the model, and for the testing of implicit hypotheses nominating alternative relationships among variables included in the model; and (f) the use of stepwise regression analyses to explore relationships existing among any variables included in the study, including demographic characteristics, to construct an improved model. The multiple regression analyses were conducted according to the protocol documented by Tabachnick and Fidell (1996) and were to include at least five cases for every variable entered as proscribed by these authors.

Summary (Main Study)

Two hundred and thirteen family members of Australian ACF residents provided cross-sectional survey data for testing hypotheses about the relationships among variables. All respondents were contacted via DONs/Managers of the ACFs. After changes were made because of responses in the pilot tests, five questionnaires were included in the mail-out. However, the Demographic Questionnaire was modified to include two questions from a sixth questionnaire that had also been pilot tested. The data analysis plan was for descriptive and multiple regression analyses.

Ethical Considerations

The ethical issues requiring consideration in this research are the same for the two sections of the methodology: instrument development and the main study. These include: (a) general issues concerning the use of human subjects, (b) issues arising when selecting a sample from a vulnerable population, and (c) issues arising when subjects are selected via a third party.

The Use of Human Subjects

Burns and Grove (1987) state that those carrying out research using human subjects must do the following to ensure their research is ethically sound: (a) balance the potential risks and benefits of the proposed research, (b) submit research proposals for institutional review, (c) obtain informed consent from participants, and (d) protect the rights of these participants.

For this study, risks to the wider community were non-existent, and risks to participants were restricted to the possibility of interviewees in the instrument development phase becoming upset when reflecting upon distressing experiences. A plan was put in place, prior to interviews, to minimise distress in participants. This plan was that the interviewer (the researcher) was to offer to terminate the interview if a respondent became upset, and to inform the interviewee of available counselling services. Additionally, should the researcher need to contact any interviewee again, she was to check that the family member's relative in the ACF had not died, prior to making that contact. This was to be done without revealing the participant's identity. One participant did become upset at interview, but requested to carry on. This participant stated it helped her to speak about her experience. She accepted

information about counselling services, DONs supplied general information about recent deaths to the researcher when repeated contact needed to be made.

Permission to carry out the proposed research was given by the Committee for the Conduct of Ethical Research of Edith Cowan University (Appendix U). The committee examined the proposal and negotiated one change with the researcher, ensuring that participants would be accessed via DONs rather than via the Aged Care Assessment Teams involved in the admission process. This was to encourage a collegial rather than an adversarial relationship with the DONs.

The researcher obtained written, informed consent to participation from participants, except in two cases. Firstly, the return of survey data elicited using an explanatory letter was deemed to indicate informed consent had been given. Secondly, several staff volunteered information for the study about the staff actions/behaviours they believed helped family members. Verbal, informed consent was obtained from these staff to allow the researcher to use the information they had given.

All participants in the study were made aware that they had the right to confidentiality, to refuse or cease participation at any time, and to have their questions answered. They were all also given contact numbers where inquiries about their participation would be answered. Where data needed to be identified for follow up purposes, code numbers were allocated, and only the researcher had access to a master list. The researcher kept this list locked away, separately from any data. The identity of participants was not revealed to others.

Sampling from a Vulnerable Population

As discussed by Sachs, Rhymes, and Cassel (1993), family members may fear the release to ACF staff of any information they provide. This might be because they believe reprisals will be directed towards their loved ones in the ACFs. For this reason, the researcher made it clear, in written and verbal communication with participants, that the identity of respondents would never be revealed by her. The researcher also pointed out to interviewees that their choice to be interviewed in the ACF would probably mean that staff would be aware of their participation. Alternative venues were offered to avoid this situation.

The Selection of Subjects via a Third Party

Selection of subjects via a third party, in this case the DONs/Managers of ACFs, has obvious implications for sampling bias that are discussed elsewhere. However, it also has ethical implications. Participants in this research may have been concerned that DONs/Managers knew they took part. This was not an issue where all residents' relatives received packages with monthly statements. However, it could not be avoided where staff distributed packages directly. All that could be done to remedy this situation was to ensure that the confidentiality of individual responses was made known to all participants. This issue was considered so important that coding to allow follow up was dispensed with after the very early stages of instrument development. In this way, participants were assured that not even the researcher knew their identity. Additionally, all responses were mailed directly to the researcher, even in the local area where boxes for questionnaires placed in the ACFs could have been emptied by the researcher. This avoided any concerns participants might have had about others having access to their completed questionnaires.

Summary (Ethical Considerations)

In this study, the usual steps were taken to ensure that the rights of human subjects were protected. Additionally, steps were taken to ensure participants knew their identity would not be revealed to others, even when this meant incurring additional postal expenses or being unable to contact respondents for follow-up. These more exceptional measures were taken because the sample was from a vulnerable population obtained via third parties.

Overall Summary

The methodology of this study took part in two phases. The first phase, Instrument Development, ensured that an instrument with documented psychometric properties, the RACRASST, was available to measure ACF residents' relatives' perceived support from the staff. In the second phase, the Main Study, the researcher collected cross sectional survey data for the testing of a hypothesised model and the development of an empirical model. The RACRASST was used in the main study, alongside several other questionnaires. Ethical issues related to the use of human subjects from a vulnerable population selected via third parties.

CHAPTER 1V

Findings of the Main Study

Introduction

In this section of the thesis, the researcher documents participants' characteristics, findings of exploratory analyses, and details of the preparation of data for multiple regression analyses. Finally, findings of the following main analyses are presented:

- Step I. Hierarchical regression analyses testing relationships among variables as hypothesised in the model (Figure 1).
- Step II. Hierarchical regression analyses testing possible alternative relationships among variables illustrated in the model.
- Step III. Stepwise regression analyses exploring possible relationships among any variables for which data were collected in this study, including demographic characteristics.

At all times, knowledge of the literature was used to guide the analytical process. The researcher used the Statistical Package for the Social Sciences (SPSS for Windows) for all analyses, with alpha set at ≤ 0.05 unless otherwise stated.

Sample Characteristics

The researcher summarises responses to the Demographic Questionnaire in this section, but does not include responses to Items 18 and 19 (from Brody et al., 1990). Details of responses to these items are included with findings of exploratory analyses.

The sample of 213 family members of ACF residents comprised participants from all Australian states and the Australian Capital Territory (ACT). No questionnaires were identifiable as having been returned from the Northern Territory, but 5 participants did not supply their postcodes. Numbers of data sets returned from each state/territory and from metropolitan/rural areas are documented in Table 11. Reference to 1996 census data (Australian Bureau of Statistics, 1996a, 1996b) showed that participants came from areas varying widely in socio-economic profiles.

Table 11

Originating Areas of Responses

State/Territory	Metropolitan Area	Rural Area	Total
ACT	12	5	17
New South Wales	14	12	26
Queensland	6	12	18
South Australia	59	7	66
Tasmania	0	18	18
Victoria	12	1	13
Western Australia	48	2	50

Most participants were middle-aged or elderly (see Table 12). Only 5 were aged 40 years or younger, and 32% were aged between 51 and 60 years. Approximately 50% of participants were aged over 60 years, and 18 of these were older than 80 years.

Most participants (56%) indicated that their health was good (85 cases) or very good (56 cases). However, 8 participants (4%) stated that their health was poor or very poor. Sixty participants (28%) reported a "fair" level of health, and 4 failed to respond.

Table 12

Participants' Ages

Age Group	Number of Participants
18-40	5
41-50	34
51-60	67
61-70	50
71-80	37
80+	18
Missing responses	2

Residents' ages, as reported by their relatives, ranged from 65 to 102 years with approximately 75% being older than 80 years. Residents were predominantly female (151, 71%). Their main diagnoses were varied and often multiple. Seventy-four residents (35%) were reported to have Alzheimer's Disease (AD), but another 10 (5%) were reported to have dementia as a main diagnosis. The length of residents' ACF occupancy varied from 2 weeks to 19 years ($M = 28$ months, $SD = 34.33$ months). Participants indicated residents received nursing home-type care in 170 cases (80%) and hostel-type care in 37 cases (17%). Two participants stated they did not know the level of care received and 4 failed to answer this item. Family members reported that residents were very happy to be living in the ACF in 23 cases (11%), quite happy in 67 cases (32%), neither happy nor unhappy in 67 cases (32%), quite unhappy in 24

cases (11%), and very unhappy in 13 cases (6%). Fifteen family members stated they were unable to tell if their relative was happy or unhappy. Four responses were missing.

Twenty-six participants (12%) indicated they had received either no formal education or only primary level education. In contrast, there were 9 participants (4%) with post-graduate qualifications, and 37 (17%) held degrees. Ninety-nine people (47%) had finished their education at secondary school, and 40 (19%) held trade qualifications. Two responses were missing.

One person failed to indicate the familial relationship held with the resident, however, this person was identifiable as a relative from comments made at the end of the questionnaire so data from this source were included for analyses that did not require an entry for "familial relationship". Other relationships were as shown in Table 13. Daughters comprised almost 50% of the sample, wives 15%, sons 11%, and husbands 10%. Seven people indicated they were children of residents but did not state whether they were sons or daughters.

Participants indicated they visited their relatives in the ACFs weekly in 89 cases (42%), and daily in 110 cases (52%). Three family members (1%) made contact less frequently than monthly, and 6 (3%) either fortnightly or monthly. A variety of modes of transport were used for visiting. One hundred and seventy participants (80%) used their own cars, 20 (9%) walked, 12 (6%) used public transport, 4 (2%) relied upon lifts, and 3 (1%) used taxis. Reported journey lengths varied from 1 minute to 8 hours ($M = 21.74$ minutes, $SD = 36.69$). The majority of participants (168, 69%) reported finding their journey to the ACF easy (68 cases) or very easy (100 cases). Six people

(3%) stated it was very difficult or quite difficult to travel to the ACF, and 34 (16%) indicated it was "not too difficult". Five responses were missing.

Table 13

Familial Relationships of Participants with Residents

Relationship	Number of Participants
Husband	22
Wife	32
Daughter or stepdaughter	102
Son	24
Daughter-in-law or sister-in-law	13
Sister	5
Niece or nephew	5
Grandchild	2
Adult child (unspecified)	7

Most participants (124, 58%) reported feeling very close to their relative in the ACF. A further 65 people (31%) reported feeling close, 11 (5%) were unsure, and 8 (4%) stated they did not feel very close to the resident. No one reported feeling "not at all close", and 5 responses were missing.

Pre-admission contact between family members and ACF residents, including telephone contact, was reported as having been daily in 139 cases (65%), weekly in 61 cases (29%), fortnightly in 5 cases (2%), and monthly or less often in 4 cases (2%). Four responses were missing.

In summary, participants in the study came from a wide variety of locations, educational backgrounds, and socio-economic backgrounds. Daughters comprised approximately 50% of the sample but many spouses also participated. Poor health was unusual in these participants, and most reported visiting the ACF at least weekly. Additionally, most participants reported pre-admission contact that was at least weekly, and feeling close or very close to their relatives in the ACFs. The majority of participants reported using their own cars for visits, and finding the journey easy or quite easy, while the mean journey time was 21.74 minutes. Most residents were female, aged over 80 years, receiving nursing home-type care, and their length of stay in the ACFs varied widely. Forty percent of the residents reportedly had a main diagnosis of dementia. Also according to family members' reports, residents varied widely in the degree to which they felt happy to be living in the ACFs.

Data Preparation and Exploration

Before the main analyses, the researcher assessed the psychometric properties of the instruments as used in this study; dealt with missing and "not applicable" responses, re-coded dichotomous responses; explored data; and screened data to ensure the necessary assumptions for the analyses were met, taking action when this was required/desirable. This process is detailed in the following paragraphs.

Re-assessment of the Psychometric Properties of the Instruments

The researcher first evaluated the psychometric properties of the following instruments, as used in this study: (a) the Relatives of Aged Care Residents Assessment of Staff Support Tool (RACRASST), (b) the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988), (c) the "Family Help" sub-scale

of the Primary Group Helping Behaviour Scale (PGHBS) (Rice, 1988), (d) the General Well-Being Schedule (GWB) (Dupuy, 1977, cited in McDowell & Newell, 1996), and (e) the two items from the Time Pressures on the Family Member Scale (Brody et al., 1990) (shown as Items 18 and 19 of the Demographic Questionnaire). Next, the researcher examined the properties of the indicator scales, devised for use in this study.

As the first step towards assessing properties of the main instruments, the researcher checked proportions of missing/"not applicable" responses for each item. Only two items had a greater than 5% incidence of these responses: Items 21 and 23 of the RACRASST. These items were deleted from the analyses. Remaining "not applicable" responses for the RACRASST were treated as missing data for reliability estimates.

Findings of reliability estimates indicated that the Standardised Item Alpha (SIA) for the 27-item RACRASST was 0.96, a figure that could not be improved upon by the deletion of further items. Additionally, it was noted that more than 50% of RACRASST item scores correlated with the total score in the range 0.40 to 0.70, and more than 50% of inter-item correlations fell between 0.30 and 0.70. This confirmed that the remaining items were neither superfluous nor irrelevant. SIAs for the MSPSS (Zimet et al., 1988), the PGHBS sub-scale (Rice, 1988), and the GWB (Dupuy, 1977, cited in McDowell & Newell, 1996) ranged from 0.94 to 0.95 and, again, deletion of further items would not have improved these reliability estimates. Inter-item and item-to-total correlations for the established instruments did not always fall within the guidelines noted above. However, deletion of any of these items may have threatened the validity of the scales, so all were retained. The SIA for the two items of the Time Pressures on

the Family Member Scale (Brody et al., 1990) was 0.82 (see Table 14 for a summary of the psychometric properties of Instruments used in this study).

Table 14

Psychometric Properties of Items from Scales as Used in the Current Study

Statistic	RACRASST	MSPSS	FGHBS	GWB	Time pressures
Inter-item correlations:					
Mean	0.50	0.56	0.30	0.54	N/A
Range	0.28-0.83	0.38-0.90	-0.06-0.87	0.31-0.80	0.70-0.70
Item-to-total correlations:					
Mean	0.67	0.72	0.53	0.75	N/A
Range	0.58-0.78	0.61-0.79	0.31-0.72	0.59-0.83	N/A
Cronbach's alpha	0.96	0.94	0.93	0.94	0.82
Standardised item alpha	0.96	0.94	0.94	0.95	0.82
Number of items	27	12	36	18	2

The two items from the Time Pressures on the Family Member Scale (Brody et al., 1990) were re-examined later in the context of the pressure index. This examination is described in the following paragraph.

Indicator scales devised by the researcher for use in this study were to measure (a) the family member's feelings of attachment for the resident (Items 11, 12, and 17 of the Demographic Questionnaire), and (b) the family member's pressures (Items 13, 14, 15, 18, and 19 of the Demographic Questionnaire). Items 18 and 19 were the two items from the Time Pressures on the Family Member Scale (Brody et al., 1990). The

following findings and actions resulted from an examination of the properties of these indicator scales:

1. The SIA for the attachment scale (3 items), was found to be low, 0.40. Additionally, upon further examination, only Item 17 appeared to successfully measure the family member's feelings of attachment for the resident. This item asked "How close do you feel to your relative in the facility (hostel or nursing home)?" Consequently, Items 11 and 12, measuring pre-admission and current contact between the family member and the resident, were omitted.
2. The SIA for the original scale of pressure indicators in the family member (Items 13, 14, 15, 16, 18, and 19) was also found to be low, 0.60. Therefore, the same statistic was calculated when various items were omitted. The optimum solution was when only two items were included. These were Items 18 and 19, the items from the Time Pressures on the Family Member Scale (Brody et al., 1990) (SIA = 0.82, see Table 14). The other items, measuring respondents' perceptions of their health and journey related factors, were omitted.

The actions described above meant that feelings of attachment of the family member were now measured by a single item, and pressures in the family member were measured by a pressure index of two items. Finally, a journey index was constructed using relevant items that had been omitted from the pressure index. The journey index included Items 14 and 15 (journey length multiplied by degree of difficulty). Item 13, referring to modes of transport, had been coded according to the degree of difficulty associated with modes of transport. This depended upon the subjective view of the researcher so, after consideration, it was omitted.

Findings of Initial Data Exploration

The researcher next examined descriptive statistics obtained using the RACRASST, the MSPSS (Zimet et al., 1988), the PGHBS sub-scale (Rice, 1988), the GWB (Dupuy, 1977, cited in McDowell & Newell, 1996), and the two indices that measured pressures and journey time/difficulty. Findings are summarised in Table 15 and are based on total scores for each instrument. For these exploratory analyses, "not applicable" responses from the RACRASST were coded as missing data.

According to McDowell and Newell (1996), Dupuy advocates the categorisation of GWB scores using total scores less 14. Categories are listed as "severe distress" for scores ranging from 0 to 60, "moderate distress" for scores from 61 to 72, and "positive well-being" for scores from 73 to 110. When 14 was deducted from the mean GWB score, shown in Table 15, it became 75.31. This fact, combined with the fact that the standard deviation of GWB scores was found to be 20 in an apparently normal distribution of scores, indicates that approximately one third of participants had scores between 55.31 and 75.31. Many family members included in this study, therefore, were experiencing "moderate distress".

Findings of data exploration also showed that participants generally reported their levels of formal and informal support to be quite high, and indicated they provided high levels of support to their family members in the ACFs. Additionally, levels of pressures (feeling torn between the resident and other commitments) reported by participants tended to be moderate, and journey difficulties/times varied widely.

Table 15**Descriptive Statistics from Scales used in the Main Study**

Scale or Index	Minimum	Maximum	Possible maximum	M	SD	N^a
RACRASST	56.00	108.00	108.00	90.32	12.31	177
MSPSS	19.00	84.00	84.00	67.20	15.24	209
FGHBS	44.00	180.00	180.00	142.83	25.13	193
GWB	32.00	122.00	124.00	89.31	20.00	200
Pressures	2.00	10.00	10.00	4.78	2.48	210
Journey	5.00	960.00	-	80.04	88.64	206

Note.

^aN varies according to the amount of missing data for each scale/index.

Missing and "Not Applicable" Responses

Missing responses were noted for all instruments, however, "not applicable" responses were only possible for the RACRASST. These were considered particularly carefully, as they were useful for Instrument revision, but had the potential to lead to the loss of data for analyses.

In the case of the MSPSS (Zimet et al., 1988), the PGHBS sub-scale (Rice, 1988), and the GWB (Dupuy, 1977, cited in McDowell & Newell, 1996), the researcher replaced missing data with series means prior to regression analyses. In the case of the RACRASST, series means were also used to replace missing data, but these means were calculated without including "Not Applicable" responses (coded as '0' during data entry). Missing data for the Demographic Questionnaire were not automatically replaced with series means. Instead, SPSS default settings for dealing with missing

data during individual analyses were used. However, "unable to tell" responses in Item 8 were re-coded as missing, as were "unsure" responses in Item 9.

In order to ensure that data use was maximised, the researcher used mean totals for scales included in the regression analyses. This practice allowed the researcher to omit RACRASST "not applicable" responses without excluding additional RACRASST data.

Dichotomous Variables

Two categorical items from the Demographic Questionnaire needed to be entered as dummy variables to allow regression analyses to be conducted for model testing. As recommended by Burns and Grove (1987), Item 1 (familial relationship) was re-coded in this way, becoming a series of dichotomous variables (spouse/non-spouse, etc.). Additionally, the researcher re-coded Item 7 to show whether or not dementia, as the main problem, was present in the resident, and entered a dummy variable for this item. Finally, the researcher constructed a dichotomous variable indicating the gender of the family member. This variable was for use in the analyses developing an empirical model. It was constructed to allow an examination of the possible underlying influence of gender on any relationship found between "familial relationship" and dependent variables. Gender of the resident was already coded dichotomously.

Data Screening

Data screening to check that variables met the necessary assumptions for multiple regression analysis resulted in a variety of actions being taken, as recommended by Tabachnick and Fidell (1996). The plan for this procedure is illustrated in Table 16.

Table 16**Plan for Confirming Assumptions Underlying the Use of Regression Analyses (from Tabachnick & Fidell, 1996)**

Assumption	Check	Corrective action
◆ Dependent variables need to be normally distributed and other continuous variables are preferably normally distributed.	◆ Kolmogorov-Smirnov test ◆ Examination of skewness and kurtosis	◆ Transformations, if any, that alter the distribution of the variables so they become more normally distributed ◆ Choose the most effective transformation
◆ Linear relationships should exist between independent and dependent variables	◆ Bivariate scatterplots between independent and dependent variables (see also examination of residuals)	◆ Not available ◆ Need to review variables used in analyses

Table continues.

Assumption	Check	Corrective action
◆ Normality and independence of residuals is required	◆ Scatterplots/histograms of residuals	◆ Not available so need to review variables used in analyses
◆ There should be no outliers that will impact upon findings	◆ no 90:10 splits in dichotomous variables ◆ no univariate outliers scores outside x SDs from the mean according to $p = 0.001$ criterion and no multivariate outliers	◆ Check data entry is correct ◆ Delete if not part of the population ◆ Transform variable or consider changing scores if case is in the population
◆ There should be no multicollinearity or singularity	◆ Correlation matrix	◆ Avoid using highly/perfectly correlated variables in an analysis

Firstly, all continuous variables were checked to see whether or not they were normally distributed. Normal distribution of the dependent variables included in multiple regression analyses is considered to be essential. However, according to Tabachnick and Fidell (1996, p. 71) solutions are "usually quite a bit better" when all the variables in multivariate analyses are normally distributed. Accordingly, independent variables as well as dependent variables were checked. Transformations of variables used in the final analyses are shown in Table 17.

Five variables included in the model were non-normally distributed according to findings of the Kolmogorov-Smirnov test for normality of distribution. Item 8 of the Demographic Questionnaire, measuring the family member's perceptions of the resident's adjustment, and the pressure index both produced data distributions that were marginally negatively skewed (-0.41 and -0.49) with negative kurtoses (-0.24 and -0.81). However, transformations failed to improve upon the distributions of these variables, so they were used in their original form. The remaining three of these variables were transformed using the guidelines presented by Tabachnick and Fidell (1996):

1. The distribution of "time since admission", hereafter referred to as "length of stay" was positively skewed and exhibited a positive kurtosis. This variable was transformed, and the logarithm used instead.
2. The distribution of "attachment" was negatively skewed and also exhibited a positive kurtosis. This was reflected and transformed, the square root being used instead. It was noted that the polarity of responses was reversed by this action.

3. The distribution of MSPSS scores was negatively skewed (0.90), with a marginal positive kurtosis (0.28). A transformation was effected using the logarithm of the reflection. This also resulted in a reversal in the polarity of responses.

As stated in Tabachnick and Fidell (1996), the polarity of responses is reversed in variables that are reflected because this procedure is one that converts a variable with negative skewness to one with positive skewness prior to the appropriate transformation. The distributions of the three new variables were closer to normal than the distributions of the variables they replaced.

Variables not included in the model were also examined to see whether or not data were normally distributed. As a result, three more transformations were effected. Initially, the journey index was replaced by its logarithm. Next, measures of previous and present contact between the family member and the resident, Items 11 and 12 of the Demographic Questionnaire, were reflected and inverted.

Table 17

Transformations of Variables for the Regression Analyses

Variable	Distribution Characteristic	Transformation
Length of stay	Positive skew, positive kurtosis	Logarithm
Attachment	Negative skew, positive kurtosis	Square root of reflection
Informal support	Positive skew, negative kurtosis	Logarithm of reflection
Journey index	Positive skew, positive kurtosis	Logarithm
Previous contact	Negative skew, negative kurtosis	Inverted reflection
Present contact	Negative skew, negative kurtosis	Inverted reflection

The second part of the plan for screening data involved the checking of bivariate scatterplots between all dependent and independent variables. These tended to confirm the presence of the linear relationships necessary for the use of multiple regression analyses.

Thirdly, preparatory regression analyses were conducted so that scatterplots and histograms of residuals could be examined. Where scatterplots of residuals present no pattern and histograms show residuals are normally distributed, this provides additional evidence that data are normally distributed, and that independent variables have linear relationships with dependent variables. Additionally, it shows that homoscedasticity exists between predicted scores of the dependent variables and errors of prediction (Tabachnick & Fidell, 1996).

When regression analyses were trialed, scatterplots of residuals generally appeared to have no pattern, although those where variables were measured by single items had a distinctive appearance. Histograms of residuals generally demonstrated normal or near normal distributions. However, a marginal negative skew was evident in the distribution of residuals where FGHBS scores were used as the dependent variable. These scores measured family members' self-reported enacted support for residents. No remedial action was initiated because of this skew as it was only marginal.

Executing the fourth part of the plan, outliers were identified. No univariate outliers threatened the validity of analyses, but one case was seen to be a significant multivariate outlier at the 0.001 level for model testing, using the computation of Mahalanobis estimates. This single outlier had the potential to unduly influence the findings of the regression analyses, and was an outlier because of an unusual

combination of scores. The case was deleted. Five more cases were identified as multivariate outliers at the 0.001 level, but only when using FGHBS scores as the dependent variable in the exploratory work to follow model testing. These were found to be cases where unusual combinations of data were entered, but not because of any data entry error. For example, a wife whose contact with her husband prior to his admission to the ACF was infrequent produced a data set identified as an outlier. The lack of frequent pre-admission contact may have been due to previous institutionalisation of the husband or to a marital separation. Another case was of a family member who reported increased contact after the ACF admission. Because these cases were from the target population group, but may have unduly influenced findings of one, identified analysis, they were filtered out during that one analysis.

Finally, checks for multi-collinearity or singularity of variables were made. High correlations among independent variables can threaten the accuracy of multiple regression analyses (Kristjanson, 1991). When dummy variables were omitted, there was no evidence of very high or total correlation in the matrices. The highest correlation was 0.61, between health and well-being. Some dummy variables were noted to be confounding variables. For example, "wife" was bound to confound "spouse" and "resident's gender". To preserve the conceptual integrity of findings, variables such as these were deemed unsuitable for entry into the same analyses.

Findings of the Main Analyses

Immediately prior to Steps One, Two, and Three of the analyses, correlations between independent variables (IVs) and dependent variables (DVs) were again scrutinised. According to Tabachnick and Fidell (1996, p. 128), a "good goal" of regression is to "select the fewest IVs necessary to provide a good prediction of the DV where each IV

predicts a substantial and Independent segment of the variability in the DV^o. So that a substantial segment of the dependent variable might be more likely to be predicted by each independent variable entered, those failing to significantly correlate with the dependent variable under scrutiny were omitted from the analyses. Throughout regression analyses, the transformations shown in Table 17 were used as replacements for the variables included in that table.

Step One

In Step One, the researcher used two hierarchical regression analyses to test the relationships among variables that were hypothesised in the model (Figure 1). According to Tabachnick and Fideli (1996), dedding upon the order of entry of variables into a hierarchical regression analysis should be theoretically based. These authors suggest that it might, for example, be appropriate to enter first any variables that might be presumed to be causally prior. In the model to be tested, the researcher deemed that incentives to support the resident would naturally precede any stress/support factors that might determine the extent to which these incentives were acted upon. For this reason, the researcher entered the variables into the equation beginning with those incentives, which formed Construct I, and continuing through the sequence of constructs as ordered in the model.

In the first analysis, summarised in Table 18, the researcher entered the family member's well-being (GWB) score as the dependent variable. Independent variables were entered as follows:

Firstly, as discussed, variables hypothesised as being incentives for the family member to support the resident were entered together. These variables were the family member's perception of the resident's adjustment to life in residential care and the feelings of attachment of the family member towards the resident. Only adjustment was found to be a significant predictor of well-being at this stage (adjusted $R^2 = 0.08$).

Secondly, stress related variables were added: length of stay, "wife/non-wife" of the resident, and the pressure index. The researcher entered wife/non-wife in preference to "spouse/non-spouse" as it was more strongly correlated with the dependent variable, although both correlations were significant. All the entered variables except for attachment and length of stay were found to significantly contribute to the variance of the dependent variable (adjusted $R^2 = 0.25$).

The last set of variables added for this analysis were support factors: informal support in the family member and formal support in the family member. The final solution showed that variables from the model significantly explaining variance in the well-being of the family member were: (a) pressures (negative, $p = <0.001$), (b) being a wife (negative, $p = <0.01$), (c) perceptions of the degree of adjustment to the ACF of the resident (positive, $p = 0.01$), and (d) length of stay (positive, $p = <0.05$) (adjusted $R^2 = 0.26$).

Dummy variables showing whether or not the resident suffered from dementia and indicating son/daughter/husband relationships were not significantly correlated with the dependent variable and so were not entered into the analysis.

Table 18

Findings of the Hierarchical Regression Analysis for Testing the Model: Well-Being as the Dependent Variable

Group Added	Independent Variable	β	Beta	I	Adj. R^2 (change)	Adj. R^2 (total)
Incentives	Adjustment	0.29	0.28	4.01***		
	Attachment ^a	-0.40	-0.09	-1.36		
						0.08
Stressors	Adjustment	0.21	0.20	3.16**		
	Attachment ^a	-0.32	-0.08	-1.19		
	Wife	-0.63	-0.19	-3.08**		
	Length of stay ^b	0.28	0.12	1.87		
	Pressures	-0.31	-0.35	-5.37***		
						0.17
Support	Adjustment	0.19	0.19	2.72**		
	Attachment ^a	-0.21	-0.05	-0.78		
	Wife	-0.66	-0.21	-3.22**		
	Length of stay ^b	0.31	0.13	2.065*		
	Pressures	-0.29	-0.32	-4.85***		
	Informal support ^c	-0.59	-0.12	-1.64		
	Formal support	0.00	0.00	0.02		
					0.01	0.26

Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

^a Square root of reflection. ^b Logarithm. ^c Logarithm of reflection

In the second hierarchical regression analysis, the researcher entered the family member's enacted support for the resident (FGHBS) score as the dependent variable. The only independent variable due to be entered at this stage, and also found to significantly correlate with the dependent variable, was feelings of attachment. This variable was shown to significantly contribute to the variance in enacted support. The contribution was positive after accounting for the use of a reflection of the variable ($p < 0.001$, $B = -0.71$, $\beta = -0.29$, adjusted $R^2 = 0.08$).

In summary, the following hypotheses emanating from the model were confirmed by the above analyses:

2. The extent to which a family member perceives that his/her relative has adjusted to living in an ACF positively predicts the degree of psychological well-being in the family member.
3. The extent to which an ACF resident's family member feels attached to the resident positively predicts the amount of enacted support the family member reports providing to that resident.
7. The extent to which an ACF resident's family member experiences pressures related to the placement inversely predicts the degree of psychological well-being in that family member.
9. The length of time that has passed since a family member has experienced the admission of a relative into an ACF positively predicts the degree of psychological well-being in that family member.

10. The familial relationship between a family member of an ACF resident and that resident predicts the degree of psychological well-being in the family member.

Hypotheses 1, 4, 5, 6, 8, 11, 12, and 13 were rejected.

Step Two

The second step of the main analyses involved hierarchical regression analyses testing possible alternative relationships among variables illustrated in the model. At the end of Step Two, confirmed relationships among variables included in the original model were as shown in Figure 2. Dependent variables remained well-being and enacted support for this step of the analysis. No further relationships between well-being and other variables in the model remained to be tested, as enacted support, the only variable not previously examined in this context, did not significantly correlate with well-being ($r = 0.01$, $p = 0.83$). However, significant correlations were present between enacted support and (a) length of stay ($r = -0.18$, $p = <0.01$) (b) (reflected) informal support ($r = -0.34$, $p = <0.01$), and (c) formal support ($r = 0.21$, $p = <0.01$). Possible predictive relationships between these independent variables and the dependent variable had not been tested for before.

The researcher entered variables for this regression analysis according to the plan described in Step One. Firstly, an Incentive for the family member to support the resident was entered, feelings of attachment (as before); then the stress related factor, length of stay; then the two support factors, informal and formal support. These findings are shown in Table 19.

Length of stay increased the amount of explained variance of the dependent variable when it was entered (negative, adjusted $R^2 = 0.11$). In the final analysis, however, feelings of attachment and informal support (both positive after accounting for reflection), and length of stay (negative) all contributed significantly to the explained variance (adjusted $R^2 = 0.19$). Formal support was not shown to be a significant contributor ($p = 0.09$).

Table 19

Findings of the Hierarchical Regression Analysis for Testing Alternative Relationships Among Variables in the Model: Enacted Support as the Dependent Variable

Group	Independent	B	Beta	T	Adj. R^2	Adj. R^2
Added	Variables				(change)	(total)
Incentive	Attachment ^a	-0.71	-0.29	-4.29***		0.08
Stressor	Attachment ^a	-0.74	-0.30	-4.54***		
	Length of stay ^b	-0.29	-0.20	-3.00**		
					0.03	0.11
Support	Attachment ^a	-0.58	-0.24	-3.59***		
	Length of stay ^b	-0.26	-0.18	-2.84**		
	Informal support ^c	-0.68	-0.22	-3.11**		
	Formal support	0.18	0.12	1.71		
					0.08	0.19

Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

^a Square root of reflection. ^b Logarithm. ^c Logarithm of reflection

Constructs

I. Incentives in the resident's family member to direct support towards the resident

II. Stress related factors in the resident's family member

III. Perceived support of the resident's family member

IV. Psychological health of the resident's family member

V. Support the resident's family member directs towards the resident

Concepts

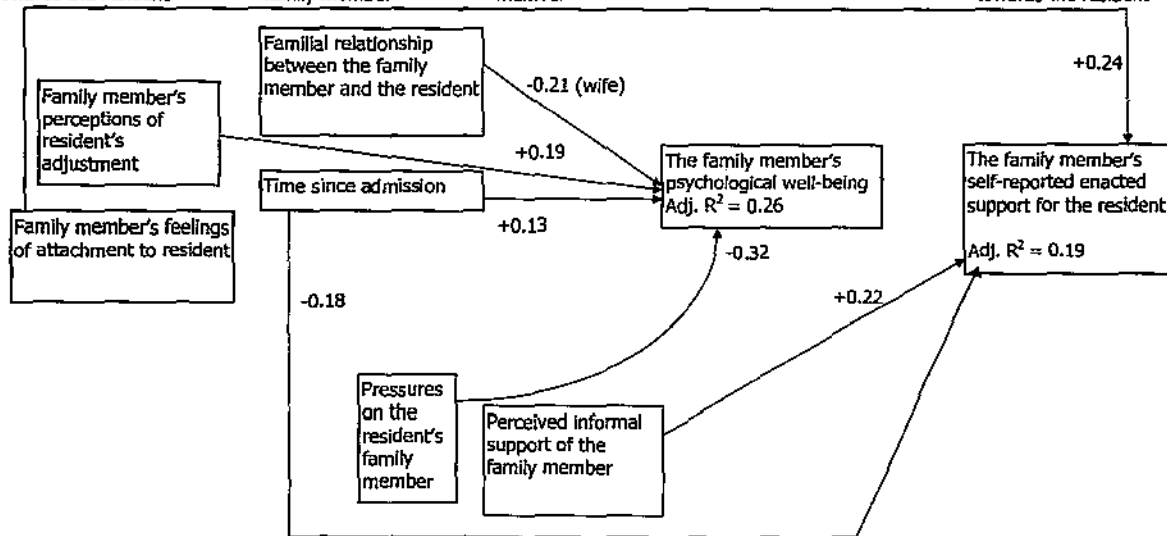


Figure 2: Confirmed relationships in the Aged Care Facility resident's family member among incentives to support the resident, stress related factors, perceived social support, well-being, and support directed towards the resident. (Beta weights adjusted to account for reflections).

Step Three

For the final step of the analysis, the researcher used stepwise multiple regression analyses to explore possible relationships among any variables for which data were collected, including demographic characteristics. Knowledge of the literature and reference to correlations between independent and dependent variables guided this process. For all these analyses, the variables shown in Table 17 were entered with transformations as shown in that table, and the two main outcome variables remained enacted support and well being. However, to construct a multi-stage model, some variables were also regressed onto "health of the family member" and pressures.

Details of these analyses are as follows:

1. With enacted support as the dependent variable, the following independent variables were entered: Informal and formal support, frequency of current and previous contact, gender of the family member, length of stay, and feelings of attachment. All of these variables were found to be significant predictors of enacted support except for feelings of attachment, a significant predictor of the same dependent variable in the previous analysis, and formal support. Table 20 shows details of significant findings.

Table 20

Findings of Stepwise Regression Analyses with Enacted Support as the Dependent Variable

Step	Independent Variables	B	Beta	T	Adj. R ² (change)	Adj. R ² (total)
One	Current contact ^a	0.80	0.32	4.71***		0.10
Two	Current contact ^a	0.72	0.29	4.37***	0.07	0.17
	Informal support ^b	-0.81	-0.28	-4.25***		
Three	Current contact ^a	0.57	0.23	3.29**	0.03	0.20
	Informal support ^b	-0.78	-0.27	-4.16***		
	Previous contact ^a	0.49	0.18	2.63**		
Four	Current contact ^a	0.62	0.25	3.62***	0.01	0.21
	Informal support ^b	-0.72	-0.25	-3.82***		
	Previous contact ^a	0.48	0.18	2.59*		
	Female family member	0.23	0.15	2.31*		
Five	Current contact ^a	0.57	0.23	3.30**	0.02	0.23
	Informal support ^b	-0.69	-0.24	-3.73***		
	Previous contact ^a	0.50	0.18	2.73**		
	Female family member	0.23	0.15	2.26*		
	Length of stay ^c	-0.18	-0.13	-2.08*		

Note.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

^a Inverted reflection. ^b Logarithm of reflection. ^c Logarithm.

2. With well-being as the dependent variable, Informal and formal support, family members' perceptions of their health, pressures, length of stay, adjustment of the resident, attachment, and wife/non-wife were entered. Only health, pressures, and adjustment were found to significantly predict well-being. Details of significant findings are shown in Table 21.

3. With health as the dependent variable, pressures, length of stay, adjustment, attachment, and spouse/non-spouse were entered. Only length of stay and adjustment failed to significantly predict the dependent variable. Details of significant findings are shown in Table 22.

4. Finally, with pressures as the dependent variable, journey index, formal and informal support, adjustment, attachment, and daughter/non-daughter were entered. Journey index approached significance ($p = 0.06$) as a predictor of pressures, however only informal support and daughter/non-daughter were significant predictors at the required level of ≤ 0.05 . Table 23 shows details of the significant findings.

The perceived formal support of the family member was not found to be a significant predictor of any of the dependent variables. However, it was found to correlate with the family member's perception of the resident's adjustment ($r = 0.32$) and with the perceived informal support of the family member ($r = 0.42$).

Figure 3 shows the empirical model constructed from the findings of the stepwise regression analyses.

Table 21

Findings of Stepwise Regression Analyses with Well-Being as the Dependent Variable

Step	Independent Variables	B	Beta	I	Adj. R ² (change)	Adj. R ² (total)
One	Health	0.82	0.62	10.67***		0.38
Two	Health	0.74	0.56	10.02***		
	Pressures	-0.25	-0.05	-4.93***	0.07	0.45
Three	Health	0.71	0.54	9.76***		
	Pressures	-0.23	-0.26	-4.69***		
	Adjustment	0.18	0.17	3.13**	0.02	0.47

Notes. *p = <0.05, **p = <0.01, ***p = <0.001.

Table 22

Findings of Stepwise Regression Analyses with Health as the Dependent Variable

Step	Independent Variables	B	Beta	I	Adj. R ² (change)	Adj. R ² (total)
One	Spouse	-0.52	-0.27	-3.83***		0.07
Two	Spouse	-0.56	-0.29	-4.23***		
	Pressures	-0.16	-0.24	-3.47***	0.05	0.12
Three	Spouse	-0.60	-0.31	-4.50***		
	Pressures	-0.15	-0.22	-3.25**		
	Attachment ^a	-0.48	-0.15	-2.22*	0.02	0.14

Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

^a square root of reflection.

Table 23**Findings of Stepwise Regression Analyses with Pressures as the Dependent Variable**

Step	Independent Variables	B	Beta	T	Adj. R² (change)	Adj. R² (total)
One	Daughter	-0.64	-0.26	-3.62***		0.06
Two	Daughter	0.62	0.25	3.67***		
	Informal support ^a	1.30	0.24	3.46***	0.05	0.11

Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

^a logarithm of reflection.

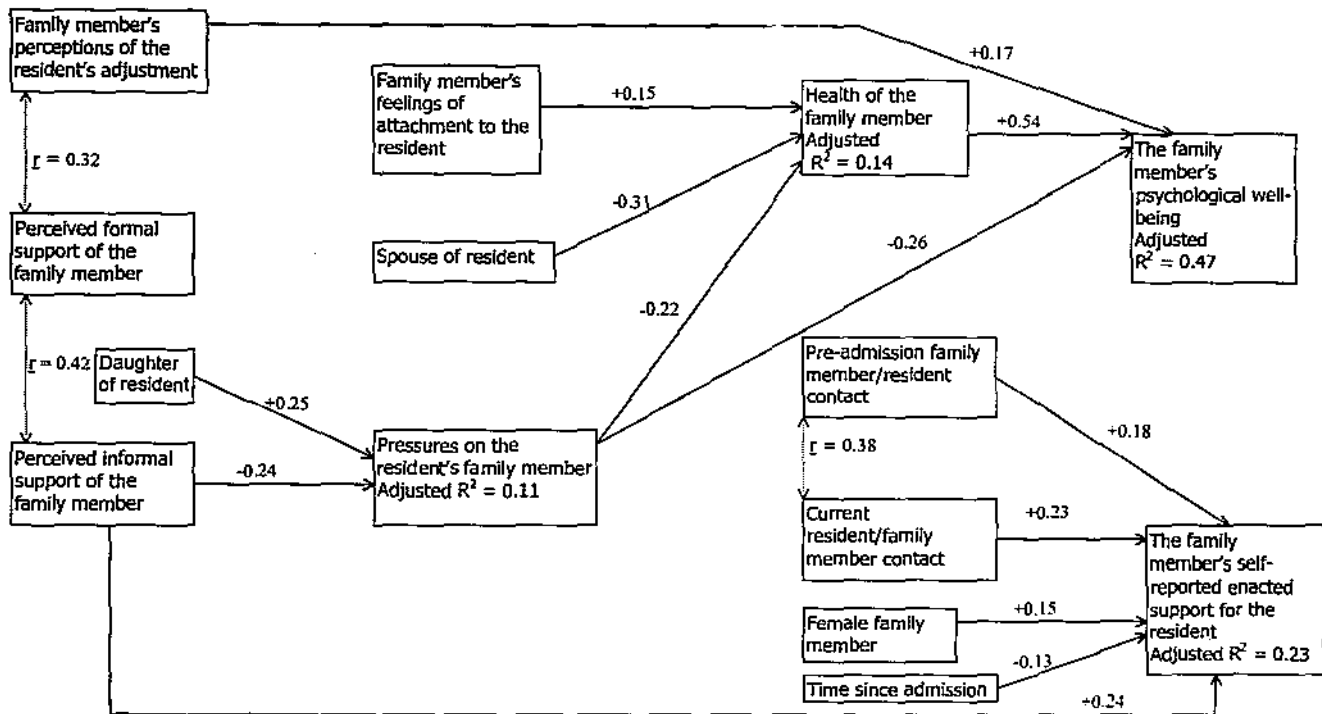


Figure 3: Empirical model constructed from findings of exploratory multiple regression analyses using the whole sample. (Beta weights adjusted to account for reflections).

Summary

When testing the original model, significant predictive relationships were confirmed between the following independent variables and the resident's family member's well-being: (a) being torn between the resident and other responsibilities (pressures), (b) being a wife/non-wife of a resident, (c) perceptions of the resident's adjustment to life in an ACF, and (d) the length of stay. Only the feelings of attachment between the family member and the resident, as perceived by the family member, were confirmed as significantly predicting the self-reported enacted support of the resident by the family member.

When including only variables from the original model but examining alternative relationships between these variables, no additional information was obtained about possible predictors of well-being in the family member. However, informal support of the family member and length of stay were both found to be significant predictors of the self-reported enacted support of the resident by the family member in addition to feelings of attachment.

An empirical model, constructed using all the available data, indicated that the family member's health, perceptions of the resident's adjustment, and pressures were all significant predictors of the family member's well-being. Additionally, feelings of attachment, being a spouse/non-spouse or daughter/non-daughter of a resident, and the perceived informal support of the family member were all seen to indirectly predict the family member's well-being. The family member's self-reported enacted support for the resident was found to be significantly predicted by pre and post-admission

contact between the family member and the resident, the gender of the family member, the length of time since the admission, and the perceived informal support of the family member.

Overall Summary

Although not randomly selected, the sample of 213 family members of Australian ACF residents was found to be diverse in its nature in most demographic respects. Findings suggested that the majority of participants tended to be in good physical health, but that many were experiencing moderately poor psychological health. Findings also showed that family members reported having high levels of perceived formal and informal support and offering high levels of support to their relatives in the ACFs.

After preparation of the data, findings of regression analyses confirmed some of the relationships among variables hypothesised in the original model. However, they refuted others. Hypothesised alternative relationships among these variables led to the development of an improved model. Finally, an empirical model was developed using all available data. This model accounted for 47% of the variance in family members' well-being and 23% of the variance in the family members' self reported enacted support for residents.

CHAPTER V

Discussion

Introduction

In this chapter, the researcher discusses methodological issues and the findings of the main study. The researcher then summarises the overall strengths and limitations of the research.

Methodological Issues

The methodological issues to be discussed fall into three categories: sampling issues, measurement issues, and design issues.

Sampling Issues

Sampling issues pertain to the validity of the RACRASST, and to the generalisability of findings of the main study.

Validity of the RACRASST. The researcher developed the RACRASST with the intention that it should be useful for the assessment of residents' family members' perceptions of staff support in ACFs throughout Australia, recognising that later adaptations might render it useful in similar settings overseas. For the instrument to be valid, therefore, it was necessary to construct and test it using data from representative groups of Australian ACF residents' family members.

As well as ensuring that large and small, metropolitan and rural ACFs were included in this part of the project, and that husbands, wives, sons, daughters, and other family members were included in the samples, the researcher addressed three specific sampling challenges to ensure validity of the RACRASST. These challenges

were related to the cultural diversity of the targeted population, changes in Commonwealth Government aged care policies during the study, and the accessibility of the targeted population. Possible interstate variations among settings were also considered. However, these were found to be minimal due to the commonwealth legislative framework within which the Australian aged care sector functions (AIHW & CDHFS, 1997). Because variations were minimal, data could be collected in Western Australia alone at some stages, without this action affecting the wider applicability of the instrument.

The first sampling challenge to be met was the extent to which cultural diversity in the population of ACF residents' family members could and should be reflected in the samples. Two pertinent issues emerged when this issue was considered. The first issue was whether or not the researcher should endeavour to include Australian Aboriginal people in the sample. The second issue was whether or not the researcher should ensure that samples included people whose elderly relatives in ACFs came from non-English speaking backgrounds (NESB).

Statistics demonstrated the following facts relevant to the first issue: that Aboriginal people form only 1% of the population of ACF residents, and that a high proportion of these indigenous residents are not aged 65 years or older. Additionally, many Aboriginal people live in remote areas, away from the population centres in which ACFs are situated and with limited access to transport and communication (AIHW & CDHFS, 1997). When these people have relatives living in ACFs, their opportunities for contact with staff are minimal. After consideration of these facts, the researcher decided not to seek participants for the instrument development phase of the study via DONs/Managers of ACFs where residents were mainly Aboriginal people from

remote areas. Therefore, no claims are made about the appropriateness of this instrument for use with this population.

Statistics also demonstrated facts relevant to the second issue. In 1991, for example, 29% of Australians aged 65 years or older were born overseas and approximately 56% of these people came from countries where English is not the principal language. However, many of these ethnic groups are under-represented within Australian ACFs (AIHW & CDHFS, 1997). These considerations suggested that family members of those from NESB, many of whom might be expected to retain unique cultural perspectives, should be included in samples used to develop and test the RACRASST, but as a minority group. This inclusion was achieved by not excluding ethnically specific ACFs when seeking the large sample selected for the factor analysis, and by seeking out a few participants from ethnically specific ACFs when small samples were sought. Additionally, some residents from NESB living in ACFs that were not ethnically specific were likely to be included by chance.

The second sampling challenge to be met related to changes in Australian Government aged care policy immediately after Stage One of the development of the RACRASST. This policy had previously recognised hostels, providing low levels of care, and nursing homes, providing high levels of care, as separate entities. After 1997, all hostels and nursing homes were deemed to be ACFs. Some residents receiving high levels of care would be housed in accommodation shared by residents receiving low levels of care, and would be cared for by the same staff.

During Stage One of the development of the RACRASST, the intention of the researcher was that the instrument would be for use in nursing homes. The sample,

therefore, was of family members of nursing home residents. After the change in policy, the RACRASST needed to be relevant to family members of residents receiving high or low levels of care so those with relatives in ACFs who were receiving hostel-type care were included in samples. This action reduced the threat to the validity of the RACRASST, but it meant that the instrument became less of a nursing innovation as some facilities offering only low levels of care do not employ Registered Nurses.

The third sampling challenge to be met was that of access to the targeted population. This challenge was a potential threat to the size of the large sample needed for the factor analysis of the RACRASST, as well as to the representativeness of all the samples used during instrument development.

There were three possible ways of contacting family members of Australian ACF residents. One option was to advertise, another was to approach the Aged Care Assessment Team (ACAT) members who assess all residents for whom residential aged care is requested, and the final one was to approach DONs/Managers of ACFs. All these sampling strategies were considered.

Widespread advertising for participants appeared to be the strategy associated to the least degree with the likelihood of obtaining a biased sample, because it did not involve a third party, but it was also likely to be very expensive. The researcher utilised advertisements in newsletters to help select small samples, but this strategy was not an option that could be considered for contacting large numbers of potential participants.

Preliminary approaches were made to members of Western Australian ACATs as part of a feasibility study to determine whether or not sufficient numbers of participants could be recruited with their assistance. It became clear that obtaining any large samples in this way would be problematic. Additionally, it was evident that any sample selected in this way could only be representative of family members of newly admitted residents, not of the general population of family members of ACF residents. So that an instrument with wider applicability could be developed, the researcher chose to access samples via the DONs/Managers of ACFs. This choice also meant that DONs'/Managers' involvement in the study was likely to promote understanding and acceptance of findings. However, as would have been the case had samples been selected with the assistance of ACAT members, samples had the potential to be biased because they were selected via a third party.

To reduce the extent to which criteria set by individual DONs/Managers might impact upon the representativeness of samples, the researcher attempted to address some of their potential concerns. Firstly, the researcher included examples of questionnaires and letters to participants with requests for assistance sent to DONs/Managers. This was to demonstrate that the burden on participants was not onerous, and that participation was entirely optional. Secondly, the researcher reassured DONs/Managers that findings would not be attributable to particular ACFs. This was so they would not anticipate comparisons between named ACFs.

During the development of the RACRASST, few details about participants were collected so assessment of any sample bias is problematic. However, 68% of DONs/Managers receiving requests for assistance during the factor analysis stage of RACRASST development agreed to help. Based on this figure, it seems unlikely that

many DONS/Managers refused to participate because they anticipated unfavourable comparisons with other ACFs in the area of family-centred practices.

However, only 34% of the factor analysis questionnaires sent out for distribution to family members were returned. DONS may have agreed to help but then failed to distribute the questionnaires. Alternatively, few of the people receiving questionnaires may have wished to participate. Family members who had fewer other commitments or better health, for example, may have been the most likely to respond. If this is the case, the RACRASST may be most suitable for use with this section of the population.

Additionally, the fact that the sample size for the factor analysis ($N = 297$) was smaller than anticipated was more of a concern than might otherwise have been the case because missing or "not applicable" responses reduced the number of useable data sets to 195. This lack of data meant that the researcher could not meaningfully use methodologies such as linear structural equation modelling to examine the structure of the RACRASST. The methodology that was used may have resulted in a less comprehensive examination of the instrument.

The generalisability of main study findings. Ideally, a large, random sample of family members of Australian ACF residents would have been selected for the main study so that findings would have the best possible level of generalisability within the Australian context. However, although the sample was fairly large ($N = 213$), random selection was not an option due to the access problems noted in the previous section. Settings were selected in a random fashion within the states, using a list of ACFs in alphabetical order. However, the sample was selected via the

DONs/Managers of ACFs, as was the case during the development of the RACRASST and for the same reasons. There was, therefore, the potential for a gatekeeper effect, an effect created by the selection of participants by a third party.

The researcher attempted to minimise any gatekeeper effect by ensuring that DONs/Managers knew the data collected for the study would be anonymous. There should have been no reason for them to fail to pass on questionnaires because of anticipated negative findings. However, DONs/Managers were also provided with sample questionnaires and these contained many more items than those used during the factor analysis stage of instrument development. The response rate for DONs/Managers in the main study was just 32%, more than 50% lower than that occurring during the factor analysis stage. It appears that the anticipated burden on participants may have influenced questionnaire distribution during the main study.

Some evidence that either a gatekeeper effect or participants' self-selection biased the sample for the main study exists in the documentation of sample characteristics. Firstly, many more participants were related to those receiving high levels of care than to those receiving low levels of care. This bias may have occurred because of the lack of nurses in ACFs providing only low levels of care. Care staff who are not nurses may have little interest in, and understanding of nursing research. They may also have less understanding than nurses of the need for family centred practices. Secondly, the majority of participants reported being in good health. Given that 50% of participants were aged over 60 years, and that poor health in home caregivers is known to be a risk factor for institutionalisation of the care recipient (George & Maddox, 1989), poor health might have been expected to occur more frequently. Either self-selection or a gatekeeper effect may have accounted for this anomaly.

A sample bias in favour of fit family members may have excluded some of the least supported family members, as social support has been shown to protect against illness (Pearlin, Aneshensel, Mullan, & Whitlach, 1996). This is suggested by the relatively high levels of informal and formal support documented as occurring in main study participants. Studies with which to compare support related findings in this population are lacking. However, in a recent Australian study in which 976 community caregivers were interviewed (Schofield, Herrman, Bloch, Howe, & Singh, 1997) 84% of respondents reported being helped by family members and friends. If this support continues after an ACF placement, high levels of informal support may be the norm rather than the exception. There is no way of knowing whether or not high levels of staff support are typical in the targeted population as published studies measuring this phenomenon are lacking. However, it may be speculated that, although DONs/Managers had no reason to opt out of the study because they anticipated that the practices of their staff would be found lacking, only those with a commitment to the support of family members may have agreed to assist the researcher.

In other ways, however, the sample characteristics were as expected. For example, most participants were women, and, according to work carried out in Australia by Minichiello (1989) most visitors to nursing homes are women. Additionally, many participants reported quite low levels of psychological well-being. The literature suggests that family members of ACF residents tend to experience guilt, grief, and uncertainty (Dellasega & Mastrian, 1995; Matthiesen, 1989), so poor psychological well-being is likely to be relatively common in this population. However, the latter finding is a little surprising in a sample of participants reporting such high levels of

health and support. Perhaps any negative effects on the health of participants of current poor psychological well-being will follow in years to come. It may also be speculated that psychological well-being in participants would have been at an even lower level without the high levels of formal and informal support reported.

Measurement Issues

In this section, the researcher discusses the use of two of the instruments, the RACRASST and the FGHBS (Rice, 1988) with reference to their immaturity and to the depth of information elicited by them. Reference is also made to the use of items included in the Demographic Questionnaire to obtain data concerning one of the key variables.

The RACRASST. The RACRASST remains an immature instrument. A major issue of concern during the instrument's development was that many items had to be discarded to ensure that the questionnaire would not be unduly burdensome for participants. A theoretical basis was used for the selection of items for deletion; the longer questionnaire was pre-tested and responses to items were examined before deletions were effected (Nunnally, 1978; Waltz et al., 1991). This was an alternative to the Q-sort procedure discussed by Waltz and associates, also based on small sample theory. The Q-sort was likely to be a cumbersome procedure given the age of many of the population of interest and the fact that 150 items were to be reviewed. The process used resulted in the availability of a comparatively brief instrument with satisfactory psychometric properties for use in the main study, and minimised the loss of items with utility. The factor structure suggested by the analysis of these findings was not entirely confirmed by the factor analysis carried out later, but there was some congruence between the two identified structures.

An additional issue of concern related to development of the RACRASST was the fact that the concept was found, at interview, to include considerable reference to resident care. This occurred even when interviewees were asked to reflect primarily upon their own experiences. Consideration was given to the fact that the instrument might measure two concepts as a result of this: "perceptions of resident care" and "perceptions of staff support". However, reflecting back to statements made during the interviews, it seemed that family members' perceptions of staff care of the residents was a dimension of the support these family members perceived themselves as receiving from staff. This assertion was supported by the findings of the factor analysis, which indicated that the RACRASST measured a single concept, with underlying sub-dimensions that included perceptions of care.

The final issue of concern relating to the use of the RACRASST was the inclusion of a "not applicable" response option. This use led to problems during the analyses of data. In the factor analysis section of the study it meant that many responses could not be utilised for analyses. However, because the questionnaire was in its formative stages, the researcher believes that the use of this response format was invaluable in deciding which items should be discarded or reworded either because they were inapplicable to many participants, or because they were not well-understood.

The PGHBS (Rice, 1988). As previously acknowledged in this thesis, the PGHBS was not an ideal measure for use in this study. It would have been preferable to obtain residents' perceptions of the support they received from their family members or to use an observational methodology to measure residents' responses to family members' support strategies. Unfortunately, large numbers of Australian ACF

residents have cognitive/communicative disabilities that render them unable to reliably respond to questionnaires, as evidenced by the fact that approximately 40% of the sample in the main study documented here indicated that their relatives in the ACFs had a significant degree of dementia. Additionally, an observational strategy would only have been possible in a study using a small sample. The PGHBS was an immature instrument, but the sub-scale used had been shown to possess acceptable psychometric properties, and it more adequately measured enacted support than any other instrument found by the researcher.

The Demographic Questionnaire. The Demographic Questionnaire was used to obtain a great deal of information from participants in addition to that which referred to the demographic characteristics of participants. For example, it contained items referring to the quality of relationships between family members and residents. These items, therefore, referred to a complex concept, one shown to be highly relevant to the community caregiving relationship in the work of Phillips (1990). However, in the research described here, relevant items asked only about the frequency of past and present contact, and the closeness of the current relationship. This approach was somewhat superficial, and may have resulted in an opportunity missed to make comparisons between community and institutional scenarios. This was because the researcher was conscious of the possibility that family members might perceive a more detailed investigation of pre-existing relationships as inquisitorial and irrelevant to the study. Such an approach would probably have led to a decreased response rate and was, therefore, avoided.

Design Issues

The use of a cross-sectional survey design for the main study allowed the researcher to collect data from a large sample on a large number of variables. Initially, a longitudinal study was considered. Such a study would have followed family members over the months following admission, collecting data at intervals. Findings of a longitudinal study may have been more interpretable. However, this option was not utilised because sample attrition, always a concern in longitudinal studies, was likely to be greater than usual since the retention of participants would be linked to the survival of disabled, elderly people. The researcher doubted the likelihood of being able to access a large enough sample of Australian ACF residents' family members to ensure that the resultant data would be sufficient to allow meaningful analyses, having already obtained repeated samples to aid in the development and testing of the RACRASST. Additionally, such a study would have been very costly. Instead, the researcher opted for a cross-sectional study where the resident's length of stay was treated as a variable. The use of a survey methodology was cost-effective and generally appropriate to obtain the level of knowledge required, although opportunities for in-depth exploration of any of the variables were lacking.

Section Summary

In summary, methodological issues raised during this study included those related to sampling, measurement, and study design. Several sampling challenges needed to be met while the RACRASST was being developed and tested so that the validity of the instrument would not be compromised. Preparatory work resulted in decisions to avoid seeking participants via ACFs primarily serving Aboriginal people in remote areas, but to actively seek out participants related to ACF residents with NESB when the use of small samples made it unlikely that these participants would be included

by chance. Changes to government policy during the development of the instrument meant that the sampling frame needed redefinition, and the need to access samples via a third party meant that the researcher needed to minimise a possible gatekeeper effect.

Despite the researcher's efforts to minimise a gatekeeper effect during the main study, as well as during instrument development, findings from the main study in particular suggest that this sample may have been biased at least in two respects. Indications are that participating family members were physically fitter than might have been expected, and family members related to residents receiving high levels of care were over-represented in the sample. Family members also reported high levels of support and fairly low levels of psychological well-being. It seems likely that a gatekeeper effect may have been responsible for at least some of the bias that appears to exist in this sample. Indications of bias in the sample throw some doubt on the generalisability of findings to the overall population of family members of Australian ACF residents.

Two of the instruments used in the main study, the RACRASST and the FGHBS (Rice, 1988), were immature, albeit with demonstrated acceptable psychometric properties. The researcher needed to dramatically reduce the number of items included in the RACRASST during the development phase, which caused concerns that all dimensions of the concept might not be addressed in the final instrument. However, the methodology used to achieve item reduction was rigorous, making it less likely that the integrity of the instrument would be compromised. Perceptions of

resident care remained a dimension of perceived support measured by the instrument. A "not applicable" response option was used throughout the development of the RACRASST and in the presentation of this instrument in the main study although it meant that some of the data collected for the factor analysis could not be used for this analysis. However, the inclusion of this option allowed for continual re-assessment of the relevance and clarity of items. Use of the PGHBS appeared to be the best available option for measuring residents' support from family members, although it was not an ideal solution. Exploration of the quality of the relationship between the resident and the family member is acknowledged to have been at a superficial level in the main study.

Finally, although it is believed that a longitudinal study would probably have contributed more interpretable findings, an anticipated high level of sample attrition meant that a cross-sectional survey was used instead. Residents' length of stay was treated as a variable to aid in the interpretation of findings and the survey methodology provided useful data that could be included in model testing.

Findings of the Main Study

The researcher discusses the findings of the main study with reference to the empirical model developed using all available data from the whole sample (see Figure 3), and incorporating reflection upon the findings of initial hypothesis testing. The empirical model accounted for 47% of the variance in family members' well-being and 23% of the variance in family members' self reported enacted support for residents. The remainder of the variance may be accounted for by measurement error and/or incomplete theoretical specificity (Woods & Cantazaro, 1988). Further testing of the model is warranted to examine these issues.

The health of residents' family members and tensions in family members between commitments within the ACF and outside it (their pressures) were variables found to influence family members' psychological well-being. The relationship between pressures and well-being was hypothesised in the original model (Figure 1), and this finding was to be expected, mainly because both health and pressures formed part of the concept of well-being as operationalised in this study. Another confirmed hypothesis from the original model stated that the family member's perceptions of the adjustment of the resident to the placement would predict the psychological well-being of that family member. However, as shown in the empirical model, this influence was not a strong one, variability in perceived adjustment accounting for 2% of the variance in well-being, although it can easily be explained. The guilt often reported by family members as occurring because they have institutionalised a loved one (e.g. Kellett, 1996; Nay, 1996, 1997; Matthiesen, 1989) is likely to be lessened if that loved one is happy in the new environment. Also, a family member's happiness is likely to be increased when a loved one is known to be content.

The frequency of existing contact between family members and residents was found to be the strongest influence on the degree of enacted support directed towards residents by their family members, accounting for 10% of the variance. This is explained by the support opportunities provided during that contact, although the length of time spent visiting was not measured. The fact that pre-admission contact was also found to be positively related to enacted support, and that it correlated positively with current contact ($r = 0.38$) tends to refute suggestions that residents are abandoned by their family members when admitted into an ACF. This concurs with findings of other researchers in the area (Fleming, 1994; Harper & Lund, 1990).

However, the findings of the study reported here also suggest that family members tend to offer less support over time. This finding does not necessarily suggest abandonment, as family members may be responding to the decreasing needs for support of residents as they adjust to the placement over time (Brooke, 1989). Additionally, it may be that family members need to withdraw in order to cope, as suggested by Nay's findings (1996, 1997).

The fact that the perceived informal support of family members was found to have a positive association with the support directed towards residents by their family members can be explained in two ways. Firstly, it could be that visiting family members reciprocate the support received from residents. Secondly, it may be usual to offer a greater degree of support to each other in some families than it is in others. The demonstrated positive association between being female and directing more support towards the resident might be also be associated with family cultures, in that women might often be expected to be the nurturers of the family. Both of these cultural aspects may parallel the association between perceptions of correct role behaviours in family members and their provision of care to community dwelling elderly relatives discussed by Phillips (1990). Family members of ACF residents may be influenced similarly by perceptions of correct behaviours.

The negative link between pressures and health, demonstrated in this study, is yet further confirmation that stress brings about ill health (Avison & Gotlib, 1994). Additionally, spouses, as the most elderly members of the sample, might be expected to have the greatest degree of ill health, as shown in the model. However, it is less easy to find an obvious explanation for the small positive association found between feeling close to a relative in an ACF and good health. Only speculation is

possible. One suggestion is that family members who felt close to their loved ones were those who had reconciled their past and present images of the care recipients, as described by Phillips (1990). These family members would feel less conflict between any support obligations and their inclinations to offer support than those who felt they no longer knew their relatives. The degree of inner conflict experienced might impact upon the health of the family member. However, such an impact on health might be expected to occur via psychological well-being. Feelings of attachment to the resident were not found to significantly predict well-being in the family member, this hypothesis being one of those rejected during the testing of the initial model (Figure 1). Perhaps, therefore, a long-term caregiving relationship between a family member and a resident sometimes brings about ill health in the family member that is blamed on the resident. Apportioning of blame seems likely to lead to a distancing of the relationship.

It is also difficult to explain why the closeness of the relationship between the family member and the resident was not shown to be a significant predictor of the support of the family member for the resident in the empirical model (Figure 3), when this relationship was confirmed in the testing of the original model (see Figure 2). It seems likely, however, that the variable "current contact" entered the stepwise regression equation in preference to "feelings of attachment" because it explained more of the variance in the dependent variable.

There are at least two possible explanations of the negative association between the perceived informal support of residents' family members and the degree of pressures reported by those family members. Firstly, instrumental support may have relieved family members of potential pressures, as would occur should a neighbour

collect children from school while their mother is at the ACF. Secondly, pressures might seem less overwhelming when viewed by a person who is emotionally supported. The originally hypothesised direct link between informal support and well-being was not confirmed when the original model (Figure 1) was tested, nor was it present in the empirical model (Figure 3). However, an indirect link between these two variables is shown in the empirical model, mediated by pressures. This model, therefore, supports the assertion of Cohen (1992), that social support buffers the negative effects of stress via its impact on stress appraisal.

The fact that daughters in this study were found to experience greater pressures than other family members of ACF residents supports the findings of Johnson (1990). This author found that daughters faced the dilemma of trying to keep all the family happy. Many daughters of residents are likely to have children to care for and/or employment responsibilities. The same, however, is true of many sons. The difference in the ways these two kinds of family members experience these commitments probably results from family members' perceptions of their obligations, discussed by Phillips (1990). In 1993, two thirds of all home caregivers to the elderly in Australia were women. Additionally, female caregivers outnumbered male caregivers to the greatest degree in the 35-54 year old age groups (AIHW & CDHFS, 1997). Perhaps daughters feel a greater obligation than sons to care for elderly relatives.

Finally, the correlation between family members' perceptions of their formal support and their informal support was somewhat unexpected. This may be explained by the hypothesis that those needing more support will access it from whatever source, or by the hypothesis that some people are more likely to access both formal and

informal support, whatever their need. The former hypothesis seems unlikely to be upheld, as it is known that there are people in need of support who fail to access it (Sarason, Pierce, & Sarason, 1994). However, it is apparent that some people are easier to support than others. These are likely to be people with good social/communication skills. The concern arises, therefore, that family members without these skills may fail to access both formal and informal support when they need it.

Equally concerning is the fact that family members' perceptions of their formal support are correlated with their perceptions of the resident's adjustment. It seems family members view staff as being more supportive to them when the resident is happier, probably because staff care is perceived as better when it leads to a resident's happiness. Although there is a rational basis for this, as good care probably increases the likelihood of residents being happy, there are clearly many variables over which staff have no control. If family members associate the unhappiness of residents with poor care, they may miss the true cause of this unhappiness and regard the staff with distrust when this is not justified. If this is the case, opportunities to work together with staff to assist residents may also be missed.

The majority of the linkages illustrated in the model based on the findings of this study, therefore, are explicated by referring to the literature. There are two areas of special interest: findings that could be explained in two or more different ways, and findings that support existing theory in an area that has not been well-explored before. An example of the former is where perceived informal support in family members is seen to influence their support of residents. An example of the latter is

where informal support is shown to buffer against the adverse effects of stress by influencing stress appraisal in residents' family members.

Strengths of the Study

This research has developed a clinically promising instrument that has acceptable preliminary psychometric properties, the RACRASST. This instrument may now be tested further and eventually used in Australian ACFs to measure family members' perceptions of staff support. The RACRASST may also have particular value in the current health care climate. ACFs in Australia all need to be accredited by 2001. To do this, staff practice needs to reflect an ongoing commitment to continuing improvement (Burns & Carey, 1999). The RACRASST is an instrument that could be used to assess existing levels of perceived staff support for residents' family members and changes in those levels. Additionally, the tool may be useful in similar settings overseas.

The researcher has also developed a resident/family member support model to be used as a basis for future research and practice. Although it requires testing with additional samples of ACF residents' family members, this model is supported by the literature, and adds to the knowledge base about the buffering effect of social support on the adverse effects of stress in family members of ACF residents. Study findings are likely to be well-accepted by Australian aged care providers because of the inclusion of DONs/Managers from the outset, and the methodology used was one leading to the greatest degree of generalisability of findings possible under the given constraints.

Limitations of the Study

Limitations of the main study relate to the generalisability of findings and the interpretability of findings. Firstly, because there are some indications that the sample selected was biased findings may lack generalisability to the whole population of Australian family members of ACF residents. Instead, the model developed from the findings may be most applicable to members of the targeted population that are in good health, related to residents receiving high levels of care, and receiving high levels of formal support.

The interpretability of the findings of this study was made more problematic because of the cross-sectional design of the study. Additionally, the sample size did not allow comparisons among sub-groups to be made with any confidence, comparisons that may also have aided in the interpretability of findings. Finally, because the formal support of family members of ACF residents was not found to be a significant predictor of any of the dependent variables, the study has done less than was anticipated to explicate the outcomes of staff supporting family members within the ACF.

The RACRASST also has its limitations. Firstly, it has not been developed in a way that makes it suitable for use in care facilities where residents are predominantly Aboriginal people. Secondly, many items needed to be deleted during its development and, although this was done using a painstaking process based on a theoretical rationale, it is possible that references to some dimensions of the concept were lost during that process. Thirdly, a smaller than desirable quantity of useable data sets for the factor analysis meant that this analysis was not conducted using the methodology likely to explore the structure of the instrument most

comprehensively. Finally, the fact that the instrument was shown to have no subscales means that the usefulness of the instrument may not be as great as originally anticipated; it cannot be used to measure individual dimensions of staff support for ACF residents' family members, only the concept as a whole.

CHAPTER VI

Conclusions and Recommendations

The first main conclusion drawn from study findings is that an instrument with acceptable psychometric properties has now been made available to measure ACF residents' family members' perceived support from the staff, albeit one that needs further testing. The second conclusion is that an ACF resident/family member support model has been made available to tentatively guide research and practice in the area, although it, too, needs to be tested with other samples.

The stronger relationships shown in the empirical model that are also supported by the literature are those most likely to be confirmed by further testing. Such relationships include those among the extent to which family members feel "torn between" commitments within the ACF and outside of the ACF (their pressures), their informal support, and their health and well-being. The relationships suggest that pressures have a negative impact on the psychological and physical health of residents' family members, and that family members may experience pressures to a lesser degree if they have higher rather than lower levels of informal support. They also suggest that daughters are the family members at greatest risk of experiencing high levels of pressures, although spouses are at the greatest risk of experiencing ill health. Additionally, it seems likely that at least some family members find their relationships with residents supportive.

Recommendations for future research, changes in practice, and further development of the RACRASST are based upon these conclusions and upon the strengths and limitations of the study documented in the previous chapter.

Recommendations

Further Research

As previously indicated, the empirical model developed in this study is presented as a model that requires testing with further samples of ACF residents' family members. In particular, the more obscure relationships shown need further explication. These relationships include those between (a) the perceived informal support of residents' family members and their enacted support for the resident, (b) the degree to which the family member feels close to the resident and that family member's health, (c) the perceived formal and informal support of residents' family members, and (d) family members' perceptions of residents' adjustment and their perceptions of the support they receive from the staff.

Longitudinal studies would probably produce findings that would be more easily interpreted. Larger sample sizes would ensure greater generalisability of findings, especially if samples could be randomly selected, and would allow for the examination of sub-groups.

Studies in which interactions among Australian ACF residents and their family members were observed and documented would increase understanding of the support directed towards residents by their family members, and might also illuminate reciprocity in this support process. Such studies would probably need to include in depth interviews with family members to interpret their actions and reactions.

Finally, further studies are needed to examine the concept of a "close" relationship between the family member and the ACF resident. These studies should be

conducted with particular reference to those family members whose health has deteriorated because of caregiving input, and to the congruence between past and present images of the care recipient in the family member.

Changes in Practice

Because informal support seems highly likely to be relevant to the health and well-being of ACF residents' family members, especially to those with competing commitments, the facilitation of informal support among residents' family members is recommended. Staff may achieve this by ensuring that areas of the ACF are available to family members, should they wish to socialise; by holding social gatherings to which family members are invited; and by encouraging the formation of groups of family members, such as residents' advocacy groups. However, because invitations to attend these kinds of gatherings may be interpreted as introducing additional commitments, staff should make it clear to family members that attendance is in no way obligatory. Additionally, by allowing open visiting, opportunities for family members and residents to exchange support at times that suit family members will be maximised. Finally, staff may sometimes need to make it clear to family members that it is acceptable for them to visit less frequently, so that the health of busy family members, often daughters, does not deteriorate.

Based upon findings of the study that are more difficult to interpret, two more tentative recommendations are made. Firstly, because family members who are poor communicators and/or appear to have few friends may be those who find it difficult to access support when they need it, staff may need to check that these people are not distressed by the placement of their relative. If they find that they are, they may be able to instigate appropriate supportive initiatives. Secondly, it

seems that family members may associate residents' unhappiness with poor staff care, perhaps missing other reasons for this unhappiness. It may help if staff (a) keep family members aware of the care their loved ones are receiving, (b) discuss possible causes of residents' unhappiness with family members, and (c) develop plans for staff and family members to deal with that unhappiness. Although these recommendations are tentative because they not based upon firm conclusions drawn from the study, they are for practices that relate to good communication between staff and family members and are likely to be seen as desirable by family members even without any evidence to suggest that they are beneficial.

Further Development of the RACRASST

The RACRASST is an immature instrument, requiring further testing with samples of ACF residents' family members. In particular, it would be helpful to trial modifications of the instrument, re-introducing one or two of the previously discarded items to increase the breadth of the instrument with reference to the underlying factor structure that has now been identified. Ideally, these items would also increase the likelihood that the instrument would discriminate between those who are well supported and those who are poorly supported. During the ongoing testing that is required to confirm the psychometric properties of the RACRASST, the use of a "not applicable" response option should be reconsidered because of the likelihood that it may be impossible to use some data sets in analyses when this response is selected. It is anticipated that the RACRASST will eventually prove to be a most useful instrument for research into staff relationships with ACF residents' family members.

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APPENDIX A

Definition of Terms

Social Support

The term "social support" is used in this thesis in accordance with the definition provided by Stewart (1993). This definition states that social support is "the interactions with family members, friends, peers, and health care providers that communicate information, esteem, aid, and reliable alliance" (p.7).

Informal Support

Informal support is regarded, in this thesis, as being the social support provided by family members, friends, and peers.

Formal Support

In this thesis, the term "formal support" is used to describe the social support that emanates from health care providers.

APPENDIX B

Instrument Development and Refinement

Stage One: Development of the First Draft of the RACRASST

Review of Relevant Qualitative Literature

The literature reviewed to obtain data used to develop the RACRASST was also reviewed in the Literature Review in this thesis, under two headings "Needs for Specific Kinds of Staff Support for Family Members" and "Evidence that Staff Support has Helped Residents' Family Members".

Relevant data obtained from the review were as follows:

- 1) Wives of newly admitted residents have been found to need emotional support and some control over the situation (Morgan & Zimmerman, 1990).
- 2) Family members have been found to wish to share their feelings with others, to need positive reinforcement from staff, and to want to be taught skills that might comfort and support their loved ones in the ACF (Campbell & Linc, 1996).
- 3) One family member was found to need to withdraw with staff permission, and to need positive affirmation from staff (Bonnell, 1996, Table 1).
- 4) Family members have been found to need information about residents' progress, the health care system, and the current status of residents (Johnson et al. 1992, see Table 1).

- 5) Former caregivers have been found to need to maintain relationships with care recipients and to continue to use their caregiving expertise (Kellest, 1996, see Table 1).
- 6) Participation in support groups has been found to be a negative predictor of burden and those experiencing high levels of burden may be the most likely to attend workshops designed to help family members (Monohan, 1995).
- 7) Educational initiatives (e.g. about the course of AD) have been found to be helpful to family members (Dziegielewski, 1991).
- 8) Including, or offering to include, family members in care initiatives has been found to increase the satisfaction of some of these family members with the care arrangement (Buckwaite et al., 1989, 1991).

APPENDIX C

Instrument Development and Refinement

Stage One: Development of the First Draft of the RACRASST

Interviews with Staff Working in Residential Aged Care Facilities

Interviews were conducted with two Registered Nurses (Division One and Division Two), and four nursing assistants, all working in one of two ACFs. Factors these staff members reported finding helpful to family members were as follows: (a) a belief in family members that staff are trustworthy; (b) family members being able to get to know the staff; (c) cheerful staff; (d) formalised relationships between staff and family members that allow family members to work with staff for the benefit of residents; (e) staff provision of information to family members about residents' disease processes and prognoses; and (f) staff recognition and affirmation of the input of family members.

APPENDIX D**Instrument Development and Refinement****Stage One: Development of the First Draft of the RACRASST****Letter to Family Members: Request for Interviewees**

(Researcher's name and address supplied and letter printed in large font)

Dear Family Member

This letter concerns the research I am carrying out as a PhD (Nursing) Candidate at Edith Cowan University, which is intended to lead to benefits for family members of nursing home residents. I currently have no link with Nursing Home, but have worked as a Registered Nurse in a variety of nursing homes for many years. During this time I have had considerable contact with family members of residents, and have often wondered if there was more that could be done to meet their needs.

This invitation is for you to take part in the first stage of my research project, which will attempt to identify what it is that family members of nursing home residents find supportive from nursing home staff. If you decide to take part I will interview you on this topic. If you agree, the interview will be tape recorded so that I have an accurate record of what has been said without the distraction of taking notes.

You will not be named during the interview, and only code numbers will be used when the material is typed. I will be the only person who has access to a master list (necessary for

follow up purposes). The list will be kept in a secure place, away from any written or taped material, at all times.

Some interviews may be conducted in small groups at the nursing home, if enough people would like this, and if a suitable time and place can be arranged. These will probably take an hour of your time. Otherwise, I can arrange to meet you alone, at a time and place of your choosing (perhaps at your home), for about half an hour. There will be no financial cost to you.

It is anticipated that findings of the study will be made available to the wider community through journal articles and conference presentations, and to nursing homes in the form of general written feedback. However, at no time will any individuals or nursing homes be identifiable.

This research has been approved by the Committee for the Conduct of Ethical Research of Edith Cowan University and is being supervised by Dr Patricia Percival and Associate Professor Ed Helmes. You may call them on the following numbers I can be contacted on

There is, of course, no obligation for you to agree to take part. Also, if you do take part you may withdraw at any time. I shall not reveal to any other person whether or not you are included in the study, although it may be obvious if you choose to be interviewed at

the nursing home. Could you please let me know whether or not you would like to help in this way either by completing the slip and mailing it in the stamped envelope provided, or by telephoning me? I very much appreciate your giving this matter your consideration, and look forward to hearing from you.

Yours sincerely

Christine Toyne RN, BN (Hons).

Expression of Interest

Please cross through the sentence that does not apply and include your name and telephone number (if applicable) in the spaces provided.

I, _____, telephone number _____, am happy for you to contact me so that I may be included in your interviews.

I, _____, do not wish to be included in your interviews but enclose some written comments. I am happy for you to use those comments in your study, provided that my identity is not revealed to others.

I, _____, do not wish to take part in your study.

Thank you for taking the time to consider this request.

APPENDIX E

Instrument Development and Refinement

Stage One: Development of the First Draft of the RACRASST

Sample Characteristics

The 30 interviewees were all family members of nursing home residents. They included 15 family members from two, large, metropolitan nursing homes; 1 from a small rural home; 3 from a small, metropolitan, ethnically specific home; and 10 from two other small, metropolitan homes. They also included a respondent already known to the researcher. This person's relative had died in a nursing home approximately one year before the study. In total, there were 13 daughters of residents, 1 step-daughter, 4 sons, 1 son-in-law, 7 wives, and 4 husbands. One of the husbands additionally reflected upon the time he had spent visiting his sisters in nursing homes. Respondents' relatives suffered from a wide variety of disorders/disabilities, and their length of stay in residential care varied from a few months to approximately 5 years.

APPENDIX F**Instrument Development and Refinement****Stage One: Development of the First Draft of the RACRASST****Consent Forms** (All printed in a large font and duplicates provided to respondents)

Metropolitan area (participation).

I,, of, telephone number, agree to take part in the study concerning the support of family members of nursing home residents being conducted by Christine Toye, a Doctoral Candidate at Edith Cowan University. I have read the information provided by Christine, and understand what I will need to do to participate in the study. I have been given opportunities to ask questions, any that I have already asked have been answered to my satisfaction, and I know whom to contact should I wish to ask more in the future. I know that I may withdraw from the study at any time. I agree that the information gathered for this study may be published provided that I am not identified.

Signed (Participant)..... Date.....

Signed (Researcher).....Date.....

Metropolitan area (tape recording).

I,, of, consent to Christine Toye, from Edith Cowan University, tape recording my interview with her. I understand that this interview is a part of her study concerning the support of family members of nursing home residents. I understand that the taped interview and its typed transcript will remain the property of Christine, and that I will not be identified on tape, or on any written material, except by a code number. I am aware that I need not answer any questions if I do not wish to do so, and agree that the information obtained in this taped interview may be published provided that I am not identified.

Signed (Participant) Date.....

Signed (Researcher) Date.....

Non-metropolitan area.

I,, of, telephone number, agree to take part in the study concerning the support of family members of nursing home residents, being conducted by Christine Toye, a Doctoral Candidate at Edith Cowan University. I have read the information provided by Christine and understand what I will need to do. I have been given opportunities to ask questions, any that I have already asked have been answered to my satisfaction, and I know whom to contact should I wish to ask any more. I know that I may withdraw from the study at any time. I agree that the information gathered for this study may be published provided that I am not identified.

Signed (Participant).....Date.....

Signed (Researcher).....Date.....

I nominate the following day/time preferences for you to call me:

- 1)
- 2)
- 3)

APPENDIX G**Instrument Development and Refinement****Stage One: Development of the First Draft of the RACRASST****Draft One: Relatives' of Aged Care Residents Assessment of Staff Support Tool**

Section One: Knowing the System.

Definition: Staff help family members to learn of the usual practices and arrangements in place at the nursing home.

Staff:

1. Tell me about the "hierarchy" of the nursing home (who does what).
 2. Keep me informed about any changes in this "hierarchy".
 3. Tell me when it is best for me to discuss any worries with them, so that I do not disturb the care of the residents.
 4. Tell me how to contact the person who has overall responsibility for the day to day care of my relative (often the Director of Nursing in a small home, but, in a large one, it may be a nurse who manages part of the home).
 5. Explain the laundry system to me.
 6. Tell me how to contact the person with overall responsibility for the residents' laundry.
 7. Tell me about how family members may help with resident care in this home (e.g. by planning care with the staff, by carrying out some care, by bringing things in).
-

Staff:

8. Tell me about any help I can get when I want to know how to assist my relative (when I don't know what to do or I don't know how to do it).
 9. Tell me about any ways in which I may "have a say" in the running of the nursing home (e.g. if there is a relatives' committee or a suggestion box).
 10. Let me know who deals with complaints from residents' family members.
 11. Let me know where and when children are welcome to visit.
 12. Tell me how I may help a group of residents if I wish (e.g. by playing the piano or bringing in cakes).
 13. Let me know about any people in the home who may be able to help me (e.g. social workers, psychologists, chaplains, or nursing staff who are able to counsel me).
 14. Tell me how to contact each of the people who may be able to help me.
-

Section Two: Knowing the Staff.

Definition: Staff help family members to identify them and become familiar with them.

Staff:

1. Are regular (not agency or casual).
 2. Introduce themselves to me when they are around and I do not know them.
 3. Are easy to identify.
 4. Greet me when I visit.
 5. Include me in their chatter.
 6. Are approachable.
 7. Are friendly.
 8. Are informal in their manner.
 9. Make a point of introducing themselves to me, even if they are not around when I visit, if their jobs include helping residents' families (possibly social workers, psychologists, chaplains, etc.).
-

Section Three: Trusting the Staff.

Definition: Staff provide evidence of their trustworthiness.

Staff:

1. Keep me informed about my relative's condition.
 2. Turn up (in person) for any meetings that are arranged with me.
 3. Discuss with me what they will do about any worries I have (e.g. change my relative's care, arrange for me to talk to a social worker).
 4. Keep me informed about my relative's day to day care (e.g. help given with meals, skin care, etc.).
 5. Explain, when my relative's care has not been "as usual" (e.g. why he or she is in bed instead of up).
 6. Keep me informed without being asked.
 7. Keep me informed when I visit.
 8. Telephone me if there is a major change in my relative's condition (unless I ask not to be called).
-

Staff:

9. Keep me informed about my relative's emotional state.
 10. Treat seriously any complaints that I might have.
 11. Keep me informed about my relative's therapy (includes things like physiotherapy, massage, activity sessions).
 12. Hold any private discussions with me in a private place.
 13. Keep their promises to me.
 14. Accept responsibility for the care of my relative.
 15. Are easy for me to get along with.
 16. Pass on any messages (e.g. from me to other staff and from other staff to me).
 17. Are honest with me.
 18. Keep me informed about any medicine ordered for my relative.
-

Staff:

19. Invite me to meetings where my relative's care is to be discussed.

20. Explain any injuries received by my relative.

And:

21. The "Head Person" (often the Director of Nursing) seems to know what is going on all through the nursing home.
-

Section Four: Staff Care Activities.

Definition: Staff provide evidence that the family member's relative is receiving, or is likely to be receiving, "good" care.

1. Residents are shown around at the time of admission.
 2. Residents' call bells are answered quickly.
 3. Staff say they are too busy to help my relative^R.
 4. Staff seem to be working in an organised manner.
 5. Staff provide skilful care to residents.
 6. A Registered Nurse is available to my relative at all times.
 7. Staff provide "warm care" to residents (smiling, being loving, willing, caring, kind, and compassionate, not using harsh words or being abrupt).
 8. Staff address my relative by his/her preferred name (first or last).
 9. Staff ask family members about residents' backgrounds.
 10. Knowledge of my relative's background is used by staff when they provide care.
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11. Staff ask family members about residents' usual behaviour.
 12. Staff check to see if there is a problem when my relative is not acting as usual.
 13. Residents are included in staff conversations.
 14. Staff treat my relative as someone special.
 15. Staff respect my relative's dignity (e.g. he/she is decently covered when going to the bathroom).
 16. Family members are asked about their relative's preferences.
 17. Staff act upon residents' preferences (e.g. in meal provision or choice of room mate).
 18. Staff support and/or distract residents when family members leave (whichever helps).
 19. Staff from other areas address residents by name when visiting (e.g. staff from the office).
 20. Staff are thoughtful (e.g. letting my relative rest before an outing).
-

-
21. Social opportunities are provided for residents (e.g. residents who can chat are seated with others who can).
 22. Staff keep my relative comfortable.
 23. Staff ensure my relative is well-groomed (hair tidy, nails trimmed, etc.).
 24. Staff ensure my relative is dressed appropriately.
 25. Staff help my relative to stay clean.
 26. Stimulating activities are provided for residents within the nursing home.
 27. Staff offer to help my relative to get out of the nursing home on occasions (e.g. to arrange a bus trip or wheel a bed onto a verandah).
 28. Staff encourage residents to take part in activities/outings.
 29. The televisions and radios of those residents who use them are not allowed to disturb others.
 30. Opportunities are provided for residents to see, hear, and/or touch pets (e.g. visiting dogs, caged birds, etc.).
-

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31. Staff notice when residents need help even when they do not ask.
 32. There are staff who talk to my relative in his or her own language.
 33. Staff use touch to show support for residents (e.g. putting a hand on an arm to re-assure).
 34. Spiritual help is available to my relative (e.g. from a religious minister).
 35. Female residents may choose to receive personal care only from female staff.
 36. Staff separate "loud" residents from those who wish for quiet.
 37. Residents are encouraged to be independent.
 38. Staff make positive remarks to residents (e.g. "you look nice today").
 39. Staff seem to think that speed is all important when caring for the residents^R.
 40. Staff separate alert residents from those who are dying and require special care.
 41. Staff treat my relative as an adult.
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42. Staff do not speak to me about my relative in front of him/her.
43. Staff treat mentally alert residents as if they are confused^R.
44. When residents ask to use the toilet, they are helped quickly.
45. Residents are only taken to watch television when they have an interest in the program.
46. Staff have given my relative pills or medicine that could make him/her more likely to fall.
47. The doctor assesses my relative thoroughly.
48. There are enough staff to care for residents when they become acutely ill.
49. My relative is cared for by staff that he/she knows.
50. Each resident has his or her "own nurse" (a staff member who usually looks after him or her).
51. My relative seems to like the staff.
-

-
52. Staff caring for my relative have been taught about the needs of elderly people.
53. Staff welcome any input I wish to have into the care of my relative.
54. Staff are careful with my relative's possessions.
55. The privacy of residents is respected (e.g. staff knock before entering rooms).
56. Resident care comes first.
57. Staff maintain a "light hearted" atmosphere (e.g. they use humour sometimes).
58. Residents are only transferred from one area to another within the nursing home when it is in their own best interests.
-

Note: ^RItem to be reverse scored.

Section Five: Staff and the Building.

Definition: Staff show that they do what they can to maintain a physical environment that will be pleasant for residents and visitors.

Staff:

1. Ensure the home is kept clean.
 2. Do not allow bad smells to linger.
 3. Ensure the home is safe for residents (e.g. taking away things that may cause falls, closing security doors where residents might wander).
 4. Add homelike touches (e.g. vases of flowers).
 5. Allow residents to have their own telephones.
 6. Allow residents to bring in their own pictures, etc.
 7. Provide safe places for children to go when they visit (e.g. keeping dangerous items locked away, setting up a "toy corner").
 8. Ensure there is somewhere family members can go to have private time with residents.
-

Staff:

9. Ensure that residents are nursed in private rooms when visitors wish to stay with them during a crisis (where private rooms exist).
 10. Arrange for residents to have some private space, even if rooms are shared (e.g. by using furniture as "walls", and asking before entering).
 11. Use the light that is available to help give an impression of lightness and brightness. (e.g. open blinds wide).
 12. Set aside an area where visitors and residents may mix.
 13. Use music to give a pleasant atmosphere (e.g. restful music in a lounge room).
 14. Ensure there are signs to show me where things are (e.g. kiosks, items and places I might need when helping my relative).
 15. Ensure there are places where male and female residents may meet from time to time.
-

Section Six: Emotional Support for the Family.

Definition: Staff provide emotional support for family members.

1. Staff listen to my worries.
 2. Staff spare the time to talk to me.
 3. I can find the staff I want to talk to with ease.
 4. Staff show that they notice my support for my relative (e.g. saying "he/she is lucky to have some one like you").
 5. "Top staff" (those in management positions) are friendly to me.
 6. Staff help residents to make or buy Christmas and/or birthday gifts for their family members.
 7. Staff help family members to hold celebrations within the nursing home.
 8. The things staff say show that they realise I know the resident better than they do.
 9. Staff invite my input into care.
-

-
10. Staff say that my input helps.

 11. I am allowed to set my own limits when helping to care for my relative (because I am best able to judge how much I can cope with).

 12. I can tell that staff know it may make me sad to think back (e.g. when they ask about my relative's background).

 13. Staff tell me when my visits help my relative.

 14. Staff try to stop me worrying when I go (e.g. saying "we'll take care of him/her").

 15. Staff show they know that residents' family members may be grieving.

 16. Staff notice when I am upset.

 17. Staff tell me that it's "all right" to be upset.

 18. Staff know what to expect when people are grieving.

 19. When I tell staff about the things I am doing and feeling, staff are able to tell me whether or not this is normal.
-

-
20. Staff ask me if I can suggest ways in which they can help residents' family members.
 21. Staff ask me how I feel.
 22. When I am going through a really bad patch, and do not feel able to visit, staff phone me to see how I am.
 23. Staff are understanding if I do not wish to speak to family members of other residents.
 24. Staff accept that I may not wish to take part in any/some kinds of resident care.
 25. If I express my anger to the staff, they do not react in a hostile way.
 26. Staff show they know that I could not look after my relative at home.
 27. Staff tell me to look after my own health.
 28. Staff realise that I may need to visit less often in order to build up my health.
-

-
29. The Registered Nurses I speak to when I visit are able to counsel me.
 30. There is a support group for family members at the nursing home.
 31. There are religious services, held at the nursing home, that I may attend.
 32. Staff invite me to come to social events held for residents at the nursing home.
 33. Staff invite me to come to social events held for family members at the nursing home.
 34. If I do not wish to come to social events, this wish is respected by the staff.
 35. When meetings of staff, relatives, and/or residents are arranged, I am asked when it would be easiest for me to come.
 36. Staff help my relative to dress smartly for pre-arranged visits/outings.
 37. I am invited to share meals and/or drinks with my relative sometimes.
 38. Staff seem to dwell on any bad points when they talk to me about my relative (e.g how he/she can no longer do certain things)^R.
-

-
39. When I see a resident behaving badly, staff explain that this is probably because of his/her illness or disability.
40. Staff tell me any bad news with compassion.
41. Staff show that they are sad too, if a resident's condition worsens.
42. I am not automatically expected to come in to see my relative when I am told there is a crisis.
43. When I show that I know the future will hold no cure for my relative, staff are thankful that I do not cling to false hopes.
44. Formal counselling is available to me, in the nursing home.
45. Future changes at the nursing home are used as an excuse for poor resident care (because it is seen as temporary)^R.
46. I can get spiritual help at the nursing home (e.g. from a religious minister).
47. Staff run information sessions at the nursing home (e.g. to explain the course of Alzheimer's Disease).
-

-
48. Staff complain about the future of the nursing home where I can overhear them (e.g. "I don't know if we'll still be here next year")^R.
 49. Staff keep me informed about government changes that affect the nursing home.
 50. Staff willingly attend to my relative's needs when I am present.
 51. Staff support each other if I complain^R.
 52. Residents are only moved from one area of the nursing home to another after agreement with family members.
 53. Counselling is available for family members who have to decide about such a move.
 54. Family members are not rushed by staff when having to make a decision about such a move.
 55. If residents are moved, extra help is given to family members who have to get to know new staff and surroundings.
-

-
56. Staff sometimes use touch to show support for family members (e.g. putting an arm round a shoulder).
57. Staff help me to "make the most" of my visits (e.g suggesting I come at times when my relative is least sleepy).

Note: ^RItem to be reverse scored.

APPENDIX H

Instrument Development and Refinement

Stage Two: Panel Review and Subsequent RACRASST Revision

Package for Panel Review

Letter to participants. (Researcher's name and address supplied)

Dear

Thank you so much for agreeing to assist me in the development of my questionnaire. The instrument is intended to measure the perceived support of family members of nursing home residents from nursing home staff, and has been developed from interviews with family members. I shall be using it during the final phase of my doctoral study, but not until more work has been done on establishing its reliability and validity, and its size has been reduced considerably. I regret having to ask you to read such a large number of items, but requesting your comments was seen as a necessary first step towards reducing this number, as well as towards refining the instrument in other ways.

The final items will be scored on a 4-point Likert Scale (strongly agree – strongly disagree). A decision has not yet been made about including a column labelled “not applicable”. I would appreciate your comments on this issue if you can find the time to make a note of them, otherwise all my requests for your input are listed on the enclosed sheet. It is estimated that complying with these requests will take you about one hour of your time.

Please feel free to ring me with any queries on My Principal Supervisor is Professor Linda Kristjanson of Edith Cowan University, telephone number She will also be happy to talk to you. Finally, I can only thank you once more for being so generous with your time and expertise.

Yours sincerely

Consent form.

I,, of, telephone number, agree to take part in the study concerning the support of family members of nursing home residents being conducted by Christine Toye, a Doctoral Candidate at Edith Cowan University. I have read information provided by Christine, and understand what I will need to do to participate in the study. I have been given the opportunity to ask questions, and any that I have asked have been answered to my satisfaction. I know whom to contact should I wish to ask more in the future, and I am aware that may withdraw from the study at any time. I agree that the information gathered for this study may be published provided that I am not identified.

Signed (Participant).....Date.....

Signed (Researcher).....Date.....

Directions: Review of newly developed questionnaire.

1. Clarity.

Please read each statement and indicate in Column A whether the statement is Clear (C) or Unclear (U). If it is unclear, please note the suggested changes below the statement.

2. Content Validity.

Please re-read each statement and indicate in Column B whether or not the statement "fits" the definition of the sub-scale (shown beside its title) by writing "Y" or "N". In Column C please write "Y" or "N" to indicate whether or not the item is redundant. If "Y" is written, please write the number of the corresponding item beside that letter.

3. Apparent Internal Consistency.

Please review the items of the sub-scale in general, and indicate, in Column D, whether or not the statements appear to measure the same thing, by writing "Y" or "N". Please also comment as you see fit.

Thank you very much for donating your time and using your experience to assist me in this way

Sample page of draft one of the RACRASST as given to panel members.

Section Two: Knowing the Staff

Definition: Staff help family members to identify them and become familiar with them.

Directions that will be given: Think about how you get to know the staff. How much do you agree or disagree with these statements?

	Staff:	A	B	C		D
				REDUNDANCY. NO.		
1.	Are regular (not agency or casual).					
2.	Introduce themselves to me when they are around and I do not know them.					
3.	Are easy to identify.					
4.	Greet me when I visit.					
5.	Include me in their chatter.					

APPENDIX I

Instrument Development and Refinement

Stage Two: Panel Review and Subsequent RACRASST Revision

Findings of Panel Review

Findings of the panel review identified problems with a number of items/sub-scales. As a result these items were reviewed, 22 being deleted, 20 being reworded, and 15 being relocated (see Table I1). The sub-scale "Staff and the Building" was unchanged by the review. The first sub-scale was re-named "Information from the Staff" and its question stem was changed. The word "nursing" was dropped from "nursing home" because of changes in government policy.

Table I1**Findings of the Panel Review of Draft One of the RACRASST**

Scale name	Item	Identified problem	Action taken:
Knowing the System	All Items	Stem, "staff", not inclusive enough. Cumbersome. Should refer to staff providing information.	<ul style="list-style-type: none"> • Stem change to "Staff keep me informed about". • Sub-scale renamed "Information from the Staff". • New definition: "Staff keep family members informed about the usual practices and arrangements in place in the home".
	1, 2	New stem allows combination of these two items.	<ul style="list-style-type: none"> • Items combined: one deleted, one reworded.
	11	As worded is really two items.	<ul style="list-style-type: none"> • Reworded.
Knowing the Staff	1	Unclear.	<ul style="list-style-type: none"> • Reworded.
	7	Redundant with 6.	<ul style="list-style-type: none"> • Deleted.
	8	Redundant with 6.	<ul style="list-style-type: none"> • Deleted.

Scale name	Item	Identified problem	Action taken
Trusting the Staff	1	Refers to "information".	<ul style="list-style-type: none"> Moved to new "Information from the Staff" scale.
	3	Unclear.	<ul style="list-style-type: none"> Reworded.
	4	Refers to "information".	<ul style="list-style-type: none"> Moved to new "Information from the Staff" scale.
	5	Redundant with 4.	<ul style="list-style-type: none"> Deleted.
	6	Redundant with 7.	<ul style="list-style-type: none"> Deleted.
	7	Unclear/redundant.	<ul style="list-style-type: none"> Deleted.
	8	Redundant with 1.	<ul style="list-style-type: none"> Deleted.
	9	Refers to "information".	<ul style="list-style-type: none"> Moved to new "Information from the Staff" scale.
	10	Unclear.	<ul style="list-style-type: none"> Deleted.
	11	Refers to "information".	<ul style="list-style-type: none"> Moved to new "Information from the Staff" scale.
	15	Does not fit definition.	<ul style="list-style-type: none"> Deleted.
	18	Redundant with 11.	<ul style="list-style-type: none"> Deleted.
20	Refers to "information".	<ul style="list-style-type: none"> Moved to new "Information from the Staff" scale. 	

Scale name	Item	Identified problem	Action taken
Staff Care	2	Too specific.	• Reworded.
Activities	13	Unclear.	• Reworded.
	36	Unclear.	• Reworded.
	40	Possibly upsetting to some respondents.	• Deleted.
	42	Refers to staff trustworthiness.	• Moved to "Trusting the Staff".
	44	Redundant with 2.	• Deleted.
	46	Too specific.	• Deleted.
	50	Redundant with 49.	• Deleted.
	51	Does not fit definition.	• Deleted.
	52	Redundant with 5.	• Deleted.
	53	Redundant with Scale 6, Item 9.	• Deleted.
	54	Does not fit definition.	• Moved to "Trusting the Staff".
	56	Unclear.	• Reworded.

Scale name	Item	Identified problem	Action taken
Emotional Support for the Family	3	Unclear and refers to knowing the staff.	<ul style="list-style-type: none"> • Reworded. • Moved to "Knowing the Staff".
	5	Refers to knowing the staff.	<ul style="list-style-type: none"> • Moved to "Knowing the Staff".
	6	Does not fit definition.	<ul style="list-style-type: none"> • Deleted.
	8	Unclear.	<ul style="list-style-type: none"> • Reworded.
	10	Unclear.	<ul style="list-style-type: none"> • Reworded.
	11	Unclear.	<ul style="list-style-type: none"> • Reworded.
	12	Unclear.	<ul style="list-style-type: none"> • Reworded.
	14	Unclear.	<ul style="list-style-type: none"> • Reworded.
	18	Redundant with 15.	<ul style="list-style-type: none"> • Reworded.
	22	Unclear.	<ul style="list-style-type: none"> • Reworded.
	27	Unclear.	<ul style="list-style-type: none"> • Reworded.
	28	Unclear.	<ul style="list-style-type: none"> • Reworded.
	29	Redundant with 44.	<ul style="list-style-type: none"> • Deleted.

Scale name	Item	Identified problem	Action taken
	36	Redundant with Scale 4, Item 24.	<ul style="list-style-type: none"> Deleted.
	43	Unclear.	<ul style="list-style-type: none"> Reworded.
	45	This refers to staff care of residents	<ul style="list-style-type: none"> Moved to "Staff Care Activities".
	46	Overlap with 31.	<ul style="list-style-type: none"> Deleted.
	47	Unclear.	<ul style="list-style-type: none"> Reworded.
	49	This refers to information	<ul style="list-style-type: none"> Moved to "Information from the Staff".
	51	This refers to staff trustworthiness.	<ul style="list-style-type: none"> Moved to "Trusting the Staff".
	52	This refers to staff trustworthiness.	<ul style="list-style-type: none"> Moved to "Trusting the Staff".
	53	Redundant with 44.	<ul style="list-style-type: none"> Deleted.
	54	This refers to staff trustworthiness.	<ul style="list-style-type: none"> Moved to "Trusting the Staff".
	55	Refers to knowing the staff.	<ul style="list-style-type: none"> Moved to "Knowing the Staff".

APPENDIX J**Instrument Development and Refinement****Stage Two: Panel Review and Subsequent RACRASST Revision****Draft Two of the Relatives' of Aged Care Residents Assessment of Staff****Support Tool**

SECTION ONE

Information from the Staff

Please think about the information staff give to you: information about the ways things are done in this home, about your relative who lives in the home, and about any help that is there for you.

How much do you agree or disagree with these statements?

Staff keep me informed about:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. My relative's condition.	SA	A	D	SD	NA
2. My relative's emotional state.	SA	A	D	SD	NA
3. My relative's day to day care (e.g. help given with meals, skin care, etc.).	SA	A	D	SD	NA
4. My relative's therapy (including medications, occupational therapy, physiotherapy, massage, activity sessions, etc.).	SA	A	D	SD	NA

Staff keep me informed about:		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
5.	Any injuries received by my relative.	SA	A	D	SD	NA
6.	The "hierarchy" of the home (who does what).	SA	A	D	SD	NA
7.	The laundry system.	SA	A	D	SD	NA
8.	When it is best to discuss any worries with them so that I do not disturb the care of the residents.	SA	A	D	SD	NA
9.	How to contact the person with overall responsibility for the day to day care of my relative (often the Director of Nursing in a small home, but, in a large one, it may be a nurse who manages part of the home).	SA	A	D	SD	NA
10.	How to contact the person with overall responsibility for the residents' laundry.	SA	A	D	SD	NA

Staff keep me informed about:		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
11.	How family members may help with resident care in this home (e.g. by planning care with the staff, by carrying out some care, by bringing things in).	SA	A	D	SD	NA
12.	Who deals with complaints from residents' family members.	SA	A	D	SD	NA
13.	How to get help, when I want to know how to assist my relative (when I don't know what to do or I don't know how to do it).	SA	A	D	SD	NA
14.	How to "have a say" in the running of the home (e.g. by joining a relatives' committee or using a suggestion box).	SA	A	D	SD	NA
15.	Any rules that apply to children's visits.	SA	A	D	SD	NA
16.	How I may help groups of residents if I wish (e.g. by playing the piano or bringing in cakes).	SA	A	D	SD	NA

Staff keep me informed about:		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
17.	People in the home who may be able to help me (e.g. social workers, psychologists, chaplains, or nurses able to counsel me).	SA	A	D	SD	NA
18.	How to contact each of the people who may be able to help me.	SA	A	D	SD	NA
19.	How any changes in government policy will affect the home.	SA	A	D	SD	NA

SECTION TWO

Knowing the Staff

Please think about how you get to know the staff.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Are regular (e.g. not agency).	SA	A	D	SD	NA
2. Introduce themselves to me when they are around and I do not know them.	SA	A	D	SD	NA
3. Are easy to identify.	SA	A	D	SD	NA
4. Greet me when I visit.	SA	A	D	SD	NA
5. Include me in their chatter.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
6. Are approachable.	SA	A	D	SD	NA
7. Can be found easily, when I want to talk to them.	SA	A	D	SD	NA
8. Who are in management positions ("Top Staff") are friendly to me.	SA	A	D	SD	NA
9. Make a point of introducing themselves to me, even if they are not around when I visit, if their jobs include helping residents' families (e.g. social workers, psychologists, chaplains, etc.).	SA	A	D	SD	NA
10. Make a special effort to get to know me, when my relative has been moved into their area from a different part of the home.	SA	A	D	SD	NA

SECTION THREE

Trusting the Staff

Please think about the way staff act towards you.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Turn up (in person) for any meetings that are arranged with me.	SA	A	D	SD	NA
2. Follow up on any discussions I have with them about my worries (e.g. change my relative's care, or arrange for me to talk to a social worker).	SA	A	D	SD	NA
3. Hold any private discussions with me in a private place.	SA	A	D	SD	NA
4. Keep their promises to me.	SA	A	D	SD	NA
5. Accept responsibility for the care of my relative.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
6. Pass on any messages (e.g. from me to other staff and from other staff to me).	SA	A	D	SD	NA
7. Are honest with me.	SA	A	D	SD	NA
8. Invite me to meetings where my relative's care is to be discussed.	SA	A	D	SD	NA
9. Do not speak to me about my relative in front of him/her.	SA	A	D	SD	NA
10. Are careful with my relative's possessions.	SA	A	D	SD	NA
11. Support each other if I complain ^R .	SA	A	D	SD	NA
12. Only move residents from one area of the home to another after agreement with family members.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
13. Do not rush family members when they have to decide about such a move.	SA	A	D	SD	NA
The "Head Person" (often the Director of Nursing)					
14. Seems to know what is going on all through the home.	SA	A	D	SD	NA

Note: ^RItem to be reverse scored.

SECTION FOUR

Staff Care Activities

Please think about how the staff care for residents in general, and your relative in particular.

How much do you agree or disagree with these statements?

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1.	Residents are shown around at the time of admission.	SA	A	D	SD	NA
2.	Residents' needs are attended to quickly.	SA	A	D	SD	NA
3.	Staff say they are too busy to help my relative ^R .	SA	A	D	SD	NA
4.	Staff seem to be working in an organised manner.	SA	A	D	SD	NA
5.	Staff provide skilful care to residents.	SA	A	D	SD	NA
6.	A Registered Nurse is available to my relative at all times.	SA	A	D	SD	NA

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
7.	Staff provide "warm care" to residents (smiling, being loving, willing, caring, kind, and compassionate, not using harsh words or being abrupt).	SA	A	D	SD	NA
8.	Staff address my relative by his/her preferred name (first or last).	SA	A	D	SD	NA
9.	Staff ask family members about residents' backgrounds.	SA	A	D	SD	NA
10.	Knowledge of my relative's background is used by staff when they provide care.	SA	A	D	SD	NA
11.	Staff ask family members about residents' usual behaviour.	SA	A	D	SD	NA
12.	Staff check to see if there is a problem when my relative is not acting as usual.	SA	A	D	SD	NA

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
13.	Residents are included in staff conversations (when this is appropriate).	SA	A	D	SD	NA
14.	Staff treat my relative as someone special.	SA	A	D	SD	NA
15.	Staff respect my relative's dignity (e.g. he/she is decently covered when going to the bathroom).	SA	A	D	SD	NA
16.	Family members are asked about their relative's preferences.	SA	A	D	SD	NA
17.	Staff act upon residents' preferences (e.g. in meal provision or choice of room-mate).	SA	A	D	SD	NA
18.	Staff support and/or distract residents when family members leave (whichever helps).	SA	A	D	SD	NA

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
19.	Staff from other areas address residents by name when visiting (e.g. staff from the office).	SA	A	D	SD	NA
20.	Staff are thoughtful (e.g. letting my relative rest before an outing).	SA	A	D	SD	NA
21.	Social opportunities are provided for residents (e.g. residents who can chat are seated with others who can).	SA	A	D	SD	NA
22.	Staff keep my relative comfortable.	SA	A	D	SD	NA
23.	Staff ensure my relative is well groomed (hair tidy, nails trimmed, etc.).	SA	A	D	SD	NA
24.	Staff ensure my relative is dressed appropriately.	SA	A	D	SD	NA
25.	Staff help my relative to stay clean.	SA	A	D	SD	NA

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
26.	Stimulating activities are provided for residents within the home.	SA	A	D	SD	NA
27.	Staff offer to help my relative to get out of the home on occasions (e.g. to arrange a bus trip or wheel a bed onto a verandah).	SA	A	D	SD	NA
28.	Staff encourage residents to take part in activities/outings.	SA	A	D	SD	NA
29.	The televisions and radios of those residents who use them are not allowed to disturb others.	SA	A	D	SD	NA
30.	Opportunities are provided for residents to see, hear, and/or touch pets (e.g. visiting dogs, caged birds, etc.).	SA	A	D	SD	NA
31.	Staff notice when residents need help even when they do not ask.	SA	A	D	SD	NA

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
32.	There are staff who talk to my relative in his or her own language.	SA	A	D	SD	NA
33.	Staff use touch to show support for residents (e.g. putting a hand on an arm to re-assure).	SA	A	D	SD	NA
34.	Spiritual help is available to my relative (e.g. from a religious minister).	SA	A	D	SD	NA
35.	Female residents may choose to receive personal care only from female staff.	SA	A	D	SD	NA
36.	Staff separate "loud" residents from those who wish for quiet, when this is possible.	SA	A	D	SD	NA
37.	Residents are encouraged to be independent.	SA	A	D	SD	NA

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
38.	Staff make positive remarks to residents (e.g. "you look nice today").	SA	A	D	SD	NA
39.	Staff seem to think that speed is all important when caring for the residents ^R .	SA	A	D	SD	NA
40.	Staff treat my relative as an adult.	SA	A	D	SD	NA
41.	Staff treat mentally alert residents as if they are confused ^R .	SA	A	D	SD	NA
42.	Residents are only taken to watch television when they have an interest in the program.	SA	A	D	SD	NA
43.	The doctor assesses my relative thoroughly.	SA	A	D	SD	NA
44.	There are enough staff to care for residents when they become acutely ill.	SA	A	D	SD	NA

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
45.	My relative is cared for by staff that he/she knows.	SA	A	D	SD	NA
46.	The privacy of residents is respected (e.g. staff knock before entering rooms).	SA	A	D	SD	NA
47.	Staff attitudes show that resident care comes first.	SA	A	D	SD	NA
48.	Staff maintain a "light hearted" atmosphere (e.g. they use humour sometimes).	SA	A	D	SD	NA
49.	Residents are only transferred from one area to another within the home when it is in their own best interests.	SA	A	D	SD	NA
50.	Future changes at the home are used as an excuse for poor resident care (because it is seen as temporary) ^R .	SA	A	D	SD	NA

Note: ^RItem to be reverse scored.

SECTION FIVE

Staff and the Building

Please think about the building in which your relative lives, and how the staff can make it more pleasant.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Ensure the home is kept clean.	SA	A	D	SD	NA
2. Do not allow bad smells to linger.	SA	A	D	SD	NA
3. Ensure the home is safe for residents (e.g. taking away things that may cause falls, closing security doors where residents might wander).	SA	A	D	SD	NA
4. Add homelike touches (e.g. vases of flowers).	SA	A	D	SD	NA

Staff:		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
5.	Allow residents to have their own telephones.	SA	A	D	SD	NA
6.	Allow residents to bring in their own pictures, etc..	SA	A	D	SD	NA
7.	Provide safe places for children to go when they visit (e.g. keeping dangerous items locked away, setting up a "toy corner").	SA	A	D	SD	NA
8.	Ensure there is somewhere family members can go to have private time with residents.	SA	A	D	SD	NA
9.	Ensure that residents are nursed in private rooms when visitors wish to stay with them during a crisis (where private rooms exist).	SA	A	D	SD	NA
10.	Arrange for residents to have some private space, even if rooms are shared (e.g. by using furniture as "walls", and asking before entering).	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
11. Use the light that is available to help give an impression of lightness and brightness. (e.g. open blinds wide).	SA	A	D	SD	NA
12. Set aside an area where visitors and residents may mix.	SA	A	D	SD	NA
13. Use music to give a pleasant atmosphere (e.g. restful music in a lounge room).	SA	A	D	SD	NA
14. Ensure there are signs to show me where things are (e.g. kiosks, items and places I might need when helping my relative).	SA	A	D	SD	NA
15. Ensure there are places where male and female residents may meet from time to time.	SA	A	D	SD	NA

SECTION SIX

Staff and Emotional Support for the Family

Please think about the bad times that you and other family members may have, and the ways in which staff can make a difference.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Listen to my worries.	SA	A	D	SD	NA
2. Spare the time to talk to me.	SA	A	D	SD	NA
3. Show that they notice my support for my relative (e.g. saying "he/she is lucky to have some one like you").	SA	A	D	SD	NA
4. Help family members to hold celebrations within the home.	SA	A	D	SD	NA
5. Say things that show they realise I know the resident better than they do.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
6. Invite my input into care.	SA	A	D	SD	NA
7. Say that my input into care helps.	SA	A	D	SD	NA
8. Allow me to set my own limits when helping to care for my relative (because I am the best judge of how much I can cope with).	SA	A	D	SD	NA
9. Show they know that it may make me sad to think about the past (e.g. when they ask about my relative's background).	SA	A	D	SD	NA
10. Tell me when my visits help my relative.	SA	A	D	SD	NA
11. Try to stop me worrying when I leave (e.g. saying "we'll take care of him/her").	SA	A	D	SD	NA
12. Show they know that residents' family members may be grieving.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
13. Notice when I am upset.	SA	A	D	SD	NA
14. Tell me that it's "all right" to be upset.	SA	A	D	SD	NA
15. Are able to tell me whether or not the things I am doing and feeling are normal, when I speak of them.	SA	A	D	SD	NA
16. Ask me if I can suggest ways in which they can help residents' family members.	SA	A	D	SD	NA
17. Ask me how I feel.	SA	A	D	SD	NA
18. Telephone me to see how I am, when I am unable to visit.	SA	A	D	SD	NA
19. Are understanding if I do not wish to speak to family members of other residents.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
20. Accept that I may not wish to take part in any/some kinds of resident care.	SA	A	D	SD	NA
21. Do not react in a hostile way, if I express my anger to them.	SA	A	D	SD	NA
22. Show they know that I could not look after my relative at home.	SA	A	D	SD	NA
23. Encourage me to look after my own needs.	SA	A	D	SD	NA
24. Realise that I may need to visit less often at certain times.	SA	A	D	SD	NA
25. Invite me to come to social events at the home.	SA	A	D	SD	NA
26. Respect my wishes, if I choose not to come to social events.	SA	A	D	SD	NA
27. Ask me when it would be easiest for me to come, when meetings of staff, relatives, and/or residents are arranged.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
28. Invite me to share meals and/or drinks with my relative sometimes.	SA	A	D	SD	NA
29. Seem to dwell on any bad points when they talk to me about my relative (e.g. how he/she can no longer do certain things) ^R .	SA	A	D	SD	NA
30. Explain, when I see a resident behaving badly, that this is probably because of the resident's illness or disability.	SA	A	D	SD	NA
31. Tell me any bad news with compassion.	SA	A	D	SD	NA
32. Show that they are sad too, if a resident's condition worsens.	SA	A	D	SD	NA
33. Do not automatically expect me to come in to see my relative when I am told there is a crisis.	SA	A	D	SD	NA
34. Understand that I do not cling to false hopes, when I show that I know the future will hold no cure for my relative.	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
35. Make available formal counselling to me, in the home.	SA	A	D	SD	NA
36. Complain about the future of the home where I can overhear them (e.g. "I don't know if we'll still be here next year") ^R .	SA	A	D	SD	NA
37. Willingly attend to my relative's needs when I am present.	SA	A	D	SD	NA
38. Sometimes use touch to show support for family members (e.g. putting an arm round a shoulder).	SA	A	D	SD	NA
39. Help me to "make the most" of my visits (e.g suggesting I come at times when my relative is least sleepy).	SA	A	D	SD	NA

The home offers:		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
40.	Religious services that I may attend.	SA	A	D	SD	NA
41.	Educational sessions for family members (e.g. to explain the course of Alzheimer's disease).	SA	A	D	SD	NA
42.	A support group for family members.	SA	A	D	SD	NA

Note: ^RItem to be reverse scored.

APPENDIX K**Instrument Development and Refinement****Stage Three: Draft Instrument Revisions from Small Sample Responses**
Package for Potential Respondents to Draft Two of the RACRASST

Letter requesting family members to participate in the study.

(for packages forwarded by DONs/Managers) (printed in large font)

Researcher's name and address supplied.

Dear Family Member

This letter concerns the research I am carrying out as a PhD (Nursing) Candidate at Edith Cowan University, research that is intended to lead to benefits for family members of nursing home/hostel residents. I have worked as a Registered Nurse in a variety of nursing homes for many years, and have had considerable contact with family members of residents. Now I am trying to find out how staff can best meet their needs.

Last year, I interviewed family members to discover the things staff could do to help them, and I have now developed a draft questionnaire from the information I was given. This draft is too long to be "user friendly", and, to shorten it without leaving out anything that is really important, I need to have it answered by about 30 family member volunteers. Until it is shortened and improved I cannot use it to assess the help that is given to family members now – so that we may see where changes might be helpful.

If you would be prepared to help me by answering the enclosed 150 questions, and noting the very few details about yourself that I need to know, this would probably take you 30 – 40 minutes. A stamped envelope is included for the return of completed forms.

Consent forms are needed, but will be separated from completed questionnaires as soon as I receive them, and locked away. I shall not reveal to any other person whether or not you have taken part in the study.

It is anticipated that findings of the research using the shortened questionnaire will be made available to the community through journal articles and/or conference presentations. Written and spoken accounts of how the questionnaire has been developed may also be made available, but individuals, nursing homes, and/or hostels will not be identifiable.

This research has been approved by the Committee for the Conduct of Ethical Research of Edith Cowan University and is being supervised by Professor Linda Kristjanson and Associate Professor Ed Helmes. You may call them if you wish, on or contact me at the University on with any queries.

I do hope you can help. Thanking you in anticipation.

Yours sincerely

Christine Toye RN, BN (Hons.)

Letter to respondents expressing interest in the study.

(for packages mailed directly to potential participants) (printed in large font)

Researcher's name and address supplied.

Dear

Thank you for saying you may take part in this stage of my research project. I really appreciate your interest. If you do agree, could you please answer the enclosed questionnaire, developed last year from information given by family members of Western Australian nursing home residents? This will allow me to decide which questions need to be kept when I shorten the questionnaire for later use, and will probably take you 30 – 40 minutes. A few additional details are also requested. A stamped envelope is included for return of the forms.

A consent form is needed, but will be separated from the completed questionnaire as soon as it is received, and locked away. I shall not reveal to any other person whether or not you have taken part in the study.

It is anticipated that findings of the research using the shortened questionnaire will be made available to the community through journal articles and/or conference presentations. Written and spoken accounts of how the questionnaire has been developed may also be made available, but individuals, nursing homes, and/or hostels will not be identifiable.

This research has been approved by the Committee for the Conduct of Ethical Research of Edith Cowan University and is being supervised by Professor Linda Kristjanson and Associate Professor Ed Helmes. You may call them if you wish, on, or contact me at the University, on, with any queries.

Thanking you so much.

Yours sincerely

Christine Toye RN, BN (Hons.)

Consent form.

Please complete and return one copy of this form, keeping the other copy for your records.

I,, of, telephone number, agree to take part in the study concerning the support of family members of nursing home/hostel residents, being conducted by Christine Toye, Doctoral Candidate at Edith Cowan University. I have read the letter written by Christine, and understand what I will need to do. I know that I may ask questions, whom to contact should I wish to do so, and any that I have already asked have been answered to my satisfaction. I know that I may withdraw from the study at any time. I agree that information gathered for this study may be published provided that I am not identified.

Signed (Participant).....Date..... Signed (Researcher) Date.....

Personal details form.

1. Does your relative receive

(a) hostel type care?

OR

(b) nursing home type care?

2. Please indicate the relationship you have with your relative in the nursing home/hostel (e.g. if you are a son or daughter, husband or wife, sister or brother of the resident).

3. How long has your relative been in this nursing home/hostel?.....

Thank you so much for your help

Directions for DraftTwo of the RACRASST.

(also included was a full copy of the questionnaire and an example of how to respond. Size 16 font was used throughout, and sub-scales were printed on paper of differing colours)

You are asked to complete these forms using your experience as a family member of a person living in a Residential/ Aged Care Facility (a hostel or nursing home).

Think about the things staff do that help you.

Think about all the staff, including those who serve the tea or work in the office.

Please read the statements in this booklet, and see how much you agree or disagree with each of them.

To show how much you agree or disagree please circle the appropriate letter(s).

For each statement you may choose either "SA" (STRONGLY AGREE); "A" (AGREE); "D" (DISAGREE); or "SD" (STRONGLY DISAGREE).

You may choose "NA" (NOT APPLICABLE) instead, but please only do this after careful thought.

Please only circle one choice for each statement, and answer all questions.

THANK YOU.

APPENDIX L

Instrument Development and Refinement

Stage Three: Draft Instrument Revisions from Small Sample Responses

Sample Characteristics

Sample characteristics are shown in Table L1. Thirty data sets were obtained from 32 family members as two wife/daughter couples completed forms.

Table L1

Sample Characteristics (Review of Draft Two of the RACRASST)

Family members of "hostel type" residents	3
Family members of "nursing home type" residents	29
Daughters of residents	19
Wives of residents	6
Sons of residents	2
Husbands of residents	3
Daughters-in-law of residents	1
Sisters of residents	1
Questionnaires completed by family members of residents of less than 3 months	4
Questionnaires completed by family members of residents of 3-6 months	6
Questionnaires completed by family members of residents of 6-12 months	8
Questionnaires completed by family members of residents of more than 12 months	12

APPENDIX M

Instrument Development and Refinement

Stage Three: Draft Instrument Revisions from Small Sample Responses

Findings of Analyses

Following the data analysis plan, statistics were recorded for each sub-scale at Step 1, prior to any item deletions. Items were deleted at Steps 2, 3, and 8 of the data analysis and statistics were also recorded after each of these sets of deletions. Statistics recorded included Cronbach's and standardised item alphas, means and ranges of inter-item correlations, and item-to total correlations (Tables M1 – M6). No items were deleted at Step 4, because none attracted a single type of response from 80% or more of participants. Items retained for Draft 3 of the RACRASST are documented in Table M10. This table also shows means and standard deviations of the scores of each of the retained items in each sub-scale.

Table M1

Sub-Scale One: Statistics at Steps One, Two, Three, and Eight

Statistic	At Step 1 (19 Items)	At Step 2 (18 Items)	At Step 3 (12 Items)	At Step 8 (5 items)
Inter-item-correlations:				
Mean	0.41	0.44	0.63	0.51
Range	-0.24 - 0.92	-0.10 - 0.92	0.33 - 0.92	0.33 - 0.65
Item-to-total correlations:				
Mean	0.61	0.64	0.77	0.64
Range	0.24 - 0.82	0.20 - 0.83	0.58 - 0.89	0.54 - 0.76
Cronbach's alpha	0.91	0.91	0.95	0.83
Standardised item alpha	0.93	0.93	0.95	0.84

Table M2

Sub-Scale Two: Statistics at Steps One, Two, Three, and Eight

Statistic	At Step 1 (10 items)	At Step 2 (9 Items)	At Step 3 (6 Items)	At Step 8 (5 Items)
Inter-item-correlations:				
Mean	0.49	0.56	0.63	0.52
Range	0.01 - 0.79	0.29 - 0.79	0.44 - 0.79	0.37 - 0.70
Item-to-total correlations:				
Mean	0.65	0.71	0.75	0.64
Range	0.28 - 0.83	0.45 - 0.83	0.63 - 0.83	0.55 - 0.73
Cronbach's alpha	0.87	0.91	0.90	0.82
Standardised item alpha	0.90	0.91	0.91	0.84

Table M3

Sub-Scale Three: Statistics at Steps One, Two, Three, and Eight

Statistic	At Step 1 (14 items)	At Step 2 (10 items)	At Step 3 (8 items)	At Step 8 (4 items)
Inter-item-correlations:				
Mean	0.38	0.54	0.59	0.50
Range	-0.10 - 0.93	0.28 - 0.89	0.28 - 0.89	0.28 - 0.68
Item-to-total correlations:				
Mean	0.58	0.70	0.70	0.61
Range	0.24 - 0.82	0.58 - 0.87	0.56 - 0.89	0.51 - 0.73
Cronbach's alpha	0.87	0.91	0.90	0.78
Standardised item alpha	0.90	0.92	0.91	0.80

Table M4

Sub-Scale Four: Statistics at Steps One, Two, Three, and Eight

Statistic	At Step 1 (50 items)	At Step 2 (46 items)	At Step 3 (31 items)	At Step 8 (8 items)
Inter-item-correlations:				
Mean	0.39	0.42	0.49	0.47
Range	-0.27 - 1.00	-0.27 - 1.00	-0.05 - 1.00	0.25 - 0.73
Item-to-total correlations:				
Mean	0.54	0.59	0.69	0.63
Range	0.09 - 0.87	0.12 - 0.88	0.22 - 0.87	0.47 - 0.69
Cronbach's alpha	0.96	0.96	0.96	0.85
Standardised item alpha	0.97	0.97	0.97	0.88

Table M5**Sub-Scale Five: Statistics at Steps One, Two, Three, and Eight**

Statistic	At Step 1 (15 Items)	At Step 2 (11 items)	At Step 3 (8 items)	At Step 8 (5 Items)
Inter-item-correlations:				
Mean	0.33	0.46	0.59	0.53
Range	-0.27 – 1.00	-0.12 – 0.86	0.29 – 0.87	0.29 – 0.67
Item-to-total correlations:				
Mean	0.50	0.62	0.73	0.53
Range	0.06 – 0.71	0.13 – 0.86	0.63 – 0.83	0.29 – 0.67
Cronbach's alpha	0.79	0.85	0.91	0.84
Standardised item alpha	0.88	0.90	0.92	0.85

Table M6**Sub-Scale Six: Statistics at Steps One, Two, Three, and Eight**

Statistic	At Step 1 (42 Items)	At Step 2 (23 Items)	At Step 3 (16 Items)	At Step 8 (5 Items)
Inter-item-correlations:				
Mean	0.36	0.46	0.55	0.59
Range	-0.27 – 0.95	-0.13 – 0.91	0.00 – 0.91	0.43 – 0.78
Item-to-total correlations:				
Mean	0.58	0.66	0.72	0.70
Range	0.15 – 0.87	0.29 – 0.87	0.30 – 0.92	0.54 – 0.85
Cronbach's alpha	0.95	0.95	0.95	0.86
Standardised item alpha	0.96	0.95	0.95	0.88

Nineteen items were deleted from Sub-Scale 6 at Step 2 of the review (see Table M7). A number of these items, which attracted more than five "not applicable" responses, assumed family members would be distressed.

Table M7

Draft Two of the RACRASST: Items Deleted at Step Two

Sub-Scale	Items deleted (>5 "Not Applicable" responses)
One: Information from the Staff	15
Two: Knowing the Staff	10
Three: Trusting the Staff	8, 11, 12, 13
Four: Staff Care Activities	32, 35, 42, 50
Five: Staff and the Building	5, 7, 9, 15
Six: Staff and Emotional Support for the Family	4, 14-16, 18, 19, 21, 24, 27, 30-36, 40-42

Items that did not meet the criteria for discriminant validity attracted higher correlations with other sub-scale totals than with the total of the sub-scale in which they were situated. Sub-scale 4 lost the most items as a result of this analysis (Table M8).

Table M8

Draft Two of the RACRASST: Items Deleted at Step Three for Failing to Meet Discriminant Validity Criteria for the Instrument

"Home" sub-scale	Item number	Correlation with sub-scale totals					
		One	Two	Three	Four	Five	Six
One	2	.80	.71	.63	.68	.35	.84*
	5	.43	.31	.37	.42	.51*	.67*
	7	.44	.33	.42	.59*	.08	.38
	10	.49	.40	.44	.60*	.30	.52*
	14	.24	.29*	.29*	.02	.10	.19
	16	.20	.22*	.20	.26*	.01	.26*
Two	3	.42	.70	.63	.74*	.37	.49
	6	.45	.69	.53	.80*	.48	.59
	9	.23	.45	.60*	.29	.45	.81*
Three	7	.69	.76*	.69	.84*	.49	.83*
	14	.56	.61*	.60	.47	.27	.34
Four	3	.36	.64*	.34	.64	.17	.49
	6	.62	.65	.78*	.68	.57	.72*
	8	.33	.69*	.42	.54	.28	.46
	11	.30	.55*	.40	.51	.67*	.57*
	12	.74	.77*	.60	.75	.29	.80*
	16	.50	.65*	.39	.60	.40	.78*
	27	.38	.50	.47	.55	.57*	.53
	34	.33	.35	.50*	.43	.33	.42
	37	.04	.07	.20*	.12	.32*	.64*
	39	.28	.38	.15	.49	.35	.50*
	41	.13	.26	.02	.31	.23	.36*
	43	.38	.47	.62*	.51	.07	.23
	44	.63*	.49*	.56*	.33	.19	.21
45	.38	.58*	.60*	.48	.31	.27	
46	.13	.47*	.30*	.25	.16	.15	
Five	4	.38	.66	.48	.71*	.45	.45
	10	.33*	.18	.38	.17	.30	.12
	14	.30	.12	.09	.03	.13	.16
Six	3	.38	.73*	.58	.61*	.57	.60
	8	.66*	.66*	.78*	.64*	.39	.57
	9	.38	.44	.49	.62*	.16	.52
	23	.38	.48*	.35	.40	.29	.44
	28	.23	.57*	.36	.73*	.69*	.56
	37	.36	.55*	.61*	.54*	.53*	.51
	39	.53	.47	.37	.59*	.21	.53

Note: Correlations of items with "home" sub-scales shown in bold type. Correlations that are greater with other sub-scales than with the home sub-scale are each shown with an asterisk. These correlations do not always appear higher because figures are expressed to two decimal places.

Sub-Scale 4 also had the most items deleted at Step 8 (Table M9). In Sub-Scale 6, Items 2 and 7 were left in the sub-scale despite the fact that they achieved an inter-item correlation of 0.78. These items were retained because they seemed essential to preserve the content validity of the sub-scale, and because, given the immaturity of the sub-scale at this point, exclusion of one or the other seemed premature.

Table M9

Draft Two of the RACRASST: Items Deleted at Step Eight

Scale	Items deleted (from those listed at Steps 8-11)
Information from the Staff	4, 8, 9, 12, 13, 17, 18
Knowing the Staff	2
Trusting the Staff	1, 2, 6, 9
Staff Care Activities	1, 5, 10, 13-15, 17-21, 23-26, 28-31, 33, 36, 38, 48
Staff and the Building	1, 11, 13
Staff and Emotional Support for the Family	1, 5, 6, 10-13, 20, 22, 26, 29

Mean scores tended to be highest in Sub-Scales 4 and 5 (Table M10). Items that were retained despite high mean scores and low standard deviations were kept to retain the qualitative validity of the sub-scales.

Table M10

Items Retained for Draft Three of the RACRASST: Score Means and Standard Deviations

Sub-Scale	Item	No.	Item	Mean	SD
1 Staff keep me informed about:		1	My relative's condition.	3.13	0.94
		3	My relative's care.	2.86	0.74
		6	The "hierarchy" of the home (who does what).	2.69	0.97
		11	How family members may help with resident care in this home (e.g. by planning care with the staff, by carrying out some care, by bringing things in).	2.97	0.72
		19	How any changes in government policy will affect the home.	2.90	0.66
2 Staff:		1	Are regular (e.g. not agency).	3.17	0.79
		4	Greet me when I visit.	3.30	0.54
		5	Include me in their chatter.	2.93	1.07
		7	Can be found easily, when I want to talk to them.	2.83	0.87
		8	Who are in management positions ("Top Staff") are friendly to me.	3.37	0.85
3 Staff:		3	Hold any private discussions with me in a private place.	2.90	1.06
		4	Keep their promises to me.	2.97	1.03
		5	Accept responsibility for the care of my relative.	3.17	0.70
		10	Are careful with my relative's possessions.	2.93	1.05

Sub-Scale	Item	No.	Item	Mean	SD
4 Staff:	2	Attend to residents' needs promptly.	2.77	0.86	
	4	Seem to be working in an organised manner.	3.10	0.61	
	7	Provide "warm care" to residents (smiling, being loving, willing, caring, kind, and compassionate, not using harsh words or being abrupt).	3.53	0.57	
	9	Ask family members about residents' backgrounds.	3.30	0.70	
	22	Keep my relative comfortable.	3.30	0.54	
	40	Treat my relative as an adult.	3.23	0.50	
	47	Make it clear that resident care comes first.	3.03	0.57	
	49	Only transfer residents from one area to another within the home when it is in the best interests of those residents.	2.97	1.09	
5 Staff:	2	Do not allow bad smells to linger.	3.27	0.69	
	3	Ensure the home is safe for residents (e.g. taking away things that may cause falls, closing security doors where residents might wander).	3.47	0.51	
	6	Allow residents to bring in their own pictures, etc.	3.50	0.51	
	8	Ensure there is somewhere family members can go to have private time with residents.	3.13	0.86	
	12	Set aside an area where visitors and residents may mix.	3.30	0.54	

Sub-Scale	Item No.	Item	Mean	SD
6 Staff:	2	Spare the time to talk to me.	3.30	0.65
	7	Say that my input into care helps.	3.00	0.74
	17	Ask me how I feel.	2.80	1.06
	25	Invite me to come to social events at the home.	3.13	0.90
	38	Sometimes use touch to show support for family members (e.g. putting an arm round a shoulder).	3.03	0.67

The wording of Sub-Scale 1, Item 3, referring to information about resident care, was altered so that it was less specific and would subsume Item 4, referring to information about resident therapy (see Table M10).

The wording of items in Sub-Scale 4 was adjusted because the stem "staff" was introduced. Also in Sub-Scale 4, the word "quickly" was changed to "promptly" because "quickly" might have inferred that the care given was rushed. Otherwise the wording of retained items was unchanged.

The Cronbach's alpha co-efficients for the sub-scales ranged from 0.79 to 0.96 before revision of the 150-item instrument. After the revision process, the total instrument consisted of 32 items in the same six sub-scales, and the Cronbach's alpha co-efficients for the sub-scales ranged from 0.78 to 0.86. All the criteria set in the analysis plan were met although the item-to-total correlations for Sub-Scale 6 were touching the upper limit. However, because of missing data, the final analyses of Sub-Scale 1 used 28 cases, and those of Sub-Scales 2 and 4 used 29 cases. All 30 cases were used in the final analyses for the remaining sub-scales.

APPENDIX N**Instrument Development and Refinement****Stage Three: Draft Instrument Revisions from Small Sample Responses****Draft Three of the Relatives' of Aged Care Residents Assessment of Staff****Support Tool**

SECTION ONE

Information from the Staff

Please think about the information staff give to you: Information about the ways things are done in this home, about your relative who lives in the home, and about any help that is there for you.

How much do you agree or disagree with these statements?

Staff keep me informed about:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. My relative's condition.	SA	A	D	SD	NA
2. My relative's care.	SA	A	D	SD	NA
3. The "hierarchy" of the home (who does what).	SA	A	D	SD	NA
4. How family members may help with resident care in this home (e.g. by planning care with the staff, by carrying out some care, by bringing things in).	SA	A	D	SD	NA
5. How any changes in government policy will affect the home.	SA	A	D	SD	NA

SECTION TWO

Knowing the Staff

Please think about how you get to know the staff.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Are regular (e.g. not agency).	SA	A	D	SD	NA
2. Greet me when I visit.	SA	A	D	SD	NA
3. Include me in their chatter.	SA	A	D	SD	NA
4. Can be found easily, when I want to talk to them.	SA	A	D	SD	NA
5. Who are in management positions ("Top Staff") are friendly to me.	SA	A	D	SD	NA

SECTION THREE

Trusting the Staff

Please think about the way staff act towards you.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Hold any private discussions with me in a private place.	SA	A	D	SD	NA
2. Keep their promises to me.	SA	A	D	SD	NA
3. Accept responsibility for the care of my relative.	SA	A	D	SD	NA
4. Are careful with my relative's possessions.	SA	A	D	SD	NA

SECTION FOUR

Staff Care Activities

Please think about how the staff care for residents in general, and your relative in particular.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Attend to residents' needs promptly.	SA	A	D	SD	NA
2. Provide "warm care" to residents (smiling, being loving, willing, caring, kind, and compassionate, not using harsh words or being abrupt).	SA	A	D	SD	NA
3. Seem to be working in an organised manner.	SA	A	D	SD	NA
4. Treat my relative as an adult.	SA	A	D	SD	NA
5. Make it clear that resident care comes first.	SA	A	D	SD	NA
6. Ask family members about residents' backgrounds.	SA	A	D	SD	NA
7. Keep my relative comfortable.	SA	A	D	SD	NA
8. Only transfer residents from one area to another within the home when it is in the best interests of those residents.	SA	A	D	SD	NA

SECTION FIVE

Staff and the Building

Please think about the building in which your relative lives, and how the staff can make it more pleasant.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Do not allow bad smells to linger.	SA	A	D	SD	NA
2. Ensure the home is safe for residents (e.g. taking away things that may cause falls, closing security doors where residents might wander).	SA	A	D	SD	NA
3. Allow residents to bring in their own pictures, etc..	SA	A	D	SD	NA
4. Ensure there is somewhere family members can go to have private time with residents.	SA	A	D	SD	NA
5. Set aside an area where visitors and residents may mix.	SA	A	D	SD	NA

SECTION SIX

Staff and Emotional Support for the Family

Please think about the bad times that you and other family members may have, and the ways in which staff can make a difference.

How much do you agree or disagree with these statements?

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Spare the time to talk to me.	SA	A	D	SD	NA
2. Say that my input into care helps.	SA	A	D	SD	NA
3. Ask me how I feel.	SA	A	D	SD	NA
4. Invite me to come to social events at the home.	SA	A	D	SD	NA
5. Sometimes use touch to show support for family members (e.g. putting an arm round a shoulder).	SA	A	D	SD	NA

APPENDIX O**Instrument Development and Refinement****Stage Four: Factor Analysis****Factor Analysis Package for Family Members**

(Printed in a large font)

(name and address supplied)

Dear Family Member

As a Registered Nurse studying at Edith Cowan University and working in an Aged Care Facility (a nursing home), I am writing to ask if you would help in a research project by answering the enclosed questionnaire. The project is intended to find out how nursing home/hostel staff help residents' family members so that our practice can be improved. The questionnaire you are asked to complete was developed from interviews with family members. However, it needs to be refined before it can be used in the project. Your answers will be used to judge the usefulness of the questions, and to decide if any changes should be made.

If you agree to take part, could you please fill in the questionnaire? This will take about ten minutes of your time, and the forms should then be returned in the reply-paid envelope. Completed questionnaires will be locked away safely, and your answers, of course, will not be identifiable.

The research has been approved by the Committee for the Conduct of Ethical Research of Edith Cowan University and is being supervised by Professor Linda Kristjanson (telephone number supplied) and Associate Professor Ed Helmes (telephone number supplied). You may call them if you wish, or contact me at the University, on, with any queries.

I do hope you will be kind enough to help.

Most sincerely

Christine Toye RN, BN (Hons.)

You are asked to complete these forms using your experience as a family member of a person living in a Residential Aged Care Facility (a hostel or nursing home).

Please think about *all* the staff, including those who serve the tea or work in the office.

Read through the statements and show how much you agree or disagree by circling the appropriate letter(s).

For each statement you may choose *either* "SA" (STRONGLY AGREE); "A" (AGREE); "D" (DISAGREE); *or* "SD" (STRONGLY DISAGREE).

You may choose "NA" (NOT APPLICABLE) instead, but please only do this after careful thought.

Please only circle one choice for each statement, and answer every question on both sides of each page.

Your answer sheet should look something like this when it is completed:

	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
	SA	(A)	D	SD	NA
	SA	A	D	(SD)	NA
	SA	A	(D)	SD	NA
	(SA)	A	D	SD	NA

Before you start: Please indicate here your relationship with the resident (e.g. son of resident)

Please state how long your relative has been in this facility

THE FIRST STATEMENT IS ON THE OTHER SIDE OF THIS SHEET

THANK YOU FOR HELPING

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Greet me when I visit.....	SA	A	D	SD	NA
2. Keep me informed about my relative's condition.....	SA	A	D	SD	NA
3. Attend to residents' needs promptly.....	SA	A	D	SD	NA
4. Ensure there is somewhere family members can go to have private time with residents.....	SA	A	D	SD	NA
5. Ask me how I feel.....	SA	A	D	SD	NA
6. Keep me informed about my relative's care.....	SA	A	D	SD	NA
7. Can be found easily, when I want to talk to them.....	SA	A	D	SD	NA
8. Seem to be working in an organised manner.....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
9. Ensure the home is safe for residents (e.g. taking away things that may cause falls, closing security doors where residents might wander).....	SA	A	D	SD	NA
10. Invite me to come to social events at the home.....	SA	A	D	SD	NA
11. Say that my input into care helps.....	SA	A	D	SD	NA
12. Hold any private discussions with me in a private place.....	SA	A	D	SD	NA
13. Provide "warm care" to residents (smiling, being loving, willing, caring, kind, and compassionate, not using harsh words or being abrupt).....	SA	A	D	SD	NA
14. Do not allow bad smells to linger.....	SA	A	D	SD	NA
15. Spare the time to talk to me.....	SA	A	D	SD	NA
16. Keep me informed about the "hierarchy" of the home (who does what).....	SA	A	D	SD	NA
17. Include me in their chatter.....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
18. Accept responsibility for the care of my relative.....	SA	A	D	SD	NA
19. Ask family members about residents' backgrounds.....	SA	A	D	SD	NA
20. Allow residents to bring in their own pictures, etc.....	SA	A	D	SD	NA
21. Keep me informed about how family members may help with resident care in this home (e.g. by planning care with the staff, by carrying out some care, by bringing things in).....	SA	A	D	SD	NA
22. Keep me informed about how any changes in government policy will affect the home.....	SA	A	D	SD	NA
23. Are regular (e.g. not agency).....	SA	A	D	SD	NA
24. Keep their promises to me.....	SA	A	D	SD	NA
25. Make it clear that resident care comes first.....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
26. Only transfer residents from one area to another within the home when it is in the best interests of those residents.....	SA	A	D	SD	NA
27. Set aside an area where visitors and residents may mix.....	SA	A	D	SD	NA
28. Sometimes use touch to show support for family members (e.g. putting an arm around a shoulder).....	SA	A	D	SD	NA
29. Treat my relative as an adult.....	SA	A	D	SD	NA
30. Are careful with my relative's possessions.....	SA	A	D	SD	NA
31. Keep my relative comfortable.....	SA	A	D	SD	NA
32. Who are in management positions ("Top Staff") are friendly to me.....	SA	A	D	SD	NA

THANK YOU FOR SPARING THE TIME TO ANSWER THESE QUESTIONS

A PRE-PAID ENVELOPE IS ENCLOSED FOR THE RETURN OF THE FORMS - PLEASE TELEPHONE (number provided) IF A REPLACEMENT IS NEEDED

APPENDIX P

Instrument Development and Refinement

Stage Four: Factor Analysis

Sample Characteristics and Findings

Responses to Draft 3 of the RACRASST were obtained from a large sample of family members of ACF residents. Findings and sample characteristics are documented in this section. This stage of the study also resulted in changes being made to the RACRASST that did not directly result from factor analyses. These changes are also documented here.

Sample characteristics. The researcher contacted 75 DONs/Managers, 51 of whom agreed to assist. The response rate was, therefore, 68.00%. These DONs/Managers took a total of 873 questionnaires. Quantities of questionnaires taken by individual DONs/Managers varied from 4 to 100. Most indicated they would hand these out to visitors, but some stated they would include them in account envelopes. The response rate from the questionnaire mail out appeared to be 34.02%, as 297 participants were obtained, however, it is not known if all questionnaires sent out by the researcher reached family members.

Participants' relatives' length of stay in the ACFs was for a mean of 31.76 months (SD 32.56 months, range 1 month – 180 months). Relationships of participants with residents were as shown in Table P1. Daughters, daughters-in-law, or step-daughters made up 41.00% of the sample; sons 15.82%; wives 10.10%; and husbands 9.09%. Approximately 11% of participants did not indicate their relationship with the resident.

Prior to factor analyses being conducted, the researcher deleted three items (5, 16, and 24) because they had attracted 20 or more missing or "Not Applicable" responses (6.70% of possible responses).

Table P1

Factor Analysis of Draft Three of RACRASST: Sample Characteristics

Relationship with resident	N
Daughters, daughters-in-law, or step-daughters	122
Wives	30
Sons	47
Husbands	27
Sisters or sisters-in-law	10
Brothers or brothers-in-law	6
Partners (unspecified)	5
Nieces	7
Other specified relationships	9
Unspecified relationships	34

Factor analysis. Factor analyses were conducted according to the analysis plan. Only 195 of the 297 cases could be used for Principal Component Analyses (PCAs). This was as a result of missing and "Not Applicable" responses remaining after deletion of the three items with the highest rates of such responses.

For the first PCA, the researcher entered six factors and viewed the results of varimax and oblique rotations. However, the sub-scale structure shown in Draft 3 of the RACRASST was not confirmed, and the structure shown was uninterpretable. When the

researcher repeated the PCA without entering a pre-determined number of factors the oblique rotation produced the most interpretable solution (see Table P2). Examination of the factors with eigenvalues greater than one suggested a possible four factor solution, these eigenvalues being 1.07, 1.38, 1.60 and 14.16. As shown by these figures and viewed on the scree plot, there was a sharp drop between the first and second eigenvalues, the decrease becoming gradual thereafter. The four factors accounted for 62.80% of the variance. Three items double-loaded. These items, 10, 18, and 28, were not separated by margins of at least 0.15. Other items loaded clearly on one of the factors.

The researcher attempted to interpret the factors using theoretical and practical knowledge. Factor 1 was suggestive of a staff/family member communication factor, Factor 2 of a care activity factor, Factor 3 of an environmental use factor, and Factor 4 of a staff/family member reliable alliance factor. There was some concordance between the suggested factors and the previously named sub-scales (see Table P2). For example, the care activity factor and proposed "care" sub-scale had many items in common, as did the environmental factor and the proposed "building" sub-scale.

However, upon re-examination, the suggested sub-scales proved redundant. This was because findings showed that the RACRASST measured a single phenomenon according to criteria set by Carmines and Zeller (1979): (a) the first extracted component accounted for much of the variance; (b) the following components accounted for small, gradually decreasing amounts of this variance; and (c) the highest loadings for most items were on Factor 1 in the unrotated factor matrix, these loadings being of 0.30 or more. Theta, Cronbach's alpha, and standardised item alpha for the scale were the same, 0.96, also suggesting that the scale was unidimensional.

Table P2**Preliminary Factor Structure of Draft Four of the RACRASST Suggested by PCA Results**

Factor	Proposed Sub-Scale	Item^a	Factor Loading^b	Eigen-value	% of Variance
One	"knowing"	Greet me when I visit	0.65	14.16	48.80
	"information"	Keep me informed about my relative's condition	0.63		
	"information"	Keep me informed about my relative's care	0.66		
	"emotional support"	Say that my input into care helps	0.74		
	"trust"	Hold any private discussions with me in a private place	0.62		
	"emotional support"	Spare the time to talk to me	0.42		
	"knowing"	Include me in their chatter	0.75		
	"trust"	Accept responsibility for the care of my relative	0.47		
	"care"	Ask family members about residents' backgrounds	0.71		
	"information"	Keep me informed about how family members may help with resident care in this home	0.69		
	"information"	Keep me informed about how any changes in government policy will affect the home	0.53		
	"emotional support"	Sometimes use touch to show support for family members	0.47		
	"knowing"	Who are in management positions ("Top Staff") are friendly to me	0.45		

Factor	Proposed Sub-Scale	Item ^a	Factor Loading ^b	Eigen-value	% of Variance
Two	"care"	Attend to residents' needs promptly	-0.53	1.60	5.50
	"building"	Ensure the home is safe for residents	-0.56		
	"care"	Provide "warm care" to residents	-0.55		
	"building"	Do not allow bad smells to linger	-0.54		
	"care"	Make it clear that resident care comes first	-0.67		
	"care"	Only transfer residents from one area to another within the home when it is in the best interests of those residents	-0.59		
	"care"	Treat my relative as an adult	-0.63		
	"trust"	Are careful with my relative's possessions	-0.73		
	"care"	Keep my relative comfortable	-0.77		
Three	"building"	Ensure there is somewhere family members can go to have private time with residents	0.55	1.38	4.80
	"emotional support"	Invite me to come to social events at the home	0.42		
	"building"	Allow residents to bring in their own pictures, etc	0.64		
	"building"	Set aside an area where visitors and residents may mix	0.65		
Four	"knowing"	Can be found easily, when I want to talk to them	0.72	1.07	3.70
	"trust"	Seem to be working in an organised manner	0.65		
	"knowing"	Are regular (e.g. not agency)	0.59		

Note: ^aStem is "Staff" ^bFactor loadings are from pattern matrix

Internal consistency co-efficients, item-to-total correlations, and inter-item correlations for the sub-scales suggested by the superseded four factor solution are shown in Table P3. Although the sub-scales identified by the PCA had been rendered redundant, figures shown in Tables P2 and P3 provide information about items measuring underlying named sub-dimensions of family members' perceived support from staff.

Table P3

Draft Four of the RACRASST: Reliability Co-Efficients, and Inter-Item and Item-to-Total Correlations of Sub-Scales Initially Suggested by PCA Results

Sub-Scales	Inter-Item Correlations		Item-to-Total Correlations		Cronbach's Alpha
	M	Range	M	Range	
One	0.52	0.20 – 0.85	0.69	0.52 – 0.81	0.93
Two	0.52	0.34 – 0.71	0.68	0.53 – 0.79	0.91
Three	0.46	0.35 – 0.62	0.58	0.50 – 0.67	0.77
Four	0.50	0.42 – 0.62	0.58	0.49 – 0.64	0.74

When treated as a single scale, without sub-scales, item-to-total correlations exceeded 0.70 in the case of nine items (M 0.67, range 0.52 - 0.78). This fact, and the fact that high correlations were seen between some items in the initially designated Sub-Scales 1 and 2, and between some items and totals in the same sub-scales, suggests slight redundancy within the scale. However, given the fact that the scale is a newly developed one, warranting further testing, it was judged important to retain all 29 items, rather than deleting those correlating highly with others or with total(s). Some of these items underwent minor changes to enhance comprehensibility based on participants' comments and an examination of items with at least 10 "Not Applicable" responses. The fourth draft of the RACRASST is shown in Appendix Q.

APPENDIX Q**Instrument Development and Refinement****Stage Four: Factor Analysis****Items Retained in Draft Four of the RACRASST**

Staff:

1. Greet me when I visit
 2. Keep me informed about my relative's condition
 3. Attend to residents' needs promptly
 4. Ensure there is somewhere family members may have private time with residents
 5. Keep me informed about my relative's care
 6. Can be found easily, when I want to talk to them
 7. Seem to be working in an organised manner
 8. Ensure the home is safe for residents (e.g. removing things that may cause falls, closing security doors where residents may wander)
 9. Invite me to come to social events at the home
 10. Say that my input into care helps (e.g. my telling staff about my relative's likes/dislikes; my helping my relative with care, meals, or activities)
 11. Hold any private discussions with me in a private place
 12. Provide "warm care" to residents (smiling, being loving, willing, caring, kind, and compassionate, not using harsh words or being abrupt)
 13. Do not allow bad smells to linger
-

Staff:

14. Spare the time to talk to me
 15. Include family members in social conversations
 16. Accept responsibility for the care of my relative
 17. Ask family members about residents' backgrounds
 18. Allow residents to bring in their own pictures, etc.
 19. Keep me informed about how family members may help with resident care in this home (e.g. by planning care with staff, by giving some care, by bringing things in)
 20. Keep me informed about how any changes in government policy will affect the home
 21. Are regular (i.e. not agency)
 22. Make it clear that resident care comes first
 23. Only relocate residents from their current rooms into different rooms or areas of the home when it is in the best interests of those residents
 24. Set aside an area where visitors and residents may mix
 25. Sometimes use touch to show support for residents' family members who are in distress (e.g. putting an arm around a shoulder)
 26. Treat my relative as an adult
 27. Are careful with my relative's possessions
 28. Keep my relative comfortable
 29. Who are in management positions ("Top Staff") are friendly to me
-

APPENDIX R**Instrument Development and Refinement****Stage Five: Test-Retest Reliability****Letter of Explanation for Participants and Findings**

Letter. Name and address supplied and letter printed in a large font.

Dear Family Member

As a Registered Nurse carrying out doctoral studies at Edith Cowan University, I am inviting you to take part in a research project. This project is intended to lead to benefits for family members of residents in Aged Care Facilities (hostels and nursing homes).

For the project, I have designed a questionnaire to measure the support residents' family members believe they receive from the staff. I now have to see if the questionnaire will give stable results over time. About 30 family members of hostel or nursing home residents are needed to complete two forms each. The second form should be filled in about two days after the first has been completed and returned.

Of course, there is absolutely no obligation for you to take part. If you do decide to help there will be no financial cost to you, but it will probably take about 20 minutes of your time. Reply-paid envelopes are provided for the return of the forms.

Names of family members helping in this section of the research are not required, so I will not know who has taken part. However, I do need to put code numbers on the questionnaires to match the two sent by each person. Also, later, the findings of the

research may be published. No people or facilities that have taken part will be identified in any published work.

This research has been approved by the Committee for the Conduct of Ethical Research of Edith Cowan University. My supervisors are Professor Linda Kristjanson of the School of Nursing and Public Health (telephone number supplied) and Associate Professor Ed Helmes of the School of Psychology (telephone number supplied). You are welcome to contact them with any queries, or to call me on A note will reach me, at no cost to you, if addressed to the following reply paid address:

.....

I do hope you would like to help in this project. If so, please open "Envelope One" when you are ready to start. This contains the first form, directions, and a return envelope. Please open "Envelope Two", containing the second form, about two days after you have completed and mailed the first form.

Thank you so much for considering this request.

Most sincerely

Christine Toye RN, BN (Hons.)

Findings. Twenty-eight family members each returned two copies of the RACRASST. Scrutiny of the correlations between individual item scores at Time One and Time Two revealed that these varied from 0.60 to 1.00. The correlation between total scores at Time One and Time Two was 0.99. More details are shown in the main text (see Table 8).

APPENDIX S**Main Study****Instrumentation and Permission for Use of the Primary Group Helping
Behaviour Scale (Rice, 1988)**

Instrumentation

1. The Relatives' of Aged Care Residents Assessment of Staff Support Tool.

- ◊ Please think about *all* the staff, including those who serve the tea or work in the office.
- ◊ Read through the statements and show how much you agree or disagree by circling the letter(s).
- ◊ For each statement you may choose *either* "SA" (STRONGLY AGREE), "A" (AGREE), "D" (DISAGREE), *or* "SD" (STRONGLY DISAGREE).
- ◊ You may choose "NA" (NOT APPLICABLE) instead, but please only do this after careful thought.
- ◊ Please only circle one choice for each statement, and answer every question.

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1. Greet me when I visit.....	SA	A	D	SD	NA
2. Keep me informed about my relative's condition.....	SA	A	D	SD	NA
3. Attend to residents' needs promptly.....	SA	A	D	SD	NA
4. Ensure there is somewhere family members may have private time with residents.....	SA	A	D	SD	NA
5. Keep me informed about my relative's care.....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
6. Can be found easily, when I want to talk to them.....	SA	A	D	SD	NA
7. Seem to be working in an organised manner.....	SA	A	D	SD	NA
8. Ensure the home is safe for residents (e.g. removing things that may cause falls, closing security doors where residents may wander).....	SA	A	D	SD	NA
9. Invite me to come to social events at the home.....	SA	A	D	SD	NA
10. Say that my input into care helps (e.g. my telling staff about my relative's likes/dislikes, or my helping my relative with care, meals, or activities).....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
11. Hold any private discussions with me in a private place.....	SA	A	D	SD	NA
12. Provide "warm care" to residents (smiling, being loving, willing, caring, kind, and compassionate, not using harsh words or being abrupt).....	SA	A	D	SD	NA
13. Do not allow bad smells to linger.....	SA	A	D	SD	NA
14. Spare the time to talk to me.....	SA	A	D	SD	NA
15. Include family members in social conversations.....	SA	A	D	SD	NA
16. Accept responsibility for the care of my relative.....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
17. Ask family members about residents' backgrounds.....	SA	A	D	SD	NA
18. Allow residents to bring in their own pictures, etc.....	SA	A	D	SD	NA
19. Keep me informed about how family members may help with resident care in this home (e.g. by planning care with staff, by giving some care, by bringing things in).....	SA	A	D	SD	NA
20. Keep me informed about how any changes in government policy will affect the home.....	SA	A	D	SD	NA
21. Are regular (i.e. not agency).....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
22. Make it clear that resident care comes first.....	SA	A	D	SD	NA
23. Only relocate residents from their current rooms into different rooms or areas of the home when it is in the best interests of those residents.....	SA	A	D	SD	NA
24. Set aside an area where visitors and residents may mix.....	SA	A	D	SD	NA
25. Sometimes use touch to show support for residents' family members who are in distress (e.g. putting an arm around a shoulder).....	SA	A	D	SD	NA
26. Treat my relative as an adult.....	SA	A	D	SD	NA

Staff:	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
27. Are careful with my relative's possessions.....	SA	A	D	SD	NA
28. Keep my relative comfortable.....	SA	A	D	SD	NA
29. Who are in management positions ("Top Staff") are friendly to me.....	SA	A	D	SD	NA

2. The Multidimensional Scale of Perceived Social Support (Zimet et al., 1988).

You are asked to show how much you agree or disagree with the following statements.

Please circle the number for each statement that best describes how much you agree or disagree.

Highest Disagreement = 1 Highest Agreement = 7

	Strongly				Strongly		
	Disagree				Agree		
1. There is a special person who is around when I am in need.....	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.....	1	2	3	4	5	6	7
3. My family really tries to help me.....	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.....	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.....	1	2	3	4	5	6	7
6. My friends really try to help me.....	1	2	3	4	5	6	7

	Strongly Disagree					Strongly Agree	
7. I can count on my friends when things go wrong.....	1	2	3	4	5	6	7
8. I can talk about my problems with my family.....	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.....	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.....	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.....	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.....	1	2	3	4	5	6	7

3. The Primary Group Helping Behaviour Scale (Rice, 1988).

Here, each item is a type of help given to residents in Aged Care Facilities.

Beside each statement is a scale ranging from "almost always" (5) to "never" (1).

- * For each item, please circle the number that shows how often you give that type of help.
- * The more often you give that type of help, the higher the number you will circle.
- * The less often you give that type of help, the lower the number you will circle.
- * Please circle only one number for each item.
- * Please answer all the items carefully, but do not spend much time on any one item.

It is important to answer according to what you actually do and not according to what you would like to do if you had more time or better health.

	Never	Seldom	Some- times	Often	Always
1) Keep resident in touch with relatives and friends by helping write letters or calling other relatives on the telephone.....	1	2	3	4	5
2) Help resident feel loved by telling or showing with hugging or kissing.....	1	2	3	4	5
3) Listen to resident's personal concerns.....	1	2	3	4	5
4) Contribute to resident's financial support.....	1	2	3	4	5
5) Store resident's seasonal clothing.....	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
6) Try to calm resident's fears and anxieties.....	1	2	3	4	5
7) Help resident remember old times.....	1	2	3	4	5
8) Manage resident's finances.....	1	2	3	4	5
9) Launder or dry clean resident's clothing.....	1	2	3	4	5
10) Arrange celebrations for resident's birthday and holidays.....	1	2	3	4	5
11) Arrange for resident's legal needs such as wills, disposal of real estate, guardianship, etc.....	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
12) Be a companion and confidant.....	1	2	3	4	5
13) Take resident on outings to home, shopping, restaurants, etc.....	1	2	3	4	5
14) Make resident's room attractive by bringing plants and other decorations.....	1	2	3	4	5
15) Supply resident with reading materials, television, radio, craft materials, etc.....	1	2	3	4	5
16) Participate in family activities at nursing home/hostel with resident.....	1	2	3	4	5
17) Try to help resident feel like a competent, worthwhile person.....	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
18) Supply resident with favourite cosmetics, shaving needs, or hygiene items like toothpaste.....	1	2	3	4	5
19) Help resident remember things.....	1	2	3	4	5
20) Arrange for hair styling and cuts.....	1	2	3	4	5
21) Inform resident of important family, community, or world happenings.....	1	2	3	4	5
22) Arrange for transportation to doctors, dentists, or other health care professionals.....	1	2	3	4	5
23) Accompany resident to doctors', dentists', or other health care professionals' offices..	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
24) Try to help resident communicate effectively.....	1	2	3	4	5
25) Supply resident with clothing, slippers, shoes, nightwear, etc.....	1	2	3	4	5
26) Telephone between visits.....	1	2	3	4	5
27) Take resident out for fresh air and change of scenery.....	1	2	3	4	5
28) Help resident feel as if she/he is still an important part of the family.....	1	2	3	4	5
29) Bring or encourage other family members to visit.....	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
30) Buy birthday or holiday cards and gifts for resident's other family members.....	1	2	3	4	5
31) Coordinate family vacations and other out-of-town trips to ensure that one family member is available if resident has needs.....	1	2	3	4	5
32) Visit with resident.....	1	2	3	4	5
33) Mark or mend resident's clothing.....	1	2	3	4	5
34) Pay for medications.....	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
35) Provide resident with familiar belongings like pictures and furniture.....	1	2	3	4	5
36) Inform other family members of resident's needs or wishes.....	1	2	3	4	5

4. The General Well-Being Schedule (Dupuy, cited in McDowell & Newell, 1996).

This section contains questions about how you feel and how things have been going with you. For each question, please tick the box to show which answer best applies to you.

1. How have you been feeling in general? (DURING THE PAST MONTH)	1 <input type="checkbox"/> In excellent spirits 2 <input type="checkbox"/> In very good spirits 3 <input type="checkbox"/> In good spirits mostly 4 <input type="checkbox"/> I have been up and down in spirits a lot 5 <input type="checkbox"/> In low spirits mostly 6 <input type="checkbox"/> In very low spirits
2. Have you been bothered by nervousness or your "nerves"? (DURING THE PAST MONTH)	1 <input type="checkbox"/> Extremely so – to the point where I could not work or take care of things 2 <input type="checkbox"/> Very much so 3 <input type="checkbox"/> Quite a bit 4 <input type="checkbox"/> Some – enough to bother me 5 <input type="checkbox"/> A little 6 <input type="checkbox"/> Not at all

-
3. Have you been in firm control of your behaviour, thoughts, emotions, OR feelings? (DURING THE PAST MONTH)
- 1 Yes, definitely so
 - 2 Yes, for the most part
 - 3 Generally so
 - 4 Not too well
 - 5 No, and I am somewhat disturbed
 - 6 No, and I am very disturbed
-
4. Have you felt sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile? (DURING THE PAST MONTH)
- 1 Extremely so ~ to the point that I have just about given up
 - 2 Very much so
 - 3 Quite a bit
 - 4 Some - enough to bother me
 - 5 A little bit
 - 6 Not at all
-
5. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)
- 1 Yes - almost more than I could bear or stand
 - 2 Yes - quite a bit of pressure
 - 3 Yes - some - more than usual
 - 4 Yes - some - but about the usual
 - 5 Yes - a little
 - 6 Not at all
-

-
6. How happy, satisfied, or pleased have you been with your personal life? (DURING THE PAST MONTH)
- 1 Extremely happy - could not have been more satisfied or pleased
 - 2 Very happy
 - 3 Fairly happy
 - 4 Satisfied - pleased
 - 5 Somewhat dissatisfied
 - 6 Very dissatisfied
-

7. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? (DURING THE PAST MONTH)
- 1 Not at all
 - 2 Only a little
 - 3 Some - but not enough to be concerned or worried about
 - 4 Some and I have been a little concerned
 - 5 Some and I am quite concerned
 - 6 Yes, very much so and I am very concerned
-

8. Have you been anxious, worried, or upset? (DURING THE PAST MONTH)
- 1 Extremely so - to the point of being sick or almost sick
 - 2 Very much so
 - 3 Quite a bit
 - 4 Some - enough to bother me
 - 5 A little bit
 - 6 Not at all
-

9. Have you been waking up fresh and rested? (DURING THE PAST MONTH)	<input type="checkbox"/> Every day <input type="checkbox"/> Most every day <input type="checkbox"/> Fairly often <input type="checkbox"/> Less than half the time <input type="checkbox"/> Rarely <input type="checkbox"/> None of the time
10. Have you been bothered by any illness, bodily disorder, pains, or fears about your health? (DURING THE PAST MONTH)	<input type="checkbox"/> All the time <input type="checkbox"/> Most of the time <input type="checkbox"/> A good bit of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> A little of the time <input type="checkbox"/> None of the time
11. Has your daily life been full of things that were interesting to you? (DURING THE PAST MONTH)	<input type="checkbox"/> All the time <input type="checkbox"/> Most of the time <input type="checkbox"/> A good bit of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> A little of the time <input type="checkbox"/> None of the time

-
12. Have you felt down-hearted and blue? (DURING THE PAST MONTH)
- 1 All of the time
 - 2 Most of the time
 - 3 A good bit of the time
 - 4 Some of the time
 - 5 A little of the time
 - 6 None of the time
-

13. Have you been feeling emotionally stable and sure of yourself? (DURING THE PAST MONTH)
- 1 All of the time
 - 2 Most of the time
 - 3 A good bit of the time
 - 4 Some of the time
 - 5 A little of the time
 - 6 None of the time
-

14. Have you felt tired, worn out, used up, or exhausted? (DURING THE PAST MONTH)
- 1 All of the time
 - 2 Most of the time
 - 3 A good bit of the time
 - 4 Some of the time
 - 5 A little of the time
 - 6 None of the time
-

For each of the four following questions, note that the words at each end of the 0 to 10 scale describe opposite feelings. Tick the box under any number which seems closest to how you have generally felt DURING THE PAST MONTH.

15.	How concerned or worried about your HEALTH have you been? (<i>DURING THE PAST MONTH</i>)	0	1	2	3	4	5	6	7	8	9	10	
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Not concerned							Very				
		at all							concerned				
16.	How RELAXED or TENSE have you been? (<i>DURING THE PAST MONTH</i>)	0	1	2	3	4	5	6	7	8	9	10	
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		Very relaxed							Very tense				

17. How much ENERGY, PEP, VITALITY have you felt?

0 1 2 3 4 5 6 7 8 9 10

(DURING THE PAST MONTH)

No energy

Very

AT ALL,

ENERGETIC

listless

dynamic

18. How DEPRESSED or CHEERFUL have you been?

0 1 2 3 4 5 6 7 8 9 10

(DURING THE PAST MONTH)

Very depressed

Very cheerful

5. Demographic Questionnaire.

- Please tick the boxes and/or write on the dotted lines to answer the questions.

-
- 1) What is your relationship to the resident? husband (or de facto husband) wife (or de facto wife) brother sister
daughter son daughter-in-law son-in-law niece nephew other (please specify)
 - 2) Please indicate your age. 18-30 31-40 41-50 51-60 61-70 71-80 over 80
 - 3) Please state the highest level of education you have received.
no formal schooling primary secondary TAFE or trade based tertiary (degree) post-grad.
other (please specify).....
 - 4) Please write your postcode here
 - 5) Please state the age of the resident here
 - 6) Is the resident male or female ?
 - 7) Please state the resident's main disability or disease.....
 - 8) How do you think your relative feels about living in the facility (hostel or nursing home)?
very happy quite happy neither happy nor unhappy quite unhappy very unhappy I am unable to tell
 - 9) Does your relative receive: nursing home type care hostel type care or are you unsure ?
-

-
- 10) Please state how long the resident has been living in this facility (hostel or nursing home)
- 11) Before the admission, on average, how often did you have contact with the resident (visits or phone calls)?
daily weekly fortnightly monthly less often than monthly
- 12) Now, on average, how often do you have contact with the resident (visits or phone calls)?
daily weekly fortnightly monthly less often than monthly
- 13) How do you usually travel to the facility (hostel or nursing home)?
public transport lifts walking own car taxi other (please specify)
- 14) How long does your journey to/from the facility (hostel or nursing home) usually take (one way)?.....
- 15) How difficult do you find your usual journey to the facility (hostel or nursing home)?
very easy quite easy not too difficult quite difficult very difficult
- 16) How is your health? very good good fair poor very poor
- 17) How close do you feel to your relative in the facility (hostel or nursing home)?
very close close unsure not very close not at all close
-

It can be difficult for people to fit everything that needs to be done into their busy lives.

On a scale of 1-5 how true are the following two statements for you?

Please circle the number that matches your feelings most closely.

		Not at all			Very much so	
18.	I feel pulled between trying to give attention to my relative in the Aged Care Facility (hostel or nursing home) and attending to other family responsibilities.....	1	2	3	4	5
19.	I feel pulled between trying to give attention to my relative in the Aged Care Facility (hostel or nursing home) and attending to my work responsibilities.....	1	2	3	4	5



Texas Agricultural Extension Service

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The Texas A&M University System

FAMILY DEVELOPMENT AND RESOURCE MANAGEMENT ■ 305 Agriculture Building ■ Campus Mail Stop 2251
College Station, Texas 77843-2251 ■ ph: (409) 845-3850 ■ fax: (409) 845-6447

October 7, 1996

**Permission from the Author for the Use of the Primary Group Helping
Behaviour Scale (Rice, 1988)**

Mrs. Christine Toye

[Redacted]
[Redacted]

Australia 6021

26.08.96

Dear Mrs. Toye:

I am pleased that you wish to use the Primary Group Helping Behavior Scale in your research. I am sending you a number of pages from my dissertation to assist you in scoring. I am happy to forward you these materials at no charge and wish you the best of luck. I would appreciate an abstract of your results when you finish.

Sincerely,

[Redacted Signature]

Carol A. Rice, Ph.D., R.N.
Health Specialist and Associate Professor

APPENDIX T**Main Study****Letter of Explanation to Potential Participants**

(name and address supplied)

Dear Family Member

This is an invitation for you to take part in an Australia wide research project intended to lead to benefits for family members of residents in Aged Care Facilities (hostels and nursing homes). I am undertaking this project as part of my doctoral studies in the School of Nursing at Edith Cowan University. It is anticipated that reports of study findings will be made available to aged care providers at conferences and/or in professional journals. This is so they will have evidence on which to base improvements in their practice.

The study concerns the support residents' family members need and receive from others, and the support family members provide for residents. If you decide to take part, you are asked to complete the enclosed forms and mail them back to me in the envelope provided. No stamp is needed. It is estimated that filling in the forms will take you about one hour.

Of course, there is no obligation for you to take part in the study. If you do participate, the information you provide will not be identifiable as you are not required to supply either your name or that of the care facility. The study has been approved by the Committee for the Conduct of Ethical Research of Edith Cowan University.

My supervisors are Professor Linda Kristjanson of the School of Nursing and Public Health (telephone number supplied) and Associate Professor Ed Helmes of the School of Psychology (telephone number supplied). You are welcome to contact them with any queries, or to call me on A note will also reach me, at no cost to you, if addressed to the following reply paid address:

.....

Hoping very much that you will find the time to help in this project.

Most sincerely

Christine Toye RN BN (Hons.)

APPENDIX U
Ethical Approval for the Study



**EDITH COWAN
UNIVERSITY**

PERTH WESTERN AUSTRALIA

Pearson Street, Churchlands
Western Australia 6018
Telephone (09) 383 8333
Facsimile (09) 383 8661

17 October 1996

Committee for the Conduct of Ethical Research

Ms Christine Toyne


Dear Ms Toyne

Re: **Ethics Approval**

Code: 96-96

Project Title: *The Perceived Social Support of Family Members of New Nursing Home Residents and its Relationship with Their Support of Their Relatives*

Thank you for your response in which you addressed the issues raised by the Committee in its letter dated 1 October 1996.

Your explanations have been accepted by the Committee and I am pleased to advise that the project now complies with the provisions contained in the University's policy for the conduct of ethical research, and has been cleared for implementation.

Period of approval is from 1 October 1996 to 31 October 1997. Please advise the Committee if you wish to extend this period of approval.

With best wishes for success in your work.

Yours sincerely


ROD CROTHERS
Executive Officer

cc. Dr P Perceval, Supervisor
Mrs G Sherratt, Secretary, HDC
Ms A Johnson, Secretary, U.S.C.



4 November 1996

Committee for the Conduct of Ethical Research

Ms Christine Toye
[REDACTED]

Dear Ms Toye

Re: Ethics Approval

Code: 96-96

Project Title: *The Perceived Social Support of Family Members of New Nursing Home Residents and its Relationship with Their Support of Their Relatives*

Thank you for your report and I wish to advise that approval has been given for an extension of time on your project, as requested by you.

Yours sincerely

ROD CROTHERS
Executive Officer

cc. Dr P Percival, Supervisor
Mrs G Sherratt, Secretary, HDC
Ms A Johansen, Secretary, D.S.C.