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**A STUDY OF FAMILIES' EXPERIENCES OF ASSISTING A
MEMBER
INTO RESIDENTIAL CARE**

A thesis presented in partial fulfillment of the requirements
for the degree of
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at Massey University

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ABSTRACT

Traditionally the responsibility of caring for an aging relative has fallen upon the family of that person, usually the spouse or the daughter(s). An increase in the state recognised age of retirement, more women returning to or remaining in the workforce, and the tendency of families to be more mobile than in the past, means that the option of being cared for in the community by family members has diminished for some elderly people.

Residential care - an umbrella term for retirement homes, hospitals and secure units - provides an alternative for families unable to care for their aged relative(s). Some research has been done on the phenomenon of relocation into residential care from the client's perspective, yet there is a paucity of information about the experience from the point of view of the families involved in this process. This piece of research sets out to address this issue and to hopefully influence the nursing practice of those who work in this area.

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TABLE OF CONTENTS

ABSTRACT	ii
ACKNOWLEDGEMENTS	iii
KEY TO TRANSCRIPTIONS.....	iv
 CHAPTER ONE:	
INTRODUCTION.....	1
 CHAPTER TWO:	
LITERATURE REVIEW	
The nursing profession and care of the elderly	7
Ageism and sexism.....	11
Grief process	13
Families and family dynamics.....	15
The caregiver role	17
Aging in New Zealand	22
 CHAPTER THREE:	
THE RESEARCH PROCESS	
The aim	27
The method	27
Phenomenology - historical perspective.....	29
Existential phenomenology of Heidegger	31
Nursing and phenomenology	34
Evaluation of research method.....	39
Participant selection	43
Interviews	44
Data collection.....	46
Data analysis.....	47
Ethical concerns.....	49

CHAPTER FOUR:

OVERVIEW OF THE RESEARCH OUTCOME	55
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CHAPTER FIVE:

THE RESEARCH OUTCOME - PART 1

Turning point	60
Autonomy and control.....	65
Commitment to care	69

CHAPTER SIX:

THE RESEARCH OUTCOME - PART 2

Loneliness	76
Guilt	82
Grief.....	87

CHAPTER SEVEN:

THE RESEARCH OUTCOME - PART 3

Abiding hope	93
Making meaning	97
Interpersonal relationships	100

CHAPTER EIGHT:

DISCUSSION

Review of the study	105
Limitations	110
Implications for practice.....	111
Recommendations.....	118
Further research.....	121
Conclusion.....	122

REFERENCES

APPENDICES

Appendix A: Open letter

Appendix B: Information sheet

Appendix C: Consent form

Appendix D: Prompt sheet

Appendix E: Non-disclosure form

KEY TO TRANSCRIPTIONS

The abbreviations and conventions given below are used in this study in chapters five, six and seven which discuss the analysis of the data.

Italics: Indicate the words quoted by the participant during the interviews.

...//...: Indicates where material has been edited out of the interview.

(): Figures enclosed in brackets indicate participant number, interview number and page number. For example participant five, interview one, page three would be recorded as (5:1:3).

CHAPTER ONE

INTRODUCTION

Human beings have always striven to control their environment and to manipulate events in order to combat the vagaries of life. To a certain extent magic, tradition and religion provided parameters which dictated how people related to each other and to their world. With the passage of time, the way in which we sought to maintain this control has changed. Dating from the Renaissance period in Italy, there has been a shift in the way in which people viewed and subsequently interacted with their environment, with rationalism and science increasingly prevailing over older beliefs. This faith in scientifically based knowledge has been well rewarded, with advances in the area of health care resulting in improved quality of life and an increase in longevity. It is not surprising that in the latter part of the twentieth century, a positivistic philosophy predominates in Western thinking and the way in which we view and respond to new challenges in our environment.

But, now there are new challenges to be met. Unlike the physical threats of the past, we are now being confronted with issues which are, in many ways, more subtle and perhaps more complicated; issues which affect and challenge our humanity, the result of life in New Zealand in the nineties. We now have an aging population, with our longevity largely the result of scientifically generated knowledge. It is predicted that, in the 21st century, up to a quarter of the people in New Zealand will be over the age of sixty

and most of those will live for twenty years in retirement (Koopman-Boyden, 1993). This increase in the number of elderly in the population is not limited to this country, but is a trend occurring throughout the Western industrialized nations. In the United States the oldest-old, those who are over eighty, are the fastest growing group in society (Burnside, 1990). Attempts to understand this issue need to be based upon knowledge generated from research. However, the unique problems and social ramifications which arise as a direct result of an aging population cannot be addressed adequately using only scientific scrutiny and manipulation. It is difficult for quantitative research alone to capture the complexity of the human issues surrounding this subject.

To consider an aging population as, at best, a challenge and, at worst, a problem, raises the question as to why this should be so. To respond to this we need to examine how and why things have changed in society, to look at recent social trends and at historical facts about population spread. The multi-generational family in which the elderly were cared for in the family home has been replaced in contemporary society by a unit comprising parents and offspring - the nuclear family. Changing employment opportunities and the smaller size of the nuclear unit have resulted in families being more mobile than in the past.

Consequently, aging relatives may be left behind when the family shifts to seek work in another area. The standard of living has increased, and so

have our expectations. There is a need and/or desire for adult family members, including women, to be in paid employment. Few families are willing, or able, to sustain a decrease in income so as to look after an elderly relative in the family home. Added to this are altered personal expectations with regard to time and space. The value we place on the pursuit of individual goals and on personal privacy is incongruent with the effort that may be required to look after an aged loved one.

Yet, historically, the aged in society have not always been so marginalised. In most traditional societies the elderly held positions of power and respect. Their status could be attributed to several factors. Not many people lived to be old and so the burden placed on their families and the rest of the group to support them was minimal; the elderly often enjoyed the prestige associated with political or religious roles; they retained control of material resources and were the source of information essential to the survival of their families and the wider group (Perlmutter & Hall, 1992). With the development of technology leading to the generation of new types of knowledge, the increasing proportion of elderly dependent individuals in the population and the emphasis in society on youthfulness, the old have lost the position of respect that they previously enjoyed.

The state's response to the aged has also changed with the passage of time. Policies developed in the early part of this century to protect older people from impoverishment and endless drudgery in the paid labour force have

had the effect of also excluding many of them from social and economic life (Saville-Smith, 1993). Recent changes in legislation aimed at maintaining the aged in the community were designed in part to reduce the government's responsibility and financial support of the aged. With the exception of individuals who are destitute and alone, the onus is now increasingly being placed on families to take responsibility for caring for their aging relatives or to assist them to relocate into residential care. Residential care facilities which have contracts with their local government funded health authorities must assess all potential residents. This is to ensure that only those with genuine needs who are no longer able to cope at home will be admitted into care. Asset testing of the elderly resident ensures that government funding of the residential placement is only available to those with limited financial resources.

These new policies can add to the stress experienced by families already coping with the the need to relocate a family member. The decision to admit an elderly relative into residential care may be a hurried one, precipitated by a particular event such as the sudden illness of that person. Complicating this decision may be concerns about costs, standards of care in the facility and the perceived disintegration of the family unit. Yet there is little information about these issues and how they affect the aged and their families (Burnside, 1990).

The anxiety and confusion experienced by many people at this time was very evident to me in my role as the nurse manager of a residential care facility. I think of Bill who had cared for his demented wife Margaret for nearly five years before her admission into the secure unit. Although he rang to check on her most days, Bill could not bring himself to visit his wife for the first three weeks. When he eventually did come he was so pleased to see her improved physical condition - she had become aggressive and unkempt while at home - that all he could do was sit with her, hold her hand and cry.

Elizabeth's experience was different but no less compelling. She told me how her mother had supported her in bringing up her son on her own. Now, after several years of trying to juggle a demanding career and care for her aging parent who had had a stroke, she could no longer cope. Her mother had become increasingly dependent and also very demanding of her daughter's time. I mentioned to Elizabeth how difficult it must have been to have arrived at the decision to place her mother into care. With a wry smile and a tired voice she said "Tell me about it!" Then in the next breath she said "I still love her very much you know."

The above situations highlighted for me the trauma that many families go through when one of their own goes into care. Feelings of anxiety and guilt, grieving for what has been or might have been, and coming to terms with the demise of the family unit all contribute to the stress experienced by family members, which can compromise their mental and physical well-being.

Conversations with relatives of those relocating into a care facility confirmed for me that the dearth of theoretical knowledge in this area is complemented by a lack of both awareness and skills on the part of many nurses who work in gerontology. We continue to focus on the elderly individual, our main objective being to complete the tasks associated with admitting that person into formal care.

The purpose of this study was to address what I perceived to be a deficit in our understanding of, and response to, families with elderly relatives relocating into formal care. To achieve this I felt it was essential to identify what the issues were for the relatives. By increasing my understanding of what the experience meant for the families, I hoped to be able to make recommendations which may lead to a more effective standard of care in this area of gerontology.

This study is presented in eight chapters. Chapter two reviews the literature containing issues which are pertinent to the study. Chapter Three begins with the aim of the research; Heideggerian phenomenology, the method used in the study, and its application to nursing research are then discussed. In Chapter Four there is an overview of the research outcome which forms the basis of the following three chapters. Chapters Five, Six and Seven focus upon the themes which emerged from the data. Chapter Eight, the final chapter, includes a review of the study, a discussion of its limitations, implications for practice, recommendations and areas for further research.

CHAPTER TWO

LITERATURE REVIEW

The process of relocation into residential care is not, unlike some phenomena associated with care of the aging population, a distinct entity which has been well researched. It was one of the reasons that I was attracted to it as a topic for this study. Consequently this discussion focuses upon selected literature on issues related to the elderly and the process of relocation. Included is a nursing perspective of gerontology, socio-cultural and familial responses to the aged and policies which affect our older citizens and their families.

The nursing profession and care of the elderly

The perceived lack of professional support experienced by many families during the relocation process, may be attributed, in part, to nursing's failure to recognise care of the older adult and their family as a speciality which is worthy of greater emphasis in both nursing education and practice.

Many nursing curricula lack a comprehensive gerontological perspective, with Alford (1992) suggesting that nurse educators suffer from "gerontophobia" in their approach to teaching about the elderly. Study of the aged is often no more than a brief diversion during the component which focuses on the concept of adulthood, with information limited to the physical

changes which occur in this latter phase of human growth and development. Concomitant with this may be the view that it is a clinical area in which students can develop good "basic" skills at the beginning of their programme. For many nursing students this may be their closest link with the elderly because, in their personal lives they have had few encounters with older adults. The predominance of the nuclear family and a contemporary society which has become more mobile means that intergenerational contact within the family may be limited (Hogstel, 1994).

This neglect on the part of the nursing profession is ironical considering the beliefs that we as nurses profess to hold. Leininger (1978) states that care is one of the cornerstones of nursing. Age is not amenable to cure - the realm of the physician - but the elderly do require care. Therefore, it is a speciality in which nurses should excel. Alford (1992) makes a case for a health wellness focus in gerontological nursing education - an innovative approach which should be included in nursing curricula as the philosophy of health promotion has always been an essential component of nursing practice (Gibson, 1991). However, there is little evidence that this has occurred.

As nurses we also like to claim that our practice is holistic, yet we tend to concentrate on the medical problems of our elderly clients - a reductionist approach which has more in common with the biomedical model (Boddy, 1987) than with nursing. And, the focus of our care remains the aged

person. Prolonged or meaningful interaction with family members of the elderly client tends to occur only when a member has relieved the nurses of some caregiving tasks, staff empathy is engendered by an imminent death, or conflict arises between family and health professionals regarding standards of care (Hogstel, 1994).

Perhaps our lack of vision as a profession with regard to care of the older adult needs to be examined in an historical context. Nursing education has tended to concentrate on acute care facilities as the clinical setting in which future nurses were educated (Hogstel, 1994). In spite of the profession's history of espousing health promotion, education and the delivery of health care to individuals in a family context across the life span (Johnson, 1990), nursing education and practice have remained largely within institutional walls. Yet, if we are to meet the needs of the growing group of elderly and their families, there needs to be a change in nurses' attitudes towards the aged. Education and research provide the most effective means of bringing about this change (Hogstel, 1994). Gerontological nursing as a speciality needs to be valued and fostered by the nursing profession.

Although there is a need for more education and research in the area of gerontology, existing nursing theories can provide a framework for gerontological nursing practice. Hogstel (1994) discusses the work of three nursing theorists, Orem, Roy and Neuman, who she suggests have developed theories and models which may be useful in nursing the elderly,

the aim being to develop a comprehensive plan of care which will assist aged clients to achieve successful adaptation to the challenges in their lives. A thorough assessment is critical when planning care for elderly people and their families. Nurses possess broad theoretical knowledge about the elderly - the universal knowledge which, anthropologists term cosmopolitan (Harveth et al, 1994). But it is the family who possess information unique to their aged relative - the local knowledge - which is critical if nurses wish to provide effective and comprehensive care. We need to take the time to understand the family situation of the older client. If competent the client should be asked about his/her personal desires. Who in the family are they closest to? Who will be involved in the decision making? The strength of emotional bonds, affinity and the quality of relationships all need to be assessed and noted (Hogstel, 1994). By assessing family dynamics nurses may be able to use the power of the family system on behalf of the client. By working with families we can also extend our role to encompass them as clients.

Nurses have access to a wide range of strategies which could be used to benefit the elderly client and their family, including stress management techniques, visualisation, positive self-talk, self-praise, meditation, humour and communication skills. Nurses can coach families to become good judges of health care services (Ade-Ridder & Kaplan, 1993), provide them with accurate information and act as a liaison person to coordinate care. These last two functions are important for they are areas which carers have

expressed concern about because of the disjointed, and at times almost secretive way health professionals have responded to questions about the elderly person's condition and care (Opie, 1991).

Nurses can also assist family members to negotiate new roles once the aged relative has gone into care. This is particularly important for the spouse who may now have to extend his or her role and adapt to life in the community on their own. It has been noted by Ade-Ridder and Kaplan (1993) that validation by staff of new roles may help family members cope with the trauma of relocating a loved one into care.

Ageism and sexism

Despite the rapid growth in the number of elderly as a proportion of the population, the position of the aged in contemporary society can, in my experience, be an unenviable one. Whether in the community or in residential care, exclusion from the mainstream of society means that, for many elderly people, life becomes a marginalised and isolated existence in which the only thing they have to look forward to is death.

According to Perlmutter and Hall (1992), there has been an erosion of status once enjoyed by the elderly in more traditional societies. Cowgill and Holmes (1972) suggest there is a direct correlation between this decrease in status and the speed of social change. Modernisation Theory lends weight to this view, with it being noted that pre-industrial society, a feature of which

was its social stability, cared for its elders more and had a greater number of close relationships to call on through the extended family (Koopman-Boyden, 1993). Because the aged are considered to have little of value to offer in contemporary society, their power and influence decreases. If people only interact with and adjust to others as long as the benefits outweigh the costs (Homans, 1961), then the aged by virtue of their low social status form a disadvantaged group within the community. According to Blau (1973), the only 'social currency' that the elderly can use in exchange relations is esteem and compliance. The 'mellowness' often witnessed in the aged may be cultivated in order to maintain the affections of those upon whom the elderly person depends.

The state has also had a role to play in the way that the elderly are viewed by the community. According to Saville-Smith (1993), legislation based upon the notion of age as a chronological entity rather than a functional one has contributed to the idea of aging as an illness. Friedan (1994) suggests that old age is seen as an accumulation of life's problems, rather than a stage of development. The state's response to aging has focused on enforced retirement and institutionalisation. Policies associated with the funding of housing tend to favour the nuclear family unit, increasing the need for residential care facilities (Saville-Smith, 1993).

If the aged form a disadvantaged group in society, then elderly women bear a double burden - to be old and to be female. The lot of the older woman in

society draws little attention - even the feminist movement has managed to ignore the plight of its aging sisters (Friedan, 1994). Yet because of women's greater longevity, they tend to often be the ones providing care for their aging spouse (Bonita, 1993) and, once their partner has died, they continue to live on in the community on their own. In caring for their spouses, many women experience physical and financial hardship, which is compounded with the death of the partner and the vulnerability of living alone.

To add to this, the older woman is further stigmatised by society as, culturally, women are defined as older than their male counterparts (Bonita, 1993). Admission into residential care would seem to be the best solution for the elderly woman and her family, yet for the aged person it may be a another loss and a further erosion of the independence and control which is a critical part of being an adult. This sense of loss can be particularly acute, when increased mental and /or physical frailty has forced the decision to relocate into care.

Grief process

The grief process, first identified and discussed in detail by Elizabeth Kubler-Ross (1969), is usually associated with the finality that is death. Although there are several stages in the process which a grieving person works through, it is now recognised that for some, grief can remain unresolved. Grief can also be a component of loss and of some of the changes that are experienced throughout the life span. The decision to admit an elderly

relative into care, and the process of relocation, can be a time of grief for the older person and their family. It is the end of an era for them as a social unit. For the elderly individual it marks a withdrawal from society, from the environment they have always known and the lifestyle that they have had. It means being parted from friends and those who have formed part of their lives - church and social groups, their doctor and dentist - and learning to cope with a new environment and new ways (Hogstel, 1994).

For the family it can also be a time of mourning. One caregiver expressed sadness at how her life had ended up as she had not expected to have to place her husband into care. There was also sadness at what might have been (Hogstel, 1994). Some express feelings of anger and anxiety about the future, and resentment over what has happened (Opie, 1992). For some - those with loved ones with dementia - the experience of grief often occurs as the inevitable deterioration robs the family member of their dignity, intellect and personhood. This has been referred to as the 'ten year funeral' (Jones & Martinson, 1992, p.174). To cope, the caregiver may become involved in the care of their loved one when they relocate into a residential facility. They continue to love, and try and communicate with, the person, yet hope that death will intervene. The actual demise of the person almost comes as a relief, the grieving being far more intense whilst the person is alive and deteriorating (Jones & Martinson, 1974).

Because the grieving process is usually associated with death, health care professionals often overlook the fact that grieving can occur during caregiving or when the caregiver relinquishes that role because their elderly relative has been admitted into a residential facility. As with the giving of information or planning of care, caregivers complain that the issues of grieving and loss are not well addressed by the health professionals. General practitioners, who are the ones who most often see the caregiver over an extended period of time, are often vague or use generalised questions when asking the person about their experience of loss (Opie, 1991). Such techniques can cause confusion or create the impression that the subject is one which the doctor feels uncomfortable with, and so the person also feels inhibited in expressing their thoughts and emotions.

Families and family dynamics

As with any other stage in the life of a family, families in retirement and old age also have developmental tasks to achieve. The psychological and physical changes which accompany aging, including adjusting to retirement from the world of work, coping with new living arrangements and diminished income, and coming to terms with the loss of spouse and peers, are all issues which affect the older family unit (Hogstel, 1994). Meeting these challenges of old age are stressful, requiring the individual to redefine self and relationships within and outside the family. The younger generation - the one time recipients of care - are now called upon to be caregivers, a role

which for most of them is new and which for some is one which they envisaged the state would fulfil.

Successful caregiving within the family hinges on reciprocity - a balance in social exchanges. Younger family members provide care because of ties of love and affection which have developed over many years. Family members such as siblings, who have had a more distanced relationship during their lives, may become more supportive of their brother or sister in old age. Gold (1991) suggests that this phenomenon functions like a social insurance policy, should other sources of social support fail. And, although these siblings will never replace spouses or adult children, they fulfil the role of friends, caregivers and confidants for the elderly individual.

When the family unit, for whatever reason, is unable to support their elderly member, the aging person may experience unnecessary institutionalisation and premature death (Hogstel, 1994). Admission of a family member into residential care is usually a stressful experience for all concerned and one which may pose an ethical dilemma for their offspring (Johnson, 1990). Johnson noted four issues encountered by daughters making the decision to place an aged parent into care: a lack of control over the situation, with advice from health care professionals inadvertently adding to their feelings of being unable to cope; the rationale for the decision, with the decision making process being described by several participants as "the hardest thing I have ever done" ; the dilemma of family needs versus those of the

aging parent; and deciding if the reason to relocate the elderly person was a valid one. Even when the decision had been made and the person placed into care, the majority of those interviewed reported reviewing the decision to ensure that it was the right thing to do. Some changed their minds and took their elderly parent home again (Johnson, 1990).

The idea that the family should be viewed as the unit of care has been a controversial one in medicine (Gilliss et al, 1989). Such an approach is problematic in that it may be difficult to identify who is actually part of this social unit. Yet it has been acknowledged (Wright & Leahy, 1989, p.1) that "nursing considers the family as the primary unit of health care." So, for nurses to be effective in this area it is important that they do interact with a group of clients - the family unit, regardless of its composition. Nursing assessments, interventions and evaluations need to be inclusive of all key members of the family group, with the consent of the elderly person, if it can be obtained. By understanding family dynamics and being supportive of the family unit, nurses can optimise outcomes for the elderly client and for their family.

The caregiver role

Families, for a range of reasons, continue to want to care for their aged members (Opie, 1992). The ability to care is affected by a number of factors: the age, health and gender of the person who will take primary responsibility for the aging individual; the mobility of the family; the

composition of the family; and current and historical interpersonal relationships within the social unit (Opie, 1992). Sometimes other family members and health professionals confuse a person's ability to care with their desire to care. Opie has identified four affective positions adopted by caregivers which affect the relationship between them and the recipient of care. Commitment, the strongest of the four positions, occurs when the caregiver accepts the disability of the person they are caring for, has a sense of relationship with them and retains a positive outlook regarding their role. Those who feel obligated to care have a more distanced relationship with their elderly relative and undertake the role because of social expectation. The next position is that of dissociation which involves a further degree of emotional distancing. Finally, there may be repudiation where there is little warmth towards the person that they are caring for and the role is seen as burdensome and distasteful. The likelihood of abuse is high with caregivers who occupy this fourth position.

The caregiver role is not an easy one. Gaynor (1990) deduced that between twenty four and thirty two months after commencement of caregiving, there was a critical transition from health to illness in the caregivers she interviewed. Two of the main problems encountered by caregivers are fatigue and depression. The person is often unsupported in the role with other family members either unaware of the situation, or unwilling to become involved. As time progresses, interaction with others not involved with the caregiving diminishes, the person loses touch with friends and may become

so exhausted that they are unable to explore options which may offer some respite (Opie, 1991). For some, the caregiver role has the added stress of being a covert activity. This 'protective caring' as it is termed is when the caregiver tries to protect the aging relative from awareness of being taken care of (Pallett, 1990). The end result may be total isolation of the caregiver and elderly relative and the possibility of physical harm to the aged individual.

Another emotion experienced by caregivers is that of guilt. This often occurs when the relative is relocated into residential care, or when the caregiver feels that they have sided with the health professionals over an issue rather than supported the decisions of the elderly family member. Discussion about money and assets of the aged relative may also be a source of discomfort for the person who may feel it is inappropriate to be exploring this very private realm (Hogstel, 1994). Comparisons with standards of care offered by formal carers can be another source of insecurity and guilt. It is very easy for those who adopt the caregiving role to become the invisible victims, vulnerable to exploitation by other family members and inadequate health care services.

Yet the caregiver role has its positive dimensions: both parents and caregiving offspring are able to relate to each other in new ways. Friendship often develops between the generations, at times replacing less harmonious ways of interacting which may have become the established pattern within

the family. For grandchildren, it can be a time to get close to their grandparents, understanding something of their heritage through contact with this older generation. For others, the caregiving role offers an alternative to employment and can provide satisfaction which may be lacking in their usual job (Opie, 1992). If the recipient of care retains their endearing qualities, and is able to respond to the caregiver, shared activities can continue bringing mutual satisfaction. For some people, the caregiving role may even become their reason to exist.

Women more often than men take on the caregiver role. As suggested by Ade-Ridder and Kaplan (1993), caregiving for women is an expected duty, whereas for men it is an unexpected expression of compassion. The notion that caring is a natural behaviour for a woman may influence decisions made by family members regarding who will care for their aging relatives. If the woman is single and/or does not work, there is an even greater expectation that she will assume responsibility for caregiving (Opie, 1991). For a woman, the act of caring for an elderly parent may be an added burden to caring for a partner and offspring - what Opie (1992) has defined as the triple load. Sometimes the woman's partner will assist - this can be critical in being able to care successfully. This unpaid labour on the part of women means that they are crucial to the functioning of the health and welfare system. Yet this willingness to accept the caregiving role has contributed to women's social, economic, and political sub-ordination (Opie, 1992).

Men do adopt the caregiving role, but usually the recipient of care is their spouse - there is less compulsion for sons to take care of their parents (Opie, 1992). As with women, the reason for deciding to provide care for a loved one is based upon affection and obligation. Yet there are differences in the way men and women fulfil the caregiving role. For a man, formal groups and services often take the place of the informal support that a woman will rely upon; because of previous experience women often cope better with performing activities of daily living for the recipient of care; men also have more problems adapting to the increased impairment of their loved one and, as they are usually older than their spouse, are often in poorer physical condition than their female caregiving counterpart (Mathew et al, 1990).

If the recipient of care requires institutionalisation, a man is more likely to be able to cope with the decision, whereas a woman often feels she has failed in the caregiving role (Ade-Ridder & Kaplan, 1993). For both men and women there is change in the type and quality of their relationship with their spouses once one of the partners has adopted the role of caregiver and the other is the recipient of care. The previous quality of the relationship affects the caregiver role (Pallett, 1990). Spouses, regardless of gender, will continue to look after their partners long after other family members would have sought institutional care.

Aging in New Zealand

The ties of love and affection, the bonds of duty and obligation, the values of ethnic groups and systems, changing demographics and economic constraints all predict the expansion of family caregiving as the nation enters the next century. (Askew Browning & Hogstel, 1994, p.406)

In the United States, only five per cent of those over the age of sixty-five live in nursing homes, and more than eighty per cent of home based care for the elderly is provided by family members (Askew Browning & Hogstel, 1994). Yet it is debatable how long this trend will continue. This is not because of any lack of will on the part of the families with older dependent relatives - the belief that families in the eighties willingly placed their elderly members into care has been proved to be a myth - but because of the increasing numbers of older adults requiring assistance. Institutionalisation of the aged, with the accompanying financial burden on families and taxpayer alike, will not be a possibility.

If community care is to be an effective option for the older adult and their family, there needs to be a combined effort on the part of those who develop social policy, government agencies, health care delivery organisations, the elderly and their families. Present policy is simplistic and, as suggested by Opie (1992), is based upon an ideological concept of the family rather than reflecting the diverse living arrangements that exist. In New Zealand, faced

with a similar situation as the United States, there has been a recognition of the need to address issues associated with an ageing population. This prompted the government to establish the Prime Ministerial Task Force on Positive Ageing. The group delivered its final report, *Facing the Future - A Possible Way Forward*, in July 1997.

The Task Force's aim was to assist the development of public consensus on: The environment that is necessary to ensure that people move through their lives towards a healthy, independent, safe, secure and dignified older age in which they are able to participate in and contribute to society, to the extent of their abilities and wishes, and enjoy the respect and support of their families and communities; and the measures that need to be taken by individuals, families, local communities, employers, voluntary organisations and Government to achieve this end. (*Facing the Future - A Possible Way Forward*, 1997, p.2)

The report proposed that life is be viewed as a continuum, that aging begins at birth and we all age differently. Significant changes in physical and mental capacity can limit the very old. It is only at this time that a distinctive need for support and services arises. As suggested by Opie (1992), there needs to be a continuum of support that embraces those who are able to live independently in the community through to those who need institutionalisation, with formal care complementing informal care.

The report also identified that our aged citizens are not an homogeneous or distinct group with identical needs. Like younger people, they have diverse capacities, interests and requirements. Because of this diversity, it is inappropriate to define retirement in chronological terms. We need to redefine what we mean by "work" and "working life". However, if we are going to be able to meet the challenges involved in re-structuring our society, there needs to be an investment in both health and education, underpinned by a strong economy which will allow people, including the elderly and their families, the freedom to follow a greater range of lifestyle choices.

A comprehensive approach needs to be employed to achieve this vision for our future. Government agencies are currently examining all legislation, policies and administrative practices to ensure that they are consistent with the Human Rights Act 1993. It is this piece of legislation which, from 1 February 1999, will include age as a prohibited ground of discrimination in the work place. In conjunction, there will be an increased emphasis upon self-reliance, with only those who are genuinely unable to provide for themselves, being offered any assistance from the state.

Contained in the report is the notion that people, encouraged by the state, will move between paid and unpaid employment, education and leisure activities, throughout their lives - a cyclical lifestyle pattern which will only

occur if non-monetary activities, such as child rearing and caregiving are recognised and valued by the state and society. Such flexibility in lifestyle may only be achieved if the existing infra-structure including transport, housing and health care delivery is re-structured. The present isolation which is the lot of many of our aged citizens, may be overcome by providing transport and housing which is affordable and accessible, and a health care system which avoids duplication, whilst extending support and funding to informal caregivers such as a family member. This is particularly important because caregiving usually becomes the responsibility of one person, rather than a combined effort on the part of the family and friends. Therefore, help for the older person in the community must also mean support for the caregiver, for the quality of both lives is inextricably linked. In keeping with the philosophy of self-reliance, people of all ages will be encouraged to take better physical care of themselves.

The Task Force on Positive Aging also envisages a role for the media of portraying images of older people and possibilities for lifestyle choices. Rather than the present marginalised existence of many elderly folk, it is hoped that our elderly citizens will become valued as trustees of our culture, their skills and experience being used by others starting out in life, thereby increasing inter-generational contact and promoting a more harmonious and inclusive society.

Review of the selected current literature provides an insight into the world of the aged and those who care for and about them. For many of us it is a world that we have little to do with until we are personally affected. It is against this backdrop that the process of relocation is examined from the perspective of the five people who participated in this study.

CHAPTER THREE

THE RESEARCH PROCESS

The aim

The aim of this research was to find out the meaning of relocation for families who relinquished care of their elderly relative to formal caregivers in an institutional setting. In using the term family, I included not only those who were related to an individual but also people who were close to or cared for an elderly person. It was hoped that the research would generate knowledge which could be used to:

1. inform nursing practice, encouraging nurses to adopt a more family centred approach in meeting the needs of elderly clients relocating into residential care;
2. identify ways of involving the family during the relocation process; and
3. improve the quality of life for families who choose residential care for an elderly family member.

The method

As with all research, the research question influenced the methodology. The empirico-analytic paradigm, which has been dominant the scientific community, particularly in the United States, has also been prominent in nursing research (Allen et al, 1986). This quantitative approach is based upon an assumption of causality - objects and situations are operationally defined and a hypothesised relationship between variables is either

confirmed, or nullified. The purpose of the research is to provide information which allows for prediction, manipulation, and therefore control, of events. Historical, socio-cultural and personal dimensions of a situation are stripped away - indeed subjectivity is viewed as a private and personal reading of reality given to error (Oiler, 1986). Yet, can human emotions and experiences be appropriately studied using any decontextualised and morally neutral methodology? Can the experience of grief be operationally defined? What is it like for a family to place a loved one into residential care? A quantitative research approach cannot easily capture the contextual complexity of these human experiences.

The distinction between the kind of approach which is appropriate for the sciences and that which is appropriate for human relations was noted by Marcel as the difference between a problem and a mystery (Marcel, 1971, cited in Riemen, 1986). When a question relates to human experiences and the meanings such experiences have for those involved, a qualitative rather than a quantitative research approach is more effective in explicating the richness and complexity of the area of interest. Because of the nature of my research question, the choice of a qualitative methodology was appropriate. However, the term qualitative approach is a collective one encompassing a number of distinct methodologies. Two criteria influenced my choice of phenomenology: the need to adopt a research method which would give meaning to the relocation process from the participants' perspective and, a

desire on my part to choose an approach which was sympathetic to the philosophy which underpins nursing.

Phenomenology - historical perspective

Dismayed at the inadequacies of science and organized religion, Franz Brentano (1838-1917) sought to reform philosophy into a discipline which would provide answers to the quintessential questions of concern to humanity. Phenomenology - the study of phenomena - with its emphasis upon description and interpretation rather than experimentation was the means by which this was to be achieved. The idea of describing and clarifying phenomena before undertaking causal studies, and the notion of intentionality, that everything that we consider to be psychical refers to an object, originated from this initial work of Brentano (Cohen, 1987). His ideas and those of his student Carl Stumpf were further developed by Edmund Husserl and Martin Heidegger in what is now termed the second phase of the Phenomenological Movement - the German phase.

Husserl, in common with his predecessors, regarded his method of phenomenology as the only way of elevating philosophy to the state of a rigorous science (Walters, 1994). In an attempt to bridge the philosophical and scientific realms, Husserl identified two types of attitude, the natural and the scientific. The natural attitude is the way in which we interact with the natural world that consists of everyday things and people. It was the latter - the scientific realm - which was of interest to Husserl, and was, according to

him, the concern of phenomenology. To make explicit the scientific realm, the researcher must disengage themselves from all subjective, aesthetic and practical concerns of life (Walters, 1994). This technique is termed bracketing and is essential in Husserlian phenomenology to obtain the rational foundations of the world.

Unlike the transcendental phenomenology of Husserl which focuses upon the description of the lived world from the viewpoint of an independent observer, others including Husserl's student, Martin Heidegger, adopted an existential approach in which there was no distinction between the natural and scientific realms. Central to the Heideggerian tradition is the ontological issue of human existence. Heidegger believed that a person could not stand apart from their world and observe it dispassionately, for to be human is to-be-in-the-world and to be one with it. The use of hyphens emphasises this concept as a unified process (Walters, 1994) which, inclusive of both subjective and objective, blends together into the complexity which is the situated human experience.

The Second World War brought an end to the German domination of the Phenomenological Movement. In post war Europe French philosophers and phenomenologists such as Sartre, Merleau-Ponty and Marcel came to the fore. The existentialist themes evident in their work can be traced to Heidegger, who is more well known in France than Husserl. Phenomenology continues to be the dominant philosophy in France (Cohen,

1987) but with the passage of time it has become more than a theoretical endeavour. As a qualitative research methodology, phenomenology has been used by other disciplines, including nursing. The Heideggerian approach in particular has proved sympathetic to the aims of those carrying out nursing research. I have adopted Patricia Benner's interpretation of Heidegger's work for this study, so the following description of Heideggerian phenomenology is particularly influenced by Benner and other nurse writers.

The existential phenomenology of Heidegger

The Heideggerian view of the person as a self-interpreting, embodied intelligence, situated in the world and concerned with it (Benner & Wrubel, 1989) focuses upon the ontological issue of what it is to be human, what Heidegger refers to as Sein or Being as opposed to Dasein which signifies people as beings who comprehend Being (Cohen & Omery, 1994). To be human in the world involves instantaneous and non-reflective interpretation of a situation, for we are both engaged in and constituted by it (Leonard, 1994), so that meaning resides neither with the person nor the situation but is a transaction between the two. This Heideggerian view of the person as a self interpreting being is supported by Bauman (1978), who contends that human consciousness and external nature, so sharply opposed in our philosophical tradition, are inextricably welded into one, the all embracing phenomenon of being-in-the-world.

This connectedness with the world is made possible because of the attributes of our humanness (Benner & Wrubel, 1989). Our bodies as well as our minds are knowers. This concept, termed embodied intelligence, is the innate capacity to unconsciously make sense of the world in an holistic way. It makes possible the development of skills like those required to ride a bike, to be an expert nurse, to recognise people and places and to remember past events. It underpins the acquisition of socio-cultural behaviours, gestures and habits - our habitually skilled body (Madjar, 1991) - that allows us to share the world with others. For example, we rely on this habitually skilled body to act appropriately in a social context, to be able to accurately judge what is an acceptable social distance or personal space (Benner and Wrubel, 1989). These learned responses are influenced by what our culture, history and language have imparted to us from birth. It is this background, a shared public understanding of what is, which provides us with a guide for how we interact with others.

Although it can never be made completely explicit, our background colours our understanding of the lifeworld, for we can never free ourselves of its influence (Walters, 1994). It arises from our situatedness, the particular cultural, historical and familial context into which we are "thrown". Our existence is involved in working out the possibilities that may come to be for us by virtue of our unique situations (Leonard, 1994), for we are not free agents. It is our background understanding that conditions our interests and questions as self-interpreting beings. We rely upon it to make sense of

situations as we engage in a dialectical process between our learned and shared cultural meanings and practices, and the events we are seeking to comprehend.

This process, which is employed by all of us in understanding our everyday lives is inherent in the interpretive method of hermeneutics, adopted by Heidegger as a means to analyse Being (Walters, 1994). Hermeneutics, however, goes beyond what is obvious and trivial, what Heidegger termed *verfallen*, to make explicit the implicit. In this sense phenomenology is reductionist as it sets out to break down meanings within everyday life, not by seeking to create knowledge which is nonexistent but to make overt what has always been, and in doing so to make explicit universals which govern human existence.

Although Heidegger is associated with hermeneutics, it has a long tradition and has also been developed as a method of inquiry by others. Hermeneutic method focuses upon the systematic interpretation of meaning (Cohen & Omery, 1994). The meaning we give to a phenomenon exists because of the context which we provide for it. In this way a phenomenon may be seen to have the same essential meaning even when it is perceived over time and in a variety of situations (Vaile & King, 1978, cited in Riemen, 1986). The researcher is not exempt from this process. Indeed, a prior understanding of the phenomenon by the person undertaking the study is an acknowledged part of hermeneutic methodology. The final document is a

meld of the lived experiences of both the participant(s) and the researcher, that originates from their being-in-the-world.

For nursing, the appeal of Heideggerian phenomenology is in part due to the existentialist concepts inherent in this tradition. In the late 1960's nurses had begun to write about the relevance of existentialism as a philosophy applicable to nursing (Riemen, 1986). Yet nursing and phenomenology are disparate endeavours, one being a practice discipline based upon the age old human attribute of caring, and the other being primarily a philosophy with a comparatively short history. The attraction of phenomenology, and in particular existential phenomenology, for nursing exists because of some shared fundamental beliefs which I shall now discuss.

Nursing and phenomenology

There are many common threads that bind nursing and phenomenology. The views of nursing and phenomenology towards people are that they are whole beings who actively create their own meanings (Walters, 1994, p.135).

Dimensions of human existence, and the meanings we attach to them, dominate the worlds of nursing and phenomenology. Assisting an elderly relative into residential care, can mean feelings of loneliness, grief and guilt for the family. As nurses, we acknowledge these emotions and our interpretations of them influence our responses to the families experiencing

the relocation process. The process of relocation into care is of phenomenological interest also for it provides insight into ontological issues about what it means to be human.

Historically, phenomenology developed in response to the perceived limitations of Cartesian dualism, a philosophy which emphasised the observable while seeming to negate human experiences and the meanings attached to those experiences. The hypothesised mind-body split has also been rejected by nurses in favour of a more holistic approach (Boddy, 1987). Nursing takes into account not only the individual, but their relationships with others, their environment and their spiritual aspirations. There is an interconnectedness between the person and what phenomenologist van Manen (1990) terms their lifeworld. This notion of the inter-relatedness of the universe is evident in the work of some nursing theorists, including Martha Rogers and Margaret Newman, both of whom view the person as being situated in and connected with their environment (Marriner-Twomey, 1989).

In contrast to the positivistic approach associated with the Cartesian tradition, neither nursing nor phenomenology are morally neutral endeavours. Each has an ethical dimension derived from a concern with the way in which humans interact. Nursing encourages its graduates to act as autonomous and self-monitoring practitioners, to be client advocates, to

observe the patient's code of rights and to adhere to standards of practice and ethical guidelines.

For the existentialist philosopher Martin Buber, the quality of a human relationship hinges upon knowing the other person. This requires openness, participation and empathy (Riemen, 1986). Buber's "I - thou" relationship involves a real encounter and genuine mutuality as opposed to an "I - it" interaction in which we relate to other human beings by experiencing and using them. This recognition of an other's humanity is apparent also in the existentialist phenomenology of Heidegger. Inherent in being-in-the-world is an intimate concern with it, and with other people and entities. This concern or care, the English interpretation of the Heideggerian term *sorge* (Walters, 1994), may be expressed in number of ways such as providing food and clothing and nursing the sick body (Crotty, 1996). What is critical for both phenomenology and nursing is the notion that people and things matter to a person. Participants in this research displayed this in their concern for their elderly relatives and the transition which they, as families, were experiencing.

For nurses, concern with people is made explicit through care. Caring is what nurses do, and implicit in this is the desire to heal - a word which is derived from health and stems from the notion of wholeness or wholism (holism), a soundness of mind and body (The Concise Oxford Dictionary, 1988). Nurses care about people, and healing is part of that caring. To heal

implies change and growth in an individual. As suggested by Riemen (1986), man is not but is forever becoming an infinite process which features strongly in the philosophy of existentialist phenomenology. For nurses, healing also implies change. This is translated into keeping open the possibilities that can be saved in the world of the sick person, while aiding him or her to let go of the possibilities that are no longer realistic (Dreyfus, 1994).

Because of the shared views of nursing and phenomenology, this method would seem valuable as one way of generating new nursing knowledge. However, there is concern that nurse researchers who have used phenomenology have not always been true to the basic concepts of the movement (Crotty, 1996). In reviewing a selection of nursing research which has adopted a phenomenological approach, Crotty suggests that it has more in common with humanistic psychology than with either the Husserlian or Heideggerian traditions.

Phenomenology, despite the diversity of the movement, is based upon a common philosophy. The phenomenologist seeks to understand a phenomenon in its unadulterated form. For Heidegger this was an ontological issue, the meaning of Being. The Husserlian approach focuses upon epistemological questions in seeking to establish a universal foundation which could transcend the boundaries of religion, philosophy and science. To achieve this Husserl suggested that we must go "back to the

things themselves" (Crotty, 1996, p.30) to start our research not from philosophies but from the things and the problems connected with them.

Nurse researchers also wish to explicate the meaning of phenomena, but their approach and goal are quite different. They seek to understand the experience of the people that they study. In doing this the emphasis is shifted from understanding the meaning of Being - the purpose of Heideggerian phenomenology - to understanding the verfallen world of being (Cohen and Omery, 1994). The desire to understand the unique experiences of individuals is also in contrast to Husserl's concept of explicating universal phenomena. For Crotty (1996), this 'new' phenomenology, as he terms it, lacks objectivity and the ability to critique the culture which determines the way in which we interpret our world.

Yet nursing is not alone in its humanistic interpretation of phenomenology. Disciplines like education, psychology, and sociology have all adopted phenomenology as one research method. Crotty (1996) acknowledges that phenomenology is an orthodoxy where heretics abound, and in which there are as many phenomenologies as there are phenomenologists. It is understandable that nurses, in seeking to answer nursing questions, would focus on the experiences of people for whom they care - after all, unlike phenomenologists, our concern is not primarily with phenomena but with human beings. It is human beings who are the focus of the paradigm cases and exemplars used by Benner (1984). The particular pattern of meanings

which emerge provide us, as nurses, with insights into the experiences of our clients, and may be used to inform practice. For, unlike phenomenology, nursing is first and foremost a practice discipline.

As a nurse, I share with Benner a nursing tradition and aspirations for the future of the profession. It is for these reasons that I have used Benner's interpretive phenomenological approach, interpreted by Crotty (1996) as 'new' phenomenology in this research. The development of theory and methodology unique to a discipline is a hallmark of professional maturity. For nurse researchers, the issue of whether the new phenomenology can be classed as part of the mainstream phenomenological tradition is not a critical one. What is important is that the research method, regardless of its origin, be appropriate to generate nursing knowledge and be robust enough to withstand academic scrutiny.

Evaluation of research methodology

Criteria developed to ascertain the rigor of a research methodology inevitably favour the research tradition which has generated them. Unlike quantitative approaches, which focus upon the objective and generalised divorced from any context, qualitative methodologies including phenomenology, also encompass the subjective realm. There is an appreciation of the unique and the situation in which it is embedded. Because of this disparity it is inappropriate to evaluate a qualitative approach by using reliability, validity and objectivity, the acknowledged

criteria of adequacy in scientific research (Sandelowski, 1996). Yet this does not mean that qualitative inquiry cannot be evaluated. What it does mean is that there was a need to generate criteria which reflected this particular research tradition, and which may be used to effectively evaluate methodologies which arise from it. Sandelowski (1996) suggests three such criteria: auditability, credibility and fittingness. These criteria correspond with reliability, internal validity and external validity respectively, which are employed to evaluate quantitative research.

Auditability - the ability of another investigator to follow the decisions made during the original piece of research - corresponds with the notion of reliability, the obtaining of similar results over repeated testing periods which is employed in quantitative inquiry (Beck, 1993). For a piece of research to be auditable, there needs to be a clear decision trail throughout the research process which can be followed and in which there is an inherent logic. Auditability is achieved through description, explanation and justification (Sandelowski, 1986).

The audit trail also includes a discussion about how the researcher became interested in the subject of the study, and how he/she views the topic being studied. The specific purpose of the study, how participants were approached and came to be in the piece of research and the impact the participants and the researcher may have had on each other also needs to be addressed. Information about how data were collected, how long this

process lasted, the nature of the setting(s), and the transformations during analysis, interpretation and presentation are important. The audit trail must also make clear how various elements of data were weighted, inclusiveness and exclusiveness of categories, and the specific techniques used to determine the truth value and applicability of this information (Sandelowski, 1986). Attention to the above issues cannot merely occur within the researcher's mind, but must be clearly documented in the form of formal and informal notes which may also include diagrams and photographs (Rodgers & Cowles, 1993).

Validity is achieved when a test or piece of research focuses upon what is stated as the research concern (Woods & Catanzaro, 1988). In quantitative research there are two aspects of validity - internal and external. Internal validity assesses whether or not the independent variable makes a difference or not to the dependent variable. External validity refers to the extent to which results of a study can be generalised to other populations (Beck, 1993). Neither of these strategies is useful in qualitative research, however validity of data is accomplished by a process of continual analysis and comparison leading to progressively refined themes. These themes may then be compared to people's experiences, ensuring that the completed document mirrors the realities of the participants. This process is a major strength of the qualitative approach (Woods & Catanzaro).

Rather than assess internal validity, qualitative researchers look for credibility - a measure of how vivid and faithful the description of a phenomenon is (Beck, 1993). The researcher needs to take into account aspects of their own involvement in the inquiry, particularly the impact of their presence and the nature of their relationship with the participants, and the process of validation of the findings with the participants. The opinion of an independent panel, and the provision of field excerpts to peers, can help to mitigate against the inclusion of non-essential themes. As suggested by Reinharz (1983), analyses are consensually validated by peers, audiences and bosses.

Fittingness - how well propositions fit into a context other than the one from which they were generated - is a more appropriate measure of qualitative inquiry than attempting to measure external validity. Fittingness involves establishing the representativeness of participants and the resulting data. The researcher needs to ensure that interpretation of data was not made to appear more similar or congruent than it really was (Beck, 1993). It needs to be stressed that qualitative inquiry focuses upon the uniqueness of human situations. Because of this orientation, replicability and objectivity, which are aspirations of quantitative research, will never be achieved and nor should they be attempted as a way of validating the fittingness of the original research outcome.

The following section outlines the method used in this study and, in doing so, provides documented evidence which is open to scrutiny and evaluation.

Participant selection

A total of five participants were accessed by approaching managers/directors of residential care facilities in the Auckland region. As noted by Woods and Catanzaro (1988), the number of informants or participants in a descriptive, qualitative study is hard to determine in advance. They suggest that five participants studied over a relatively short period of time is a reasonable number for a master's thesis. The initial contact was made by distributing copies of an open letter (Appendix A) to fellow members of the Gerontological Section of the New Zealand Nurses Organisation at their quarterly meeting and asking members to display and/or distribute copies in their homes/hospitals. I was present to discuss the research topic and answer any questions from the group. I hoped my letter would attract people who, with their elderly relatives, had had experiences of different types of care facilities - homes, hospitals and secure units - during the relocation process. The purpose of this was to maximise the scope of the study.

Criteria for selection included participants being agreeable to the research requirements stated in the information sheet (Appendix B); being related to and/or considered a significant other of the person admitted into residential care; having been involved in the process of relocation of the family member;

and this event occurring within the last year. The second and third criteria were aimed at screening out people who had had only a casual role in the relocation process. The latter point meant the inclusion only of people for whom the process was a recent experience, thus providing a richness and clarity of perception which may be increasingly distorted with the passing of time.

As a result of the open letter, I was contacted over a period of several weeks by people who were interested in taking part in the study. I took the names and addresses of those who were suitable, and who, after our phone conversation, remained interested. This was followed up by a visit from me.

Interviews

The interviews, which were conducted by mutual arrangement in the participants' homes, took place over a four month period. The five interviewees were each interviewed twice, each deciding after the second interview that he or she had no more to add to the data. There were also informal conversations and correspondence between myself and the participants throughout this phase of the research project.

Interviewees included three men and two women and, although provision had been made for non-related caregivers to be included in the study, this situation did not arise. One of the male participants had joint interviews with his wife, as both had been involved in assisting this man's father into rest

home. Two of the men had the experience of placing a spouse with Alzheimers type dementia into secure care. The remaining two interviewees discussed relocating a parent into care - one into a secure unit and the other one into a hospital. All participants were of European descent. They ranged in age from middle adulthood to older adults, and all lived in a metropolitan area.

The interviews initially focused upon the two questions included in the prompt sheet (Appendix D):

1. Describe what it was like to make the decision to relocate a relative into residential care,
and
2. What did the relocation process mean for you?

These were key questions but they served as a lead-in to further discussion and an indepth account of the experience. Interviews took the form of a focused conversation. I was mindful of the need to keep "orientated to the substance of the thing being questioned" (van Manen, 1990, p.98). This involved thinking carefully, as the interview was in progress, about which aspects of the experience should be followed up in more depth with further questions and discussion. It also meant going over the data from the first interview so that certain areas could be revisited during the second session. The participants also had the opportunity to do this as they each received transcripts of their interviews. The interviews, although informal, were structured to encourage reflection by participants and myself upon what was

being expressed. They were a shared exploration of the phenomenon of relocation and, as such, had potential therapeutic benefits for the interviewees.

Data collection

Data were collected in the form of taped interviews which were then transcribed. Interviews were conducted at a time and place agreed upon by both the participant and the researcher. Prior to the taped interviews, I visited each participant to explain the study, answer any questions and give them an information sheet and a prompt sheet. At this point I arranged for the prospective participants to contact me to confirm if they still wished to take part in the study.

For those who indicated an interest during this initial meeting, I took the opportunity to briefly practise with the tape recorder so that the taped interviews would not be compromised by mechanical problems. I hoped that familiarity with the tape recorder for the participants and myself would mean that the interviews for both parties would be informal and relaxed.

Prior to the first taped interview I completed the consent form (Appendix C) with each participant. Before each of the sessions I reiterated with the participant their right to have questions answered and to withdraw if they wished to do so. Tapes were labelled with pseudonyms prior to the interviews. The duration of the interviews was determined by the amount of

information that each participant had to give. When the participant felt that they had no more to say, and/or saturation point was reached, I discontinued gathering data. Initially I had hoped to transcribe the interviews myself, but due to time constraints, I had them transcribed for me. The person who transcribed the tapes understood the need for maintaining confidentiality and signed a non-disclosure document (Appendix E). I explained to the participants how confidentiality would be maintained during the transcription process and they were agreeable to this.

Data analysis

Phenomenology aims to transform personal lived experience into consensually validated social knowledge. To achieve this involves not only the participants in the study but also the researcher and those who read the final document. The process of analysis used in this study is that outlined by Reinharz (1983):

1. The first transformation is performed by the participating person who, in the context of a research situation transforms private experience into action and language and makes these available to the researcher. In this study taped interviews were used to record this first step of the process. Such self-revelation requires an atmosphere of trust and mutual respect between the participant and the researcher.
2. The second transformation is performed by the researcher who, unable to enter and sense directly another's experience, has to produce his or her

own understanding of that experience from information communicated by the participating person.

3. Having grasped the participant's experience, the researcher then needs to transform it into conceptual categories or themes which capture the nature and meaning of the experience, rather than merely recording it.
4. The researcher then has to transform the understanding and themes into a coherent, meaningful account - such as a research report or a conference paper - that makes the knowledge public and open to scrutiny.
5. The final transformation has to be performed by those who have not participated in the research process, but who as the audience need to create their own understanding of the phenomenon, clarifying existing understandings and asking new questions about human experience.

These phenomenological transformations are not a linear progression, but an inductive interpretive process by which the private becomes public. So, every phenomenological description has in some sense a forced quality to it (van Manen, 1990) and, as suggested by Madjar (1991), runs the risk of idiosyncratic interpretation. For a description to be a comprehensive and accurate account of the phenomenon, it must contain only those themes which are essential to the experience we are interested in. Some meanings which become evident during the analysis phase are not unique to the phenomenon, but are incidental themes. It is therefore critical to discover

attributes that make a phenomenon what it is and without which the phenomenon could not be what it is (van Manen, 1990).

So, what is a theme and how can thematic aspects of a phenomenon be made explicit? Themes are the structures of experience (van Manen, 1990). They give meaning to it, drawing together the amorphous raw data into recognisable patterns. A theme is a simplification of experience, capturing a part of the whole, yet it is not something which is discovered only at certain places in the text, but rather is woven throughout it. Identifying themes may be accomplished in a number of ways. The process adopted in this study is classed as a selective or highlighting approach in which the text is listened to and read several times and statements and or phrases which are particularly revealing about the phenomenon are identified as an example of a theme which is essential to the experience (van Manen, 1990). These bald statements form the basis of a more comprehensive description of the phenomenon, merging with the researcher's interpretation of his/her own lived experience and information gleaned from field notes, reading and other research activities.

Ethical concerns

Addressing ethical issues which may arise as a result of research is part of the research process. Ethics is defined as "the moral value of human conduct and of the rules and principles that ought to govern it" (Collins Dictionary of the English Language 1985, p.502). Woods and Catanzaro

(1988, p79), endorsing the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, provide a guide to ethical issues:

1. respect for a person as an autonomous agent
2. maximising benefits and minimising harm
3. the equitable sharing of the burdens and benefits of research by the population.

The participants in this research project were a vulnerable group because of the potentially stressful nature of the research topic, and also because of the age and status of some of them, that is, elderly and living alone. In discussing the relocation process, which for each member of the group had occurred within the last eighteen months, participants revisited an experience which was at best frustrating and at worst, very painful.

Taking into account the above guidelines, the sensitivity of the topic and the vulnerability of the group, the following criteria were adopted to ensure that ethical concerns were addressed as part of the research process.

(a) Access to participants

The open letter which was distributed through the Principal Nurse/Managers of the residential facilities, stressed that prospective participants must initiate contact concerning participation, either through the management of the care facility or directly with me. This eliminated the risk of prospective participants feeling coerced into

taking part in the study and, demonstrated a degree of motivation on their part to be included in the research.

(b) Informed Consent

Informed consent is considered to be an ongoing negotiated process. Initially prospective participants must have the capacity to consent to be in the study. Consent must be voluntary and freely given. Consent forms were only completed after the participant had the study explained to them, read the information sheet and had questions answered to their satisfaction. The information sheet and consent form stipulate that the participant has the right to ask further questions during the project and have them answered to their satisfaction. These points were reiterated prior to each taped interview.

(c) Confidentiality

Participant confidentiality was maintained by the use of pseudonyms on tapes and transcripts rather than the names of the participants and others who may have been mentioned in the course of the interviews. Tapes and transcripts were kept in a locked cabinet. Only the researcher, the supervisor and the person doing the transcribing had access to them. The final text was screened to ensure that privacy and anonymity of participants was maintained. At the end of the study all tapes and transcripts will be stored for a period of five years and then destroyed. If the participant wished to keep the tapes or transcripts of their interviews, these would have been screened for

any third parties or institutions and in consultation with the participant, names would be deleted. This situation did not occur.

(d) Potential harm to participants

Procedures to protect the privacy and anonymity of the participants were explained to those taking part in the study, in order to allay any fears that they may be identified. Recalling what, for many participants, may have been a stressful time in their life may have caused distress. As a Registered Nurse with experience in dealing with people in stressful situations, I could be supportive of and sensitive to the needs of the participant if they did become upset during an interview. The tape recorder would have been turned off if this had happened. I reiterated participants' right to refuse to answer questions and/or to withdraw from the study if they wished to do so. Also, with the participant's permission, I was willing to seek assistance for them by contacting a counsellor and/or their family medical practitioner. Fortunately, this situation did not arise. A transcript of each interview was provided for the participant prior to the next meeting so that, if the person was unhappy with what they have said, this could be clarified, altered or deleted at the time of the next meeting, thus decreasing the stress that they may have felt in being involved in taped interviews. The transcript also acted as a starting point for subsequent sessions.

(e) Participant's right to decline

As stated in the information sheet and the consent form, participants had the right to decline to answer any question and could withdraw from the study without fear of penalty or the need to give any explanation. If they chose, information which they provided could be deleted from the study and destroyed. Neither of these situations eventuated.

(f) Arrangements for participants to receive information

As stated in the information sheet and consent form, the participant had the right, at any stage of the study, to have asked further questions which must be answered to their satisfaction. The information sheet also provided the participant with the researcher's and supervisor's phone numbers and the instruction that they could be contacted without hesitation if there were any problems or queries. This did not occur. The informal meeting prior to the first taped interview provided the person with the opportunity to receive information about the study. A summary of the study was provided for each participant.

(g) Use of the information

Information gathered during the course of the research was used by the researcher for the purpose of producing a thesis. This was to meet the requirements for completing a Master of Arts in Nursing. The thesis may be used as a basis for articles and conference papers, but the commitment was made that it would not be possible to

identify participants or settings in any of these documents or presentations.

(h) Other ethical concerns

There is always some degree of stress and possibly grief when people experience change. For many families, assisting an elderly relative into residential care may be a last resort and the final step in what has been a period of upheaval which will have affected all concerned. In my interactions with participants during this study, I hoped to create an atmosphere where participants felt both comfortable and safe. I was flexible in scheduling interview sessions so that the people involved experienced a minimum of inconvenience.

CHAPTER FOUR

OVERVIEW OF THE RESEARCH OUTCOME

Analysis of data in a phenomenological study leads to the generation of themes. These are not discrete entities, rather there is overlap, a relatedness of varying degrees, with themes running into one another. For the researcher, particularly someone inexperienced in phenomenological methodology, as in this study, the process of sifting through and making sense of the data may be a daunting one. In explicating themes of a phenomenon, Heideggerian phenomenology draws upon existentialist concepts which provide a framework for reflection and interpretation of experience. Van Manen (1990) contends that four fundamental concepts - spatiality (lived space), corporeality (lived body), temporality (lived time) and relationality (lived human relation) - are universal to all human beings regardless of their historical, cultural or social situatedness. I have included a brief explanation of these four existential dimensions as they were used as guides during reflection and writing, and the generation of the final set of nine themes.

The concept of space from an existential perspective is not limited to considerations of distance or dimension, but rather how space affects the way a person feels. Different 'spaces' will evoke different emotions - a person will feel differently about their home as compared with a sports stadium. The backdrop of an institution such as a hospital or rest home

often has negative connotations which colour the experience of relocation for the families. This is because of the activity associated with these places which provides the background for, and adds meaning to, an experience. As suggested by Gudykunst and Kim (1984), our interpretations are socio-culturally defined.

An individual's socio-cultural background will also influence how time is interpreted. This is subjective time as opposed to objective time, that which is measured by a clock or calendar. To be independent and have control of a situation is part of our Western culture. The stress and uncertainty involved with relocating an elderly relative into care challenges these norms. Consequently for the families the process may seem to be never ending, something far more drawn out than the days or months that is the temporal reality of the situation. Time, in the form of past experiences also has an influence on how a person copes with current issues and, to some extent how they view the future - with hope or some degree of apprehension.

A person's impression, and their response to another, is influenced by how that other person looks. For some, the catalyst to relocate a relative into care is a deterioration in that person's physical condition - a change in corporeality - which may have come about gradually or may be acute, as was the experience of one participant whose mother suffered a severe stroke. Often, in conjunction with altered physical appearance and abilities, is a change in how an elderly person relates to others, particularly family

members. When we interact with another individual, we transcend ourselves. For many, this seeking meaning in our relationship with others provides a purpose for human existence (van Manen, 1990). Altered relationality between the aged person and their family can result in the feeling that caring for that person at home is pointless, having little benefit for the elderly relative yet at great personal cost to the family.

In this research, there seemed to be a process involved in relocating a loved one into residential care. Yet each participant's experience was different. Mirroring this chronological account was the lived experience of those who I interviewed. Each of the participant's interviews was like a tapestry - threads of experience woven together to form a unique picture. Yet each person's experience of the relocation process contained themes that were common to this phenomenon - the tapestries were different pictures of the same view.

Analysis of data from this study generated nine themes which were evident in each of the participant's interviews. Other potential themes proved to be incidental as they were identified infrequently by only some of the participants and were therefore not deemed to be critical attributes of the phenomenon. The nine conceptual categories, which are discussed in chapters 5 - 7, form a thematic cluster intrinsic to the phenomenon of relocation for these participants and are as follows:

1. Turning point: the point that is reached by the family when they are no longer able to care for their elderly relative in the community and alternative arrangements need to be considered.
2. Autonomy and control: the state of independence associated with being an adult in our society. The process of relocation, at times, undermined the family members' sense of control over the situation.
3. Commitment to care: the degree of support provided by the family for their relative.
4. Loneliness: the potential for, or actual feeling of, missing some one and/or a way of being, which may occur with the admission of the elderly person into care.
5. Guilt: the feeling that social expectations and/or moral duty may not have been fulfilled, associated with the decision and/or relocation of a relative into a residential facility.
6. Grief: the potential for, or actual feeling of, loss because of the altered family structure and dynamics that follows a family member's admission into residential care.
7. Abiding hope: the ongoing desire for the elderly relative's well-being.
8. Making meaning: reflection on, and the significance of, the relocation process for the family.
9. Interpersonal relationships: the impact of the relocation of a family member upon relationships within and outside the family unit.

These themes capture the personal experience of the participants and in conjunction with information contained in the literature review give a more comprehensive insight into the phenomenon of relocation into care.

CHAPTER FIVE

THE RESEARCH OUTCOME - PART 1

This is the first of three chapters in which the nine themes are discussed in detail supported by the data. The themes discussed in this chapter are the turning point, autonomy and control, and commitment to care.

Turning point

What is it that initiates the relocation of a family member in to residential care? For each of the participants who shared their experiences with me there was a turning point, a realisation that the present situation was no longer tenable. The decision was a culmination of external events and personal reflections. For some, the decision was abrupt and had a finality about it, as happened to Betty. Both Betty and her mother appreciated the profound change in circumstances which had occurred in the space of a few hours and which was irrevocable:

We loaded her into the ambulance and the ambulance drove off down the drive and Mum said 'I will never be back here' and I knew she was right and just before the GP had left he had said quite clearly 'you are not to look after her' (5:1:3).

Yet, for others, admission into care was viewed as a temporary measure which became final only with the passage of time. Fred hoped that whilst in

care, a trigger could be found for his wife's behaviour, and she would then be able to be treated and return home:

So there should be a reason for everything that happens...//...make notes when something happens about what was the immediate circumstances, situation, whether it is oral, whether it is to do with toileting, eating, anything you can think of and the idea being that over a period of weeks we hope something is going to manifest itself as appearing to be, even a possible trigger. I couldn't find that (1:2:2).

For Fred, the lack of a remediable cause for his wife's behaviour, meant that he had to accept his spouse's permanent admission into care.

People suffering from Alzheimers or dementia are thought not to be aware of the stress placed upon other family members to care for them. Even those with unimpaired cognitive function may have a different perspective from their family regarding the right time to move into residential care. Although Paul and Helen felt that Paul's father was happy with the decision to relocate into care, their experiences proved otherwise:

Every place in Auckland he said was absolutely wonderful but then he would tell the Principal Nurse, he would take her aside and tell her these amazing stories which he thought we couldn't

hear...//...I had a talk to him on his own about the fact that he actually couldn't keep doing this...//...(that the neighbours) just couldn't keep being there when he wanted them and not being there, that he actually had to decide to stay or make some plans, but this actually couldn't go on (4:1:5 & 2:3)

Taking responsibility for their elderly relative in the community prior to admission into care affected each of the participants in a physical (corporeal) way, which took its toll, whether it involved increased travelling or more intensive input. Bill was so exhausted looking after his wife that out of desperation he went overseas:

In the middle of 1993 I just about went under...//...and I took off to Bali, why I still don't know...//...the person with Alzheimers doesn't want to go to sleep, but wants to sleep during the day, well the carer can't go to sleep at night, is an absolute wreck when the morning comes and then the whole problem starts all over again (2:1:8 & 9 & 14).

In spite of physical and mental exhaustion, socio-cultural expectations regarding family responsibilities in caring for the elderly and a human concern for their aged relative meant that all the participants felt loyalty to their aging loved one. Interviewees all attempted to provide increased care for their family member during the turning point, whether it was visiting

frequently or attempting to modify the environment so that they could continue to remain at home. Fred made temporary alterations to the home unit he and his wife owned, in this case so that his spouse's verbal outbursts would not annoy their neighbours:

... and the yelling is very acute indeed to the extent that when she had several of these attacks I actually put woollen blankets around the windows to make a sound barrier at night (1:1:4).

Concomitant with increased family support was a change in the relationship between the elderly person and other family member(s). This varied from a relinquishing of control on the part of the aged person to a realisation that the elderly person was incapable of functioning fully as a member of the family unit. For Pauline, staying with her father made her realise how much he had deteriorated and how difficult the situation had become:

And I remember one weekend...//...I went home to look after him and I think it was just dreadful and I lost my temper with him so often and he didn't know it was me...(3:1:6).

Yet participants did not reach their decision to relocate lightly - it was a process which usually started with the feeling that all was not well with the current situation, including a feeling of unease about certain changes in

behaviour on the part of their loved one. For Betty this occurred with an alteration in her mother's cognitive abilities:

My mother had always been a very good buyer of gifts and we realised ... I realised that much of what she had bought was totally inappropriate (5:1:1).

Over a period of time unease gave away to stronger emotions when it became apparent that there were problems with the elderly relative. Paul and Helen understood there was a problem but felt frustrated at their inability to resolve it, because of Paul's father's difficulty with making decisions - a part of his condition which no one recognised:

Yeah, just that period of time when you felt like shaking him and saying this is what you need to do, but only he could make that decision really (4:2:2).

As the situation becomes more difficult, frustration and ongoing anxiety may lead to feelings of anger, particularly when the person feels that they have little control over what is happening, as was the case with Bill:

And by that time I got really furious with the GP...//...Anyway she went back...//...and once again I sat in the waiting room and when she came out of there he said well everything is alright. He never

consulted me and that is when I decided to change GP. It took us another four years...(2:1:3)

Bill's wife's deterioration was very gradual, something which Bill could see happening and yet which he could do nothing about. Confirmation of her diagnosis of Alzheimers type dementia helped Bill come to terms with the situation and plan how he would cope with his wife's condition.

The turning point - the point reached when the elderly individual and relatives can no longer continue to live in the current situation, is different for each family. It is arrived at only when family members believe they can no longer cope, often the result of physical and/ or mental fatigue in attempting to fulfil obligations of loyalty and affection. The deteriorating situation, which can include an altered relationship with the elderly person, may engender feelings of loss of control and anger for the family, and in particular, for the member who is the caregiver.

Autonomy and control

A loss of control was a recurring theme for families during the relocation process. Autonomy and control are an integral part of being human. When our autonomy is threatened, it is a normal response to feel angry. Anger is an innate emotion and yet it is culturally defined. Interpretation of, and response to, a situation is shaped by a person's background, and their ability to instantaneously make sense of the social context and to act appropriately.

A person may feel angry when they perceive that they have been treated unfairly, that they have been diminished and their autonomy threatened. Anger drives behaviour designed to right the injustice so that the individual can regain control of their life.

A person's perception of control is not fixed. Access to opportunities in life is more likely to make a person feel that they are able to influence what happens to them. Conversely, having to cope with a life crisis can undermine an individual's confidence and subsequently influence their response to the situation (Lefcourt, 1982). This perceived loss of control is not something which, like the current interpretations of grief, has recognised stages that can be worked through with the passage of time. Loss of control can have a profound and far reaching effect, leaving the individual vulnerable to additional problems (Silver & Wortman, 1980).

The data indicate that, for the participants in this study, feelings of loss of control varied in intensity and incidence. However, underpinning each of the situations which generated these feelings was the issue of relationality. Changes in behaviour and, for some elderly individuals, personality and intellectual function, altered the way in which the families and their aged relatives interacted. Betty felt that she had to take on a mother's role as her parent was no longer able to take responsibility for decision making. She found this change difficult:

It is extraordinarily hard for the children because it is a total role reversal and...//... they are having to take the decisions of the parent, the person who is the parent (5:1:21).

Relationships between families and health professionals involved in the relocation process also impacted on how the family member providing care perceived the situation and the control that they had over events. The caregiver, because of close contact with their loved one, often noticed subtle changes in their elderly relative that were not always apparent to health care professionals. A fragmented approach on the part of health care professionals contributed to the caregiver's feeling of loss of control over the situation, and this was further exacerbated by a lack of information or, for one participant, contradictory advice. Paul and Helen attempted to rectify this situation, which for them was compounded by distance, by choosing one person - the district nurse - to act as their key contact person.

A rapid deterioration in a person's condition can overtake both the family and the health care professionals, exposing gaps in the delivery of care. This was what happened to Pauline, who was called to the family home by her mother because of problems with her demented father. It was a late night experience which left Pauline feeling helpless:

We got the care team out ...//... he wasn't going to bed and there were a guy and two girls and one of them was a student and they

left the talking to her, the student and she got him into bed...//...and we said that this frequently happens but he gets up again. No, no that wasn't going to happen. Oh I remember this, and they were standing up to go and down he came again...//...they got him back to bed and were gone by five past eleven...//...And after that there was nothing, and he got up again and he was off again but there was nothing left after that (3:1:8).

Trying to cope with a situation over which the caregiver has little control, and which is further compromised by a health system which is fragmented and inadequate, can lead to feelings of abandonment for the person attempting to be supportive of, and make decisions for, their elderly relative. Betty's poor experiences with the hospital in which her mother was a patient meant that she felt compelled to visit frequently to ensure that her mother was being well looked after. Interactions with staff only served to reinforce her feelings of isolation and loss of control:

... and she had three little pots of bran sitting on her table and so I trotted out and said to the staff where is my mother's dinner?...//...they said well that is what she ordered...//...I said couldn't you get her some sandwiches or something. Oh we are too busy and it is meal time. By the end of ten weeks I was absolutely exhausted and then they said to us that Mum would have to be discharged home...//...they weren't sure until the day

she actually went out whether she would be hospital care or rest home care (5:1:5 & 6).

Feelings of anger, which resulted from a perceived loss of control by the family caregiver, may change over time to bitterness and scepticism directed at the health care system. For some participants, as well as coping with the alteration in the quality of their relationship with their elderly loved one, their experiences with health care providers left them feeling marginalised and alone. In spite of the restructuring of the health care services, New Zealanders still have faith in the welfare state and the quality of care it provides - it remains part of our collective psyche. To have this belief undermined through personal experience may leave the person feeling uncertain and vulnerable in what is an already stressful situation.

Although participants had poor experiences, and at times things seemed out of control, it did little to deter their commitment to care for their elderly relative.

Commitment to care

Caring arises from love. If a person loves another then they will care about that individual, and will relate to them in a particular way. To care about someone is to overcome self interest, to transcend ourselves. The feelings of loneliness, guilt and grief - themes which have emerged in connection with the process of relocation and which are discussed later - only exist

because the family member cares about their aged relative. Yet nowadays the term care has been de-valued. So many individuals and groups profess to have this quality (van Manen, 1990). Rest homes and geriatric hospitals are collectively termed residential care, and nursing is called the caring profession, yet what is really meant when a person says that they care?

To examine caring from the participants' perspectives is to go beyond the public and publicised notion of care, to connect with an essential attribute of our humanity. The care displayed to each other by members of a small group such as a family has been termed cover care (Verschure, 1980 cited in Boddy, 1985) This type of care encompasses a range of relationships, is direct, emotionally warm, intimate and fulfils a range of needs and demands. Betty, in discussing roles within the family, provides an example of this type of caring:

...and when I came back from overseas, Mum had very carefully stored everything (laundry) up for six and a half weeks because she did not feel safe enough to give it to my sister, because she did not know how it would return and I know this to be true (5:2:3).

For Betty, caring for her mother meant ensuring that her laundry was done and that she always looked presentable, something which she knew was important to her.

In cover care the roles are interchangeable and based upon reciprocity. For some of the participants the physical and emotional support provided during the relocation process was reimbursed financially by the elderly relative. Alternatively, participants expressed the notion that they were only doing what their relative had or would have done for them when the need arose. Reciprocity and interchanging of roles existed but were occurring over an extended time frame - past experiences of being cared for by the now elderly relative engendered caring on the part of the family member during the present relocation process. This loyalty based on a shared history is illustrated by Bill who had looked after his wife who suffered with Alzheimers disease:

...you can't walk away from it, well you can but you shouldn't walk away from it...//...you have to remind yourself over a long period of time that this is not the woman that you married, you know it is a complete change but at the same time it is still the woman that you ... I got married in 1953 so it is a long time, so you still like to think that provided things don't get much worse you can still do a job of sorts (2:1:21).

This ability to care is not innate - the emotional and physical requisites arise from socialisation in early childhood. The person develops an awareness of, and concern for others' needs and of societal expectations about appropriate ways to respond to those needs. The care participants displayed towards

their elderly family members illustrates the way in which, as human beings, we make sense of the world and react appropriately in a particular social context. Their caring encompassed physical and emotional aspects - the caring for and caring about the elderly person. It was only when the family member could no longer cope physically, and/or the environment was no longer suitable for their elderly relative, that they decided to relocate them into formal care. This does not infer that their caring had diminished or ceased, but rather that it had taken another form.

With the distancing from direct caregiving which occurred with relocation, participants adopted the role of advocate on behalf of their aging family members. People acted as a buffer between their elderly loved ones and the health professionals to whom they had relinquished direct care. For Paul and Helen this involved arranging for Paul's father to have a glass of beer in the evening, something which Paul's father felt uncomfortable about asking for himself. For Fred, advocacy entailed providing information about his wife's care. For others, the role is more demanding, as illustrated by Betty:

And we said to the geriatricians who came please take her off that (drug) and they refused. So we had to pay \$200 as a family to bring out a private neurologist to get her off the medication, so she wouldn't break a hip and so that she could retain some control and some dignity, so that she wouldn't be incontinent all the time. And I am not very forgiving of this particular geriatrician for that and if I

know other families are going through that I don't hesitate to say my piece (5:1:18).

There is a social expectation (Ade-Ridder & Kaplan, 1993), supported by government policy, that caring is woman's work. This is deemed to be particularly so when the woman is single and has no dependents. This notion and the resulting pressure to conform was identified by two of the women participants. One of these participants had even considered moving back to the family home to look after her father because of his increasing confusion. Although each of the participants provided care for their loved one in different ways, the quality of care and commitment to the caring role was evident in all the interviewees regardless of gender. What was an issue for those participants who were in paid employment was the difficulty in working and, at the same time, attempting to be supportive of their relatives during the relocation process:

I went in there one day at meal time. I was trying to work and then to drive in there and that was really quite a physical effort, but that is what you do, that was my mother...(5:1:5).

The idea that there can exist mutually exclusive worlds encompassing family and work is a myth. With a growing elderly population, and the majority of adults choosing or having to be in paid work, the ability of families to care long term for their elderly is compromised. Even the relocation process itself

- the need to take time off from work to discuss their elderly relative with health care professionals and to visit suitable facilities - proved to be stressful to some degree for those who were working.

Caring for each other is part of family life. What was remarkable about the participants in this research was the quality of the care that they provided for their elderly relatives during the relocation process. For Fred this involved acknowledging the effort that would be required of him to support his wife, making plans in advance of how he would achieve this and listing these tasks:

...I am not quite sure of the particular stage but I consciously realised that when dealing with a disease, and it is a disease, of which the powers tell you that there is no cure, I realised then that it had to be 100%, in other words it had to be a project whereby it had to be number 1, number 2, number 3 and that was going to be it (1:1:9).

The care and support provided by the family members for their elderly relatives was given without hesitation. There was no conscious decision to care - it was not an issue that was even considered. The participants willingly invested their energies in caring. This degree of loyalty can best be described as commitment - a commitment to care. In making such a commitment, the family member with the primary responsibility for caring for

their aged relative, assumes a role which is stressful and may be a lonely one.

CHAPTER SIX

THE RESEARCH OUTCOME - PART 2

The themes discussed in this chapter are loneliness, guilt and grief.

Loneliness

Alone, alone, all, all alone,

Alone on a wide, wide sea!

And never a saint took pity on

My soul in agony

(Coleridge cited in Chatto & Windus, 1978, p.19)

In the above excerpt, Coleridge captures the feeling of desolation and turmoil that can result from isolation and subsequent feelings of loneliness. Man, by nature, is a gregarious animal. So, for most of us to be alone is to be lonely, to possibly feel frightened and rejected. As suggested by Weiss (1980), the experience of loneliness is being without some definite needed relationship(s). It is a disruption in relationality - the interactions that we maintain with others in a shared interpersonal space. Entering into and maintaining relationships is part of our humanness. It is something that a person does because of their background, the public and shared information which they have been exposed to from birth, as well as their innate ability to unconsciously make sense of the world and to act appropriately in a social context - the culturally skilled habitual body. To form relationships with

others enhanced the chances of survival for our ancestors - those who did not do so, did not always survive (Weiss, 1980).

Loneliness may occur due to social isolation, usually the result of geographical uprooting, or emotional isolation when a person loses someone to whom they were emotionally attached to. The lonely person misses their loved one and misses being loved. The days can become empty when there is no one to share life's joys and burdens, with and there can be sadness for a way of being that no longer exists. Fred, after his wife was admitted into care, expressed his sense of loss and the need to confront the situation to cope. Occupying his time in a deliberate attempt to overcome his feelings of loneliness seemed to him to be merely avoiding what was a reality:

That was like living in a vacuum for the first two or three weeks because it did take that kind of time...//...Also, I was reluctant to take the advice of well meaning friends around me, and including my own family, to get into things, the obvious things, the bowls, well golf if I am up to it, anything that I can do...// ...to get into things for the sake of getting into things almost made me some sort of a coward and I wouldn't face reality if I did that kind of thing (1:1:5).

The experience of loneliness is pervasive in contemporary society - the consequence of social isolation, the dominance of the nuclear family unit, greater mobility and the anonymity that is part of urban living. We feel comfortable discussing subjects which would shock our Victorian forebears, yet find it easier to attach blame to the lonely person rather than examine the processes which have given rise to their situation. To acknowledge loneliness is taboo. It is almost as though there is a fear that loneliness may be contagious. Or perhaps it is that loneliness is a reminder of the human condition, that we are born to be lonely. We come into this world alone and that is how we shall leave it. "Loneliness is one kind of 'dying' that most of us learn about sooner or later" (Elliot, 1988, p.55). Life is a tension between the loneliness of isolation and the vulnerability of connection. The process of admitting a family member into care can make explicit the limitations of our contemporary existence:

I think it is pertinent to mention that we live in a retirement home, so I'm in my own in a unit, so that meant that I didn't have the normal recommendation of physical activity in the sense of getting out and doing the garden and doing kind of work around the place that one would have if they had their own home, so that was another little thing (1:1:5).

For Fred, what had once been viewed as an advantage - a low maintenance home unit - now had its drawbacks as he coped with life on his own. For

many elderly people, isolation from the rest of the community only becomes an issue when they are confronted by the loss of their spouse, either through death or admission into care.

Loneliness also has a corporeal dimension to it. Lack of social interaction can blunt our responses to others. The lonely person may lose their spontaneity and confidence in relating to people, seeking human contact not because of any particular affinity or attraction but rather to assuage the feelings of loneliness. There is an apprehensiveness and intensity about the lonely person which is often physically apparent to others. Being lonely may also contribute to an increased awareness of the person's own bodily presence. One participant, whose wife has deteriorated rapidly in the last three months, mentioned that he felt there was not a lot he could do for her and how that makes him feel lonely. He also now has the opportunity to look at himself and is realising that he is becoming physically frailer - a situation which makes him feel uncertain about what the future may hold.

Few individuals will go through this life without experiencing what it is like to be lonely. Yet people hesitate to admit that they have been or are still lonely, and are too quick to forget or downplay the impact loneliness had or has upon their lives (Creagh, 1995). It is forgotten in the past as though to acknowledge it somehow lessens us as a person, makes us more vulnerable. This temporal re-defining of past loneliness allows us to cope with something which threatens our well-being. Yet the present affords no

such sanctuary, for unlike grief, a present loneliness borne of emotional or social isolation does not diminish with time, because it involves the ongoing absence of a cherished figure rather than traumatic loss. The spectre of loneliness stretches ahead into the future as the loved one cannot be substituted for by another. To cope with this, the lonely individual may change their standards for appraising their situation so that they conform to the shape of a bleak reality.

The environment may also evoke a sense of loneliness and abandonment. A strange place and stressful situation heightens a person's awareness of being alone and helpless. The following is Betty's description of her mother's discharge from hospital - a place in which Betty felt alienated and unsupported:

So I went out and asked where my mother was and she was sitting in the day room in a high little chair ...//...There was no offer from anyone to take her down...//...so with a wonky back, a desperately distraught mother and me no better, I pushed her into the lift which of course had stuck and nobody helped and so I had to give it a final shove into the lift with my mother holding on to her three bags and a walking stick (5:1:11).

Even the familiar can seem strange and routines pointless when a loved one is no longer there and is not coming back. For Bill, behaviours which once provided structure in the relationship, now served to highlight his loneliness:

And night times of course, a bit of ... a big king size bed and you go in there and you are on your own. I am not saying I found it hard but at the same time it is a period of time you have to get used to it, put it that way...//...cooking for one sometimes I say what the heck do I do it for you know. That sort of thing but when she was here you know I knew because I wanted to make sure she was physically alright (2:1:10 & 11).

Whether loneliness is the the result of physical separation or emotional isolation, it is not a socially acceptable condition. Those who experience loneliness usually suffer in silence, their feelings of isolation compromising the sustaining and/or forming of new relationships. The feeling that life has no longer any purpose can be a precursor to depression. Compounding the feeling of loneliness is the knowledge that it is self generated, that the decision to relocate a loved one into care has created the situation in which the caregiver now finds him or herself. Add to this the stressful nature of making such a decision, and the possible resistance on the part of the elderly person and/or other family members, and it becomes apparent why participants identified guilt as a theme associated with the relocation process.

Guilt

For the family member assisting a loved one into residential care, there may exist a feeling of guilt. Guilt - the feeling that one has done something wrong which needs to be remedied - is a socially constructed emotion. To feel guilty implies that a person has an understanding of social values and norms, and appropriate ways in which to right the wrong that has been committed. It is about relationality, about transgression, debt and reparation. Guilt is a social emotion which can function to ameliorate emotional upheavals which may threaten the group and as such, involves a person in ongoing appraisal of self and other's thoughts and actions (Barrett, 1995). Because the definition of guilt includes reference to the committing of a moral offence, a sin or crime (Collins, 1985), there is a metapersonal dimension. Guilt may involve more than a transgression of the human social order. For those with religious convictions it may compromise their relationship with the absolute Other, God.

These inter and meta personal underpinnings of the emotion of guilt combine to strongly influence human behaviour in a number of ways. There may be a tendency to take responsibility for preventing bad things from happening; a belief that one has control over negative events; a propensity to empathise with others; and a desire to honour personal and moral commitments. One participant identified how she felt guilty about not moving back to the family home to help her mother take care of her confused father.

Another expressed relief that their decision to place their father in a rest home had been vindicated because of how much he was now enjoying life:

That is sort of difficult to separate what you would like to do and what you think is best for Dad...//...it is very comforting to see that we did the right thing because I am sure if he had still been in his house, even if he was coping living there, he would still be lonely. He has got through all that (4:2:2 & 9).

Within a relationship, feelings of guilt may serve several purposes, namely stimulating relationship enhancing patterns of behaviour, and redistributing emotional distress within the dyad, with the guilt making the transgressor feel worse than the victim. But, what happens when this cannot happen, when the partner is unable to rectify the situation as is the case when a spouse places a loved one into care due to physical and/or mental deterioration? This unresolved guilt may lead to feelings of anger and hostility or possibly depression (Zahn-Waxler & Robinson, 1995). Alternatively, the person may make some other attempt at reparation, as Fred did when he took his wife out of residential care after four months and managed to look after her at home for a further year. When his wife was re-admitted, Fred felt he had done all that he could and that there was no reason to feel any guilt:

You look at those words again, don't feel guilty about not feeling guilty. If you don't feel guilty again don't worry about it, you shouldn't feel guilty (1:2:1).

Yet a feeling of ambivalence, even failure may exist, and this is something the person tries to resolve:

There are times you think well I put her in here, I wonder if she might have been better off at home. And, of course, that is just outside the realms of reality...//...that the professional people in a reputable private hospital can't do anything about that deterioration is an answer in itself (1:2:2).

Because there can be no true resolution to the situation, the person may be left in a kind of limbo.

Unlike loneliness, which has an instinctive, biological basis (Weiss, 1980), the ability to feel guilty is an acquired thing. A new born baby is unable to feel guilt. Socialization to conform to certain values - to care for our aged, to support our marriage partners in sickness and in health - and to experience empathy (human concern), is a necessary prerequisite for feeling guilty. Transgression of these social mores, and the subsequent feelings of guilt, features strongly in the human psyche, as is reflected in our mythology, folklore and literature which transcends both time and culture. For the adult,

feelings of guilt are an instantaneous and non-reflective interpretation of a situation - our embodied intelligence - based upon socio-cultural norms instilled since birth.

A person may feel guilt retrospectively, coming to terms with a situation which they did not fully understand at the time. This happened to Bill who was unaware of his wife's illness and therefore made no allowances for her sometimes unusual behaviour. A person may also experience potential guilt, avoiding a situation which they know will make them feel guilty if it should become a reality. This was the case for Betty, who chose a care facility which was close to her and her sister because close proximity of family was important for her mother's well-being:

We knew that she would be very close to two of us and that would be very important for her so that she didn't feel deserted. I just ... I just could not have lived with that (5:1:9).

The affect of guilt, and the associated emotion of shame, can be evidenced in a corporeal way. As with loneliness, the person experiencing guilt may be inhibited and apprehensive in his dealings with others, actively seeking an opportunity to right the wrong. Wallbott & Scherer (1995) note that cultures, usually those found in the West which value independence and individuality, emphasise guilt and, consequently the importance of reparation. Cultures in which collectivism is valued view guilt and shame as separate entities, with

an emphasis placed upon shame. Rather than seeking to make reparation, such cultures have developed and ritualised the concept of shame, recognising that there are different types which may be displayed physically by averting the eyes, blushing, covering the face and the avoiding of social contact (Wallbott & Scherer, 1995).

Sometimes a particular environment may induce feelings of guilt. Visiting several rest homes made one of the participants realise how different his spouse was from the people in the places that he had visited. He could not imagine placing her into residential care, even for a short term stay, because she may have become distressed at the behaviour of the other residents:

The contrast of what Mary still was like...//...I just couldn't see her going along with all those people and making all funny noises and dribbling and whatever...//...Well she isn't like that at all...//...and to put her amongst those people (2:2:5).

Guilt functions as a regulatory mechanism in social interaction in that it may lead a person to behave in such a way as to ameliorate the effects of a previous transgression. For those who experience guilt associated with relocating a loved one into care, a sense that adequate reparation has been made may be difficult to achieve, for it is not a situation which can be reversed. The solution may lie in finding ways in which the family member

can feel that he or she has done all that is within his/her power for the loved one, and that social expectations have been fulfilled.

Grief

The subject of grief has become a fashionable one. Books have been written and seminars organised to help people cope with their experiences, particularly the death of a loved one. Yet, do we cope in our everyday lives any better in dealing with grief, whether it be our own or somebody else's? Displays of grief, like discussions about loneliness, make many people feel uncomfortable, for they are a reminder of our own experiences, real or potential. In a society which has become fascinated by the pursuit of happiness and the illusion of attainable perfection (Parker, 1987), the emotion of grief remains marginalised.

Grief is about loss - to perish or destroy (The Concise Oxford Dictionary, 1988) - and in life there is the potential to experience many losses, whether it be the loss of a loved one, loss of a way of life, loss of a physical or mental ability or the loss of a treasured possession. The loss of something valued makes us lesser in some way - our wholeness or integrity is breached and we are vulnerable. Because, as humans, we are capable of love - human concern - we inevitably will experience loss and subsequently grief, for grief is the price of love. If we love somebody then we risk losing that person - a curtailment of the lived relation we maintained with that individual. This may be because of death, or because their feelings for us have changed, or

because of the onset of illness, as in the case of a person with Alzheimers where the capacity to love is diminished or lost.

The grief process is often portrayed as comprising a series of stages, with different terminology and steps being employed by different researchers. Kubler-Ross (1969) identifies five steps: denial, anger, bargaining, depression and acceptance. Denial is a powerful mechanism. It can act to protect an individual from a situation which they find untenable, as Pauline illustrates when discussing her mother's response to her father's diagnosis:

One thing with my mother was that she was absolutely terrified that it was Alzheimers and for some reason when it wasn't Alzheimers and it was multi-infarct syndrome, it seemed to make it better for her...//...There is a stigma attached to it and if people dare mention Alzheimers she would say 'It's not Alzheimers.' The result is the same of course (3:1:8).

Removing one's self physically from the situation may also help the person cope with an emotionally draining experience. Betty found that physically getting away helped her cope with her mother's ongoing health problems, which she found depressing:

I said I have got to go, I have got to get away and have a complete break and so I went off to Europe. And I think if I hadn't

done that I would have joined the rest of the carers in the funny farm (5:2:2).

This time-out provided Betty with the opportunity to distance herself from the situation and come to terms with her grief over the changes which had occurred to her mother.

Because grief can be overwhelming, some of the other participants, like Betty, developed ways in which to cope with their emotions. Two people compartmentalised the process as a way of being able to adjust to the changes which were occurring. Bill spoke of how he managed to cope with his wife at home and during the relocation process:

I put it at the back of my mind...//...I believe it is one of the reasons I got through all these difficult times, compared to some other people...//...I found myself being able to do that sort of thing (2:2:14).

Pauline talked about how she coped with her father's mental deterioration and his inability to recognise her:

I think I had all these feelings fairly parcelled up, you know you can part with love and be fairly sort of matter fact about the whole thing (3:2:6).

Although people develop ways of coping with their grief, the work of mourning does not have a neat and timely progression. The person may continue to experience or re-visit any of the emotions that are part of grieving. New grief may bring to the fore unresolved sorrows from the past. And there can be grief for what might have come to be in the future, as the following discussion between Bill and his wife's doctor illustrates:

So I asked him about overseas trips and his answer was the more unfamiliar the surrounds are the more confused she is going to get. In other words don't go...//...And I was extremely disappointed because you know that is what we had worked for (2:2:14).

Because grief is usually associated with a dramatic loss such as a death, it may not be recognised in those who experience it during the process of relocating a loved one into care. What happens when grief is not seen to exist, when it is hidden and not publically recognised? The admission of an elderly person into residential care may be viewed by many people as a source of organisational and financial strain for the family involved, but very few other people perceive the underlying grief of members that surrounds the demise of what was previously an independent and integrated family unit. Betty describes what it was like to pack up her mother's things after she was admitted into residential care:

Absolutely ghastly, mostly depressing...//...we asked her what particular things she wanted keeping...//...all her special things are in our homes...//...If she ever wants to see something in particular we tell her where they are or show her, take them and show her (5:3:6).

One participant displayed his grief in a physical, yet probably subconscious way by sighing during the interviews, a behaviour associated with mourning according to Parker (1987, p.7), who noted the words of a person who had experienced the recent death of a relative: "Sighing. We sighed all the time. It lasted for ages. Weeks and weeks".

People may find their culture in this particular situation offers little comfort. There may be no ritual to mark the loss and no permission to grieve. The person helping to relocate their loved one responds accordingly, knowing intuitively that mourning would be deemed inappropriate by their peers. In interactions with others, the person down plays the event, the result of instantaneous, non-reflective interpretation of the situation. Doka (1989) refers to this experience of unrecognised loss as disenfranchised grief. The person may also doubt their right to grieve, compounding the problem by self-disenfranchisement. And, because there is has not been a traumatic loss as would be the case with a death, it is difficult for families with people in care to resolve their grief and come to accept the situation. To cope with this, many families make the decision, whether consciously or

unconsciously, to discontinue or minimise the visits to their elderly relative who is in a facility.

The word process is an accurate descriptive term to associate with the experience of grief, for it implies it is an ongoing emotional journey to which there may be no end. The experiences of the participants support this. As suggested by Parker (1987), given the opportunity, a person may round off the sharpest edges of their grief and learn to live with the loss - a changed person.

CHAPTER SEVEN

THE RESEARCH OUTCOME - PART THREE

The themes discussed in this chapter are abiding hope, making meaning and interpersonal relationships.

Abiding hope

Loss of control, loneliness, guilt and grief are themes which are evident in the phenomenon of relocation - themes which would indicate that the process can only be a stressful and depressing one for those experiencing it. Yet, hope was also evident in the stories of those who participated in this research. To hope is to have a belief in the future based upon past experiences. Hope is generated at the interface of these two temporal states, it is a creation of the present. I have used the term abiding hope because of the meaning of abiding which is something which is enduring and permanent (Collins, 1985). As all the participants retained hope for their elderly relatives it seemed a fitting definition.

Hope has little to do with the realisation of what is hoped for, it may exist even when the specific thing hoped for proves impossible to achieve. One participant had hoped that, if the health professionals could control his wife's inappropriate behaviour, he may have been able to take her home. They had not been able to achieve this, yet he still retained hope and chose to keep his wife's belongings:

I thought well I'll give the place a good tidy up now in terms of my wife's clothes and her knick knacks...//...I must organise a family kind of conference...//... and I think no, no, no that is just saying that is the end. May be it is but it is not for me to say it is, so we just leave it the way it is (1:2:6).

Hope in the face of despair involves humility, patience, non-acceptance and active waiting (Nowotny, 1979). Active waiting implies action, doing something to achieve what is hoped for and possibly fulfilling that hope. For Paul and Helen, their insistence that Paul's father be relocated into care, proved to be the right decision and their hopes were fulfilled:

He is certainly happier now and he is sort of happier week by week. He has re-established all his old hobbies. He has made new friends...//...So actually he sounds quite busy, busier than he has been for ages (4:2:8 & 9).

This does not mean that hope is a constant, for there is always the possibility of despair. Within the scope of the human experience there exists a dynamic tension between hope and despair. To despair is to be in a state of hopelessness. At times, when circumstances overwhelm a person, a feeling of despair can dominate, as illustrated by Fred in his comments about his wife's deteriorating condition:

There are times when she has an attack whilst I am there and you have got to be, what shall I say, very stubborn in your beliefs that there is any possibility left of doing any thing about it...//...I think she will see me out and when I saw her today, I just feel it doesn't really matter whether she does or she doesn't, that is the way you feel, you know there is no end to it (1:2:14 & 15).

Unlike hope, despair is paralysing. It immobilises the person, they become transfixed, a bit like the way people who looked on Medusa were turned to stone, according to Greek mythology. Despair is the result of a desire for the perfect - the absolutizing instinct (Lynch, 1979). This search for perfection is a concept which has already been discussed in the section on grief. As an idea, it is based on a faulty premise - that perfection exists and is attainable, when in reality it does not and never will. For those in perpetual despair the only way out is either to regain hope or to commit the ultimate act of hopelessness, suicide. To hope is to be able to retain a positive attitude in the face of life's misfortunes rather than to attempt and fail to attain the non-existent ideal.

To love someone is to have hope for that person and their future, an act of human concern. Love and hope are motivating emotions for relationality. Conversely, interaction with others provides the person with meaning in life, a reason to be. A person who has hope reaches out to others. They exhibit authenticity and direction, something which is observable in their physical

presence. The person admitting a loved one into residential care often has hope for that person and for their future. The hope is abiding even when the focus of that hope may alter radically. Initially, Betty had hoped that her mother would make a good recovery, and she made plans accordingly:

We thought that there was a possibility, once the swelling had reduced, that she may regain some level of functioning and we wanted to keep her home safe for her, so we put my niece into the property...//...Mum knew her home was there, all her possessions were there, that everything was safe (5:1:4).

However over the next six months, Betty's mother deteriorated to such an extent that she required hospital care. Her quality of life is now very poor and she often expresses a wish to die. Because of the change in circumstances, this is also Betty's hope now. This experience illustrates another attribute of hope, namely that the hoped for event - in this case death - may be something which would be deemed a negative outcome in other circumstances. Yet when life's possibilities are increasingly diminished, hope transcends self and the lived world to extend beyond the finite and the mortal.

Each of the participants retained hope for their loved one. For some, the focus of that hope changed with the passage of time, as did the intensity of the emotion. Yet an abiding hope remained. To be able to hope is a human

attribute which has a metaphysical basis. It is because the participants retained hope that they were able to make meaning out of the stressful experience of relocating a loved one into care.

Making meaning

At some stage in our lives we are confronted by the fundamental dilemma of human existence - what is life about? Is there a point to our being here in time and space, is there meaning in the experience of the lived world? Or, is it purposeless and random with the only absolute being death? As with hope and despair, there exists a dichotomy between a meaningful life and a purposeless existence. The reality for each is determined by that person's interpretation of their lived world.

As social beings, we look beyond self to others to provide us with a purpose in life, a reason to be. We make decisions about how we will spend our time, where and with whom. Being able to make and exercise these choices provides us with a framework for existence which we imbue with meaning. So, what happens when patterns of relating with others change, when a loved one is no longer able to live independently in their own home, and when the future appears to hold little promise for that person? The decision to relocate a loved one into care occurs because there seem no other options. As was noted by one institutional administrator: "No one's first choice is a nursing home" (Smallegan, 1985, p.364). It can be difficult to find anything positive about the process of relocation.

Yet the participants in this study did manage to make meaning out of what was happening to them and their loved ones. Indeed, the more traumatic the relocation process was the more important it appeared to be for participants to glean something positive out of the situation, to reframe their experiences in an attempt to gain some sort of emotional equilibrium.

Fred and Bill's spouses both suffer from Alzheimer's disease. Fred knew that his wife's condition would deteriorate, so they decided to enjoy the time that she had with the family by doing things which they would not have done if they had not been aware of her diagnosis:

... for example at that particular time we were subscribers to the philharmonic orchestra, all the shows that the opera society ran, the Mercury Theatre, Eden Park sports facility...//...this involved having the family to share in doing this and to that extent that meant that I had a quality of life...//...and we would have family to help in terms of transport or going with us which would not have happened if Harriet had not had the disease. So I have got to recognise that there is another side to the coin (1:1:9).

For Bill, the knowledge he gained in caring for his wife has been re-directed into helping others who have relatives with the disease. He regularly attends meetings of a local Alzheimers support group and has connections with the national body, ADARDS.

Two of the other participants who are health care professionals utilise their experiences of relocation in their work with the elderly and their families. Betty, who is employed in a large rest home and hospital, describes it in this way:

My experience is unique to me and their experience is unique to them, but there is some common ground and I can help them with the process that they are going through even if I obviously do not know in detail their personal experience. So, the way I have coped with it is to detach and to use it as a positive learning curve rather than a destructive experience but I know for a lot of people it can and very easily is a destructive experience (5:2:6).

In reaching out to others these participants are demonstrating human concern, indicating by their actions that people matter. The cultural mores which people develop from birth, will have influenced the way in which these participants responded to other families' experiences of the relocation process. At the same time this interaction provides a sense of support for these people themselves, giving meaning to a situation which may still have negative connotations.

As with hope, the focus of making meaning or sense of the relocation process may change with time as the situation alters for the family member and their aged relative. What does not change is the indelible impact the

relocation process has upon the caregiver and the need to attach a positive meaning to this experience.

Interpersonal relationships

Relocating an aged relative into residential care changes irrevocably the relationship between the family members and that person. The alteration in dynamics may be subtle, as occurred with one family in which the decision making was gradually relinquished by the elderly person. Or it may be more pronounced, as Betty illustrates when discussing her mother's decreased cognitive functioning:

...the other thing that is very hard to cope with is that physically your parent is alive, and emotionally, and in almost every other way, most of them is dead and you are caring for somebody who has a habitus of your relative, of your mother but really she is not there any more, and that is very hard (5:1:21).

Compounding these changes in the relationship between the family members and their aged relative is the awareness by both parties of the difference between living in one's own home and residing in residential care. Despite attempts to personalise the institutional environment, the lack of privacy and control experienced by the resident in such settings may be evident to his or her relatives. Conversations may become stilted, and there may be a lack of spontaneity in the interaction as family and the elderly

person try to adapt to the new impersonal surroundings. Time may seem to drag during such visits, and some families never feel comfortable in the residential care environment. Subsequently, the number of visits often decreases, further compromising the relationship between the family and the aged individual.

Because of the stressful nature of the relocation process, the family member responsible for admitting their relative into care may turn to a variety of sources for support. In the first instance it is usually other family members and friends who are called upon to provide assistance. Bill illustrates this when he talks of the help he received from these two groups when his wife deteriorated markedly over a period of three years:

...I talked to a lot of people. Last year I went for the first time since 1979 to the country of my birth for a month - I had to get out of here and I have got a sister in one city and a brother, much younger brother who lives in another city and I spent sort of half the time with each. And of course they were extremely interested in how things were going...//...and we talked an awful lot about it, I had a lot of very late nights, or early mornings...//...and up to a certain extent that is what happens here in New Zealand. I have got two couples that over the years have supported me enormously, I never would have survived without them (2:1:6).

These relationships provide the caregiver with a safe environment in which to reflect upon their situation. With such support the person feels more comfortable when making decisions. There is validation of the family member as a human being and as a carer.

Not all relationships may prove to be so positive or supportive. The stress of relocating an aged relative into care may bring to the fore old hurts and resentments which may exist within the family. The response to Betty's request for help when their mother suddenly became ill, clarified for her the relationship with her brother and sister-in-law:

...my brother was on holiday when Mum had the stroke and it took four days of constant effort on my part to try and find him to get a message to him and tell him what had happened and he drove up to Auckland to be with me...//...and my sister-in-law said "You have no idea how difficult it was for me wondering what was happening to him when I was down there with three children." And I said: "Haven't you any idea what it was like to see my mother in that state?" And I just wanted my brother. And I don't ask now if I have anything to tell him about Mum, I tell him directly.. (5:1:16).

For the family member the process of relocation can act as a catalyst for the development of new relationships with support groups and health

professionals involved with their aged relative. Fred relied on information and help from his local Alzheimer's support group in caring for his wife prior to her admission into care:

...and it got to the point whereby when something new came along, with the benefit of attending support groups pretty faithfully and listening to other people who were further down this same road that I was, with that kind of knowledge I almost then seized on something new in terms, of well there must be some way of getting over that, and how do you do it, and that would lead you to asking for advice (1:1:10).

Relationships with support groups and health professionals tended to intensify as the time for admission into residential care became imminent. For all the participants, the quality of the relationship with the formal caregivers had a profound influence on their choice of institution and their ability to feel comfortable with their decision to relocate their loved one into care. Pauline was attracted by the people who ran the secure unit where her father was admitted and, as a health care professional, was also comforted by the familiarity of the surroundings:

The two chaps that run the place there were...it had a vibrancy about it, there were things sort of happening...I mean it was clean, it was tidy but people were doing things and it sort of felt

good...//...they were both from psychiatric backgrounds, that also helped. There were also men around in the kitchens and helping there and your Polynesian workers, all of which I am used to (3:2:4).

As with family and friends, relationships with health professionals did not always prove to be positive. For some of the participants, the lack of a cohesive approach, with no health professional taking overall responsibility for coordination of the relocation process, did little to enhance the relationship between the receivers and providers of care. And a lack of communication between the parties only compounded this, as Betty could testify. Without the benefit of a family conference, Betty's mother was discharged into her daughter's care at short notice. Betty, who was not well herself, then had to take responsibility for transferring her mother to a private hospital - a task which left her physically and emotionally exhausted.

The way in which an individual copes with the experience of relocating their loved one into care may be enhanced or compromised by the quality of their relationships with those around them. Because none of us are islands, we depend on others for their love, encouragement and support to make meaning of our lives and to validate our existence.

CHAPTER EIGHT

DISCUSSION

Review of the study

The aim of this study was to uncover the meaning people attached to the phenomenon of relocation. I feel the use of a phenomenological approach has allowed me to achieve this goal. In turn, I have been able to use the participants' experiences to suggest ways in which nurses can enhance their practice in this area.

The nine themes, which emerged from the data gained from the five participants, give insight into the lonely and stressful nature of the relocation experience for the families who took part in this research. Yet it was also evident that there were positive dimensions for the participants.

Relocation is a journey which has a distinct beginning, which I termed the turning point. However the nature and depth of feeling expressed in the interviews suggests it does not have a clearly defined end. The change in family dynamics that occurs when a person transfers into a care facility, and the lack of flexibility in the way in which we cater for the needs of the elderly and their families, means that often people learn to tolerate rather than accept the situation.

The phenomenon of relocation has come to be because of the way we now live - residential care on the scale it presently exists, was neither an option nor a requirement for previous generations. It is ironical that relocation, a product of our contemporary society, seems to be so poorly managed. In a world which enjoys an ever increasing level of technological sophistication, we appear to have difficulty in addressing issues which are critical to human happiness and well-being.

The degree of social change which has occurred in the last three decades means that, although a family may live in a community, interaction between the family and those around it may be limited. We often do not know our neighbours well, nor do we have the time or inclination to find out about them. The increasing anonymity of suburbia can mean that, when an elderly relative requires increasing support, there are few options available. Family members, who may not be living in the same house or even the same location as the person requiring care, are left to resolve the problem as best they can. It often becomes the responsibility of one person - usually a spouse or daughter - with the possibility that that individual may experience increased isolation and the ensuing stress of having to cope alone.

Social expectations that a person, if able, should be in some form of paid employment, and that families should take care of their aged, can result in a dilemma when an elderly family member is no longer able to cope independently in the community. This situation arose for one of the

participants who contemplated leaving the workforce to look after their increasingly more dependent relative. However, the lack of financial support given to those, whether family or otherwise, who care for the aged made this impossible. A desire on the part of a family member to care for an elderly relative is often thwarted because of the financial realities of the situation. Consequently, one participant placed their family member into care, although for a time, she had attempted to continue to work and meet the needs of her aged relative - a task which many would find unattractive, and with which they could be ill equipped to cope.

The lack of support within the community and workplace for people with elderly, dependent family members means that relocation into care is often decided upon because there are no other options. Finding a suitable facility is usually the responsibility of the family with the initial inquiries being done by one person. Being on one's own, in combination with a lack of experience, often engenders feelings of trepidation and uncertainty. This was compounded for some of the participants by their elderly relative's lack of enthusiasm for the proposed solution. Feelings of guilt and loneliness are a natural reaction to a situation which, as a family, is usually borne in isolation. Others often have little appreciation of the grief that the placement of a family member into care may cause. And this lack of support, particularly for the person who has been responsible for the aged person's care, may compromise their ability to come to terms with the situation.

Data analysis revealed that contact with health professionals tended to occur only when the elderly person and their family experienced problems. Support was therefore reactive rather than proactive and relationships between family and health professionals were forged out of the necessity to address immediate problems. It was the families, through concern for their loved ones, who drove the process. This was often difficult to do, for aside from being inexperienced, some of the participants felt that they had little control over what was happening, mainly due to a lack of, or conflicting information.

Although the relocation experience proved stressful, participants remained committed to caring for their elderly relatives and retained hope for their futures, regardless of the focus of that hope or the likelihood that it would be fulfilled. To care and have hope were indicative of the family caregiver's ability to glean something positive out of the situation and to make sense of what was happening to them as a family. As health professionals it would seem helpful to support families in their commitment to care, in sustaining their hopes, and in helping them find meaning in what may be a depressing experience. Yet this study suggests that health professionals have failed to do this well, if at all.

The experiences of the participants in this study indicate that, as a society, we are not supportive of families with elderly, dependent members. Options available to provide care for our aged citizens seem limited. The present

health system, coupled with inadequate social policy - an issue identified by the Prime Ministerial Task Force on Aging, 1997 - seems to only perpetuate the myths that old age equates to illness and that the need for an increased level of care can best be met by formal caregivers in a residential setting.

Health professionals who focus upon the elderly individual as opposed to a person who is a member of a family, can contribute to that family's isolation, negate their needs and overlook the resources that the family may have to offer. Perhaps it is not surprising then that the process of relocating a family member into care seems to have no end, even when that person has lived in the residential facility for some time. For it represents the dislocation of the family unit, a disruption to dynamics and patterns of interaction which have developed over the years. It seems to be an aspect of care which we as nurses seem to have little appreciation of, and even less inclination to address.

There is always going to be a need for residential care and the process of relocating a family member into such a facility will always entail some degree of stress. However the results of this research indicate it is an area of nursing in which there exists great scope to develop a more dynamic approach to practice. Before this can happen we will need to confront our own biases as a profession, for we seem to view gerontology as the poor cousin of more prestigious areas of nursing, and in our practice appear contented to perpetuate the present system.

Limitations

In nursing there has been a perceived schism between knowledge for practice and the reality of practice (Schon, 1983). There is an assumption that research and theory exist to guide clinical performance. Yet few clinicians have availed themselves of research generated knowledge, usually finding that the research they encounter has little to do with the reality in the workplace. This situation has occurred because problems which arise in clinical practice are seldom the subject of nursing research (Pringle, 1989). The areas of interest of the nurse researcher and nurse practitioner have often had little in common.

To redress this imbalance a dynamic relationship between practice, research and theory is needed. Clinical concerns need to become the major focus of nursing research. Knowledge generated from nursing inquiry will promote a theoretical framework to inform practice, which in turn will provide the focus for ongoing investigation. As a research approach, phenomenology, which shares some common philosophical perspectives with nursing is more than a descriptive or interpretive methodology. It is a critical philosophy of action (van Manen, 1990), providing nurses with knowledge which may be used to change the way in which they nurse.

However, although the phenomenological method is consistent with the philosophical underpinnings of nursing, and is useful in the generation of nursing knowledge, this approach, as with all research methodologies, has its

limitations. Phenomenology provides only one perspective on the relocation experience. A broader and more complex understanding of the topic would require other methodologies, particularly those which use multiple data to examine the phenomenon from different perspectives.

In this research the small number of participants - five in total - provides a somewhat limited insight of the lived experience of families relocating a loved one into care. Increasing the number of participants and the number of interviews over time - each participant was interviewed twice within a four month period - would provide a richer and more detailed account. The age range of the participants, their common background and culture - white, middle-class and urban - means that, from a socio-cultural perspective, the study has a narrow base. At the present time most elderly Maori and Polynesian people remain in the community with their families. Yet with greater longevity and increased influence of mainstream society upon Maori and Pacific Islander peoples, this pattern may change. Research into how these families would cope with relocation and their particular needs at such a time could prove to be worthwhile.

Implications for practice

The relocation experience is, in a way, a reflection of public attitudes and social policy regarding the aged. However, this discussion focuses on the results of this study and the implications for nursing practice.

Participants experienced a range of emotions during the relocation process. They had to cope with rapid change, make difficult decisions and forge new relationships. It is critical for nurses involved in the transition into care to understand that, to some extent and dependent upon individual circumstances, the whole family unit is under stress. The nurse needs to be sensitive to the circumstances within the family and respond in a supportive manner to psychological and physical signs of stress and fatigue in family members. Anger, sometimes directed inappropriately at the health professionals involved, needs to be accepted for what it is - a reaction to a difficult situation and not a personal attack on the individual. Before and during the relocation process, it is timely to acknowledge and celebrate the caring that the family has provided for their loved one, as well as their commitment and their effort and to take time to listen to their experiences and be accepting of them.

Because every family is different, identification of the family's values and beliefs, and their inclusion in the care plan are important if nurses are to provide effective care for the elderly person and their relatives. The decision to relocate a family member into care may be difficult. At this time the nurse may be required to provide both a professional opinion and to act as a mediator between the elderly client and the family if there is conflict over the need for residential placement. A supportive health professional who is able to give information is conducive to informed decision making on the part of the client and their family. The ability to make decisions, and to feel

comfortable with those decisions, allows the family to retain or regain some control over a situation in which loss of control may be acknowledged as a problem by some of the people involved. Support for the autonomy of the family unit by health professionals helps family members gain the confidence to be able to explore changes which may be occurring in family dynamics, and perhaps develop links with others who have experienced or are experiencing the relocation process.

Relocation into care does not imply that the family no longer wishes to take any part in caring for their loved one. In the majority of situations, nobody knows the elderly person as well as their own family, and usually there is a very real need for them to continue having input into the care of that aged relative. When an elderly person enters residential care there is the possibility that the family may be forgotten or marginalised as health professionals take over the caring and, perhaps place new emphasis on the aged individual divorced from their social context. A partnership approach to the relationship between health professionals and family members may facilitate continuing family involvement in the care of their relative, decreasing the stress which they may be experiencing at this time and making the relocation process less traumatic. If nurses are to involve families actively in the care of their loved ones, we must be prepared to have our professional decisions about what is in the best interests of all concerned challenged by the family. We must also be prepared to support people who advocate on behalf of their loved one.

The physical absence and emotional isolation which the family may experience at this time of relocation can engender feelings of loss and loneliness. People are often hesitant to admit to feeling lonely. It is as if it is a personal failing. And, because it is not something amenable to cure, many health professionals also avoid the issue and, in doing so, compound the problem. As nurses we need to be sensitive to how the family is feeling, to acknowledge with them that the experience of loneliness is normal and quite common when an elderly loved one has been relocated into care. To make time to listen to a person when they choose to express what it means to them to feel lonely can provide some degree of comfort. Providing an environment which is welcoming, respecting the family's privacy and involving those who wish to be included in the facility's activities, can reduce feelings of loneliness, particularly when it is a spouse who is left on their own at home. For some, assisting in the residential care facility can be helpful for both the person, the aged relative and the staff. Most of us like to feel that we are needed.

Loneliness may lead to introspection on the part of the former caregiver and a feeling that there is now a pointlessness about their life. People need support at times like this. Nurses can help by monitoring each person's physical and psychological well-being, and offering strategies which may prove helpful in decreasing their feelings of being alone. Gaining the courage to change long established routines and to adopt new interests are two such ways which may be appropriate, but should not be rushed. By

acknowledging and sharing our own experiences of loneliness, nurses can build trust and establish a bond with our elderly clients' families.

"Do not feel guilty about not feeling guilty" was a sentiment expressed by two of the participants in this study. Both had spouses with Alzheimers disease who needed to be in formal care. That this phrase was used at all, gives an insight into the pervasiveness of feelings of guilt which may arise when an elderly individual goes into a residential facility. This feeling of being guilty encompasses a sense of wrongdoing, and a need to make reparation. As with feelings of loneliness, people often do not wish to admit that they may feel guilty for making the decision to transfer their relative into care.

Nurses need to be sensitive to how relatives are feeling, and it can be useful to re-visit the reasons for the decision, to re-affirm the choices they made. Professional opinion, where appropriate and given without bias, can also do much to reassure families that their decision making process was sound. Such discussions and the willingness on the part of nursing staff to explain to other family members about the person's need for care can do much to alleviate tension when the relocation process does not have everyone's approval. Opportunities to have a continuing association with their aged relative may reduce feelings of guilt. This participation also discredits the notion that relocating a loved one into residential care is nothing more than 'putting them into a home' - out of sight, out of mind.

Unlike loneliness and guilt, feelings and expressions of grief have become more publicly acceptable in recent years. Nurses learn about the grief process, yet possessing this knowledge does not imply that we cope any better when we are confronted by grieving relatives. Grief is a very real part of the relocation process, and families need to know that it is both normal and acceptable for them to experience grief at this time. Yet, because there has been no death or permanent separation, nurses may overlook behaviour which indicates a grief reaction. Physical appearance such as stooped posture or resigned facial expression, expressions of anger or needing to escape, bargaining based upon sometimes unrealistic expectations, and symptoms of depression are all part of the cycle of grief. For some the grief is never resolved, and for others there is an acceptance of the situation. This new grief experience may bring to the fore old sorrows and disappointments. Nursing acceptance of expressions of grief may also include helping the family come to terms with unresolved past hurts. Nurses need to be aware that some people, particularly spouses of those relocated into care, may need professional intervention or the help of a support group to regain and maintain their mental well-being.

Although the relocation process can be a stressful and disheartening experience for many families, participants in this study all expressed a feeling of hope for the future of their loved ones. There can be considerable variation in the focus of people's hopes, and these hopes may change over time. We need to acknowledge and value hope, however this does not

mean that nurses should remain silent when families cling to unrealistic expectations. Working with the family - by listening, clarifying, reassuring and encouraging - may help them to have a more realistic basis for hope for the future. When an elderly person's quality of life is poor and their prognosis is not good, it is understandable that some family members may experience despair. Persistent feelings of despair may suggest the need for further help, such as counselling or pastoral care, if this is acceptable. Sometimes, people just need an opportunity to talk and have someone listen. The nurse's ability to listen and to identify positive aspects within the situation can also help to minimise these feelings. If family members trust the nursing staff and know that their elderly relative is safe, comfortable and well cared for, it is easier to cope with feelings of despair.

Aligned with the experience of hope is the ability of people to make sense of, and find meaning in, the relocation process. For some there is a strong desire to help others. Participation in support groups can provide a vehicle for this to happen, with both the person and others benefiting from the contact. A difficult situation may be re-framed to become an achievable challenge. Some, however, may need an opportunity, and encouragement, to identify any positive aspects in what they are experiencing. For people entering into residential care because of their increasing frailty, time with family members is precious. It is important that the care facility is conducive to family gatherings and the celebration of special family events. Sometimes

families can take the time to do things together that they may not have considered in the past. Nurses can encourage this family interaction.

Relocation may alter family dynamics. It can be a time when old alliances end and new allegiances and relationships are formed, both within and outside the family. Staff need to be knowledgeable about possible support groups and facilitate contact by the family if they wish. Diversity within the nursing team in terms of age, gender and ethnic mix, gives an opportunity for families to identify and relate to a staff member with whom they feel most comfortable during and after their elderly relative's transition into care.

Recommendations

The following recommendations result from this study.

- 1. Nurses, both in the area of gerontology and in nursing education, need to collaborate to formulate a vision of how the profession is to meet the needs of elderly New Zealanders and their families.*

The nursing profession needs to address the lack of knowledge of, and the negative connotations associated with caring for the aged, which appear to exist within nursing. In designing nursing curricula in both the undergraduate and postgraduate programmes, we need to revise how we perceive and care for our older citizens. Courses and workshops, based on current research should aim at developing gerontology as a speciality valued

by the profession. Complementing this educational initiative is the need for the development of clinical pathways which should support those who have an interest in the care of the elderly and their families. Such career pathways would offer encouragement for nurses contemplating specialising in this area of nursing

2. Care of the elderly needs to be based upon a philosophy of health and well-being.

At present care of the aged employs a simplistic approach aimed at curing, if possible, or minimising the symptoms of illnesses and disabilities which can affect the elderly. However, people age differently and, therefore have diverse health needs. Rather than focusing on increased frailty and disease which may occur in the aged, there is the need for a more comprehensive approach in the form of a service aimed at maintaining a high level of mental and physical wellness in the elderly population. Apart from addressing the physical concerns of people and their families, such a service could offer other assistance such as networking by older adults to achieve particular goals, legal and financial advice and retirement planning. Based in the community for ease of access, the emphasis would be on health promotion and providing appropriate care to meet individual requirements. The need for care, rather than chronological age, would determine eligibility.

3. Care of the elderly needs to focus upon the family as the unit of care with an emphasis on the aged family member.

Time is needed to develop a rapport with an elderly person and their family. Establishing community based gerontological nurses who regularly monitor the health of elderly persons is one way of offering care and support not only to the aged individual, but also their relatives. Knowledge of the family and the elderly member, accumulated over time, promotes a more holistic and individualised approach to care and can enhance the development of a trusting relationship between the nurse and the clients. This in turn provides an environment which is conducive to discussion about options for the future, whether this be continuing to care for the person in the home or a residential facility. The nurse can provide information about how to choose a facility which will meet everyone's requirements. If such a need arises, admission into formal care becomes a planned, gentle transition supported by a health professional who has had an ongoing relationship with the family and who has shared the experience of caring for the elderly family member within the home.

4. The nursing profession need to have input into social policies which have an impact upon the elderly and their families.

If new and innovative ways of caring for the elderly are to be developed, then nurses, with knowledge gained at the workplace, need to be involved.

To achieve this the bodies representing the nursing profession in this country need to identify and foster those nurses with expertise in gerontology who have proved themselves to be innovative practitioners in this area. Such individuals need to share a vision for the future of gerontological nursing in New Zealand, be enthusiastic in the pursuit of this and be able to articulate their ideas from a nursing perspective. Nursing organisation(s) need to seek representation for members of the group on committees concerned with the development of social policy which affects the elderly and should support the group in lobbying those in parliament who have an interest in issues which impact on the aged.

Further research

As a consequence of this study there are many areas for further research - a larger sample and successive studies may provide other insights into the relocation phenomenon. Also, it would be interesting to identify if the experiences of the participants were influenced by where they lived, which was an urban environment. Would people in a small, rural New Zealand community have different insights into what it was like to place a relative into care? What is the experience of relocation like in other countries, particularly those which, like New Zealand have experienced an increase in the aged population and a subsequent growth in the number of care facilities? Cultural beliefs and practices may also influence people's experiences and a similar study within an ethnic minority group could give other perspectives on the relocation process.

Although it is refuted by politicians and health care professionals alike, the elderly, their families and those who care them have little status in contemporary society. The need for residential care for the elderly raises questions about societal values and the distribution of power within the social system - issues which could be appropriately addressed using other qualitative approaches such as grounded theory or critical social theory.

The results of this study indicate that we, as health professionals, could do more for the aged person and their family when it comes time to relocate into residential care. Some of the themes which emerged during the research also indicate a need to examine the wider issues, including prevalent attitudes and social policies which affect the elderly. They are areas that could prove profitable for further study.

Conclusion

A summary of this research has been provided for each of the participants.

The impetus for undertaking this study was my concern for the families involved in relocating an elderly relative into residential care. The results of the research, complemented by discussions with the participants and my own experiences, highlights the incongruity between the lived reality of the situation and the idealised perception held by many health professionals, including nurses.

I hope that the insights gained from this study may contribute to a more enlightened and comprehensive approach to the way in which we care for our aged and their families, for they are not going to go away, and with the passage of time most of us one day will have the experience of being old.

REFERENCES

Ade-Ridder, L., & Kaplan, L. (1993). Marriage, spousal caregiving and a husband's move to a nursing home. *Journal of Gerontological Nursing*, 19(10), 13-23.

Alford, D. (1992). Wellness and health promotion in the elderly. *Nursing Outlook*, 40(5), 221-226.

Allen, D., Benner, P., & Diekelmann, N. (1986). Three paradigms for nursing research: Methodological implications. In P. Chin (Ed.), *Nursing research methodology: Issues and implementation* (pp. 23-38). Rockville, MD: Aspen Publications.

Askew Browning, M., & Hogstel, M. (1994). In M. Hogstel (Ed.), *Nursing care of the older adult* (pp. 406-435). New York: Delmar Publications.

Barrett, K. (1995). A functionalist approach to shame and guilt. In J.P. Tangney & K. W. Fischer (Eds.), *Self-conscious emotions: The psychology of shame, guilt, embarrassment and pride* (pp. 25-63). New York: Guilford Press.

Bauman, Z. (1978). *Hermeneutics and social science: Approaches to understanding*. London: Hutchinson.

Beck, C. T. (1993). Qualitative research: The evaluation of its credibility, fittingness and auditability. *Western Journal of Nursing Research*, 15(2), 263-266.

Benner, P. (1984). *From novice to expert: Excellence and power in clinical practice*. Menlo Park, CA: Addison-Wesley Publishing Company.

Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness*. Menlo Park, CA: Addison-Wesley Publishing Company.

Blau, Z. S. (1973). *Old age in a changing society*. New York: New Viewpoints.

Boddy, J. (Ed.). (1987). *Health: Perspectives and Practices*. Palmerston North: Dunmore Press.

Bonita, R. (1993). Older women: A growing force. In P. Koopman-Boyden (Ed.). *New Zealand's aging society: The implications* (pp. 189-212). Wellington: Daphne Brasell Associates Press.

Burnside, I. (1990). A scarce professional: The geropsychiatric clinical nurse specialist. *Clinical Nurse Specialist*. 4(3) 122-127.

Chatto & Windus. (1978). *The rime of the ancient mariner*. London: Chatto & Windus.

Cohen, M. Z. (1987). A historical overview of the phenomenologic movement. *Image: Journal of Nursing Scholarship*, 19(1), 31-34.

Cohen, M. Z., & Omery, A. (1994). Schools of phenomenology: Implications for research. In J. Morse (Ed.). *Critical issues in qualitative research methods* (pp. 136-156). Thousand Oaks, CA.: Sage.

Collins Dictionary of the English Language. (1985). Hanks, P. (Ed.). London: William Collins.

Cowgill, D., & Holmes, L. (Eds.). (1972). *Aging and modernization*. New York: Appleton-Century-Crofts.

Creagh, T. (1995). *Loneliness: A taboo topic for New Zealand*. New Zealand: Colcrom Press.

Crotty, M. (1996). *Phenomenology and nursing research*. Melbourne: Churchill Livingstone.

Doka, K. (1989). *Disenfranchised grief: Recognising hidden sorrow*. Lexington MA: Lexington Books.

Dreyfuss, H. (1994). Preface. In P. Benner (Ed.). *Interpretive phenomenology: Embodiment, caring and ethics in health and illness* (pp.vii-xi). Thousand Oaks, CA: Sage Publishers.

Elliot, E. (1988). *Loneliness*. Eastbourne: Kingway Publications.

Fitzgerald, R. (Ed.). (1979). *The sources of hope*. Sydney: Pergamon Press.

Friedman, B. (1994). *Fountain of age*. London: Vintage.

Gaynor, S. (1990). The long haul: The effects of home care on caregivers. *Image: Journal of Nursing Scholarship*, 22(4), 208-212.

Gibson, C. (1991). A concept analysis of empowerment. *Journal of Advanced Nursing*, 16, 354-361.

Gilliss, C., Highley, B., Roberts, B., & Martinson, I. (1989). *Towards a science of family nursing*. California: Addison Wesley Publishing.

Gold, D. T. (1991). Late life sibling relationships. *The Gerontologist*, 30(6), 741-748.

Gudykunst, W., & Kim, Y. (1984). *Communicating with strangers: An approach to intercultural communication*. New York: Random House.

Harveth, T., Archbold, P., Stewart B., Gadow, S., Kirsching J., Miller, L., Hagan, J., Brody K., & Schook, J. (1994). Establishing partnerships with family caregivers. *Journal of Gerontological Nursing*, 20(2), 29-35.

Hogstel, M. (Ed.). (1994). *Nursing care of the older adult*. New York: Delmar Publications.

Homans, G. (1961). *Social behaviour: Its elementary forms*. London: Routledge & Kegan Paul.

Johnson, M. (1990). Nursing home placement: The daughter's perspective. *Journal of Gerontological Nursing*, 16(11), 6-11.

Jones, P., & Martinson, I. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. *Image: Journal of Nursing Scholarship*, 24(3), 172-176.

Koopman-Boyden, P. (1993). *New Zealand's aging society: The implications*. Wellington: Daphne Brasell Associates Press.

Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.

Lefcourt, H. (1982). *Locus of control: Current trends in theory and research*. Hillsdale, NJ: L. Erlbaum Associates.

Leininger, M. (1978). *Transcultural nursing: Concepts theories and practices*. New York: John Wiley & Sons.

Leonard, V. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.). *Interpretive phenomenology: Embodiment, caring and ethics in health and illness* (pp. 43-63). Thousand Oaks, CA: Sage Publishers.

Lynch, W. (1979). The absolute enemy of hope. In R. Fitzgerald (Ed.). *The sources of hope* (pp. 36-43). Sydney: Pergamon Press.

Madjar, I. (1991). *Pain as embodied experience: A phenomenological study of clinically inflicted pain in adult patients*. (Unpublished PhD thesis, Massey University, Palmertson North..

Marriner-Twomey, A. (1989). *Nursing theorists and their work*. St. Louis: C. V. Mosby.

Mathew, L., Mattocks, K., & Slatt, L. (1990). Exploring the roles of men caring for demented relatives. *Gerontological Nursing*, 16(10), 20-25.

Nowotny, J. (1979). Despair and the object of hope. In R. Fitzgerald (Ed.). *The sources of hope* (pp. 44-66). Sydney: Pergamon Press.

Oiler, C. (1986). Phenomenology: The method. In P. Munhall & C. Oiler (Eds.). *Nursing research: A qualitative perspective* (pp. 69-83). Connecticut, MA: Appleton-Century-Crofts.

Opie, A. (Ed.). (1991). *Caring alone: Looking after the confused elderly at home*. Wellington: Daphne Brasell Associates Press.

Opie, A. (1992). *There's nobody there: Community care of confused older people*. Auckland: Oxford University Press.

Pallett, J. (1990). A conceptual framework for studying family caregiver burden in alzheimer's-type dementia. *Image: Journal of Nursing Scholarship*, 22(1), 52-58.

Parker, M. (1987). *A time to grieve: Learning to live with sadness and loss*. Auckland: Reed Methuen.

Perlmutter, M., & Hall, E. (1992). *Adult developing and aging*. New York: John Wiley and Sons.

Prime Ministerial Task Force on the Aging. (1997). *Facing the future: A possible way forward*. Wellington: Author.

Pringle, D. (1989). Another twist on the double helix: Research and practice. *The Canadian Journal of Nursing*, 21(1), 47-60.

Reinharz, S. (1983). Phenomenology as a dynamic process. *Phenomenology and Pedagogy*, 1(1), 77-79.

Riemen, D. (1986). The essential structure of a caring interaction: Doing phenomenology. In P. Munhall & C. Oiler (Eds.). *Nursing research: A qualitative perspective* (pp. 85-108). Connecticut, MA: Appleton-Century-Crofts.

Rodgers, B., & Cowles, K. (1993). The qualitative research audit trail: A complex collection of documentation. *Research in Nursing and Health*, 93(16), 219-226.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.

Saville-Smith, K. (1993). The state and the social construction of aging. In P. Koopman-Boyden (Ed.). *New Zealand's aging society: The implications* (pp. 76-94). Wellington: Daphne Brassell Associates Press.

Silver, R., & Wortman, C. (1980). Coping with undesirable life events. In J. Garber & M. Seligman (Eds.). *Human helplessness: Theory and applications* (pp. 279-340). New York: Academic Press.

Schon, D. (1983). *The reflective practitioner*. New York: Basic Books.

Smallegan, M. (1985). There was nothing else to do: Needs for care before nursing home admission. *Gerontologist*, 85(25), 364-369.

The Concise Oxford Dictionary. (1988). Sykes, J. (Ed.). Oxford: The Clarendon Press.

Walters, A. (1994). Phenomenology as a way of understanding nursing. *Contemporary Nurse*, 3(3), 134-141.

Woods, N., & Catanzaro, M. (1988). *Nursing research: Theory and practice*. St Louis: C. V. Mosby.

Van Manen, M. (1990). *Researching the lived experience: Human science for an action sensitive pedagogy*. London, Ontario: The Athlone Press.

Walbot, H., & Scherer, K. (1995). Cultural determinants in experiencing shame and guilt. In J. Tangney & K. Fischer (Eds.). *The psychology of shame, guilt, embarrassment and pride* (pp. 465-487). New York: Guilford Press.

Weiss, R. (1980). *The experience of emotional and social isolation*. London: MIT Press.

Wright, L., & Leahy, M. (1989). *Nurses and families: A guide to family assessment*. Philadelphia: F. A. Davis Company.

Zahn-Waxler, C., & Robinson, J. (1995). Empathy and guilt: Early origins of feelings of responsibility. In J. Tangney & K Fischer (Eds.). *The psychology of shame, guilt, embarrassment and pride* (pp.143-172). New York: Guilford Press.

APPENDIX A

A STUDY OF FAMILIES' EXPERIENCES OF ASSISTING A MEMBER INTO RESIDENTIAL CARE OPEN LETTER

Dear Sir/Madam

I am a Registered General and Obstetric Nurse completing a Master of Arts in Nursing and Midwifery through Massey University. To meet course requirements I need to complete a piece of research. I have had wide nursing experience, but my area of interest and present employment is in the care of the elderly. In particular I am interested in the affects on families and on family dynamics when an elderly person moves into residential care i.e. a hospital or rest home.

My research will involve studying the experiences of people who have had a relative, or some one that they are close to or care for, who has gone into care in the last year. You will need to have been actively involved in assisting the person's move to the hospital or home and be willing to participate in taped interviews, the length and number of which will be determined by the amount of information which you have to contribute.

The tapes and the transcriptions will be kept confidential. They will be given to you at the end of the study, if you wish, otherwise they will be destroyed after a five year period. Names and settings for the research will remain confidential - the written study will focus upon common themes emerging from the interviews. The purpose of the research is to provide knowledge which will be of benefit to nurses who work in residential care settings, thereby improving the standard of care for the elderly and their families who use these facilities.

If you believe that you fulfil the criteria and would like to know more about the study, I may be contacted through the Principal Nurse Manager of the facility, or directly on (09) 5346747.

Yours faithfully

Annette Stewart

APPENDIX B

A STUDY OF FAMILIES' EXPERIENCES IN ASSISTING A MEMBER INTO CARE INFORMATION SHEET

My name is Annette Stewart and I am completing a Master of Arts through Massey University. To meet course requirements I am doing a study of family experiences in assisting a member into residential care. I am the sole researcher. I may be contacted at home on (09) 5346747 or at work on (09) 6308430. My supervisor is Jo Ann Walton from the Department of Nursing and Midwifery, Massey University, Palmerston North. She may be contacted on (06) 3504326.

The study examines what it is like for families or individuals who are close to or care for an elderly person, to make the decision to relocate that person into residential care and to describe what the relocation process was like for them.

You are asked to:

Participate in a number of interviews of approximately one hour each. The number and duration of the interviews will depend on the amount of information that you have to give. The interviews will be taped, but should you request it at

any stage during an interview, the tape recorder will be turned off. The interviews will take the form of a conversation, so there are no right or wrong answers, just your experiences as you choose to tell them.

Decide with the researcher the venues, dates and times which are acceptable to you.

Sign a consent form prior to the taped sessions which gives your permission to be interviewed for the research.

You may expect that:

The taped interviews will be confidential, only myself, my supervisor and the person transcribing the tapes will have access to them and the transcripts. Tapes will be coded using a pseudonym, not your name. Names of other individuals and organisations will also be assigned pseudonyms. All such information will be stored in a locked filing cabinet.

You will receive a transcript of each of your interviews before the next meeting with the researcher. All tapes and transcripts will be destroyed at the end of five years following the completion of the study unless you choose to exercise the option discussed in the following note.

In the event that you should choose to retain tapes or transcripts of your interviews, I will in consultation with you, delete any information which may threaten the privacy and anonymity of a third party.

If you take part in the study you have the right to:

Refuse to answer any particular question, and to withdraw from the study at any time. At your request any information which you have provided will be deleted from the study and destroyed.

Ask further questions about the study that occur to you during your participation.

Provide information on the understanding that it is completely confidential to the researcher. All information is collected anonymously, and it will not be possible to identify you in any reports that are prepared from this study.

Be given access to a summary of the findings of the study when it is concluded.

APPENDIX C

A STUDY OF FAMILIES' EXPERIENCES OF ASSISTING A MEMBER INTO RESIDENTIAL CARE CONSENT FORM

I have read the information sheet, understand the study and have had the opportunity to ask questions and had them answered to my satisfaction. I understand that future questions I may have about the research or participant's rights will be answered by the researcher.

I understand that I have the right to decline to answer any question and may withdraw from the study at any stage without having to justify this decision or incur any penalty. If this should occur I can ask to have any information which I have provided deleted and destroyed. I understand that the information that I shall provide will be kept confidential.

I voluntarily consent to participate in this study under the conditions set out in the information sheet of which I have a copy. I agree/do not agree to the interviews being taped.

Signature of the participant:

Name:

Date:

APPENDIX D

A STUDY OF FAMILIES' EXPERIENCES OF ASSISTING A MEMBER INTO RESIDENTIAL CARE PROMPT SHEET

I am interested in what it is like for families helping to relocate an elderly relative into residential care. This sheet is designed to help you think about experiences which are relevant to the study and which I will ask you to describe during the taped interviews.

There are two key questions which I would like you to consider:

Describe what it was like to make the decision to relocate a relative into care,
and

what did the relocation process mean for you?

During the interviews I would like you to share all the thoughts, perceptions and feelings you can recall until you have no more to say about the two events.

Although the above are key questions, it is hoped that the information that you give will lead to further discussion, providing a comprehensive account of your experiences.

Remember there are no right or wrong answers, just your experiences as you choose to tell them.

APPENDIX E

A STUDY OF FAMILIES' EXPERIENCES OF ASSISTING A MEMBER INTO RESIDENTIAL CARE NON-DISCLOSURE FORM

Non-disclosure of Information

Typist

I _____

agree not to disclose the name of, or any information that would lead to the identification of the participants in the research study being undertaken by Annette Stewart. The audiotapes, transcriptions and computer disks will not be made available to anyone but the researcher and her supervisor and will be kept securely while in my possession. I will not retain copies of the audiotapes, computer disks or transcriptions.

Signed:

Name:

Date: