

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

**CONTINUING-THE-COMMITMENT-TO-CARE:
FAMILY MEMBERS' EXPERIENCE OF BEING VISITORS
IN A LONG-TERM CARE FACILITY**

A thesis presented in fulfillment of the requirements
for the degree of Master of Arts
at Massey University, Palmerston North.

Lia Holloway

1999

ABSTRACT

The purpose of this phenomenological study is to describe and interpret the phenomenon of being a visitor to an older relative in a long-term care facility as experienced by eight family members. These family members were previously their relatives' primary carers in the community. Each family member was interviewed about two months after their relative entered a care facility, and seven of the family members again three months later. Their narratives gave rich descriptions which showed how being a visitor was an integral part of each family member's life.

The study shows that most family members are very committed to continuing the caregiving relationship when they visit their relatives. Emotional commitment is especially high. Family members perceive their visits as benefiting both their relatives and themselves. Their attempts to continue to participate in caregiving, though mostly respected, are sometimes discouraged and, on occasions, seem to be resented by some staff. For this and other reasons family members perceive some lack of control in their interaction with staff and with their relatives. Thus being a visitor is a stressful and yet also a valuable experience to which they learnt to adjust themselves.

Family members sought support and guidance from nurses especially in setting their visiting goals and in communicating with them and their relatives. This was particularly the case with cognitively impaired relatives. Even after routine patterns of interaction had been established, further assistance was needed as the health of a relative declined or their own circumstances changed. A better understanding of family perspectives is important if family roles are not to be determined only by organisational and resident perspectives. Health providers, including nurses, need to appropriately balance responsibilities toward family members and residents to make visits meaningful for both. In turn, family members have knowledge and skills which have accumulated usually over a long time of caregiving from which nurses can learn.

The main theme of this study is continuing-the-commitment-to-care. This is supported by four essential themes: *perceiving-visiting*, *learning-to-live-with-visiting*, *continuing-with-visiting*, *valuing-commitment-to-visiting*.

ACKNOWLEDGEMENTS

Many people helped me to bring about this thesis. I would like to thank the study participants who shared their experiences with me. An understanding of being a visitor from your viewpoint would not have been possible without your generous involvement.

To my family, Daniel, Michaela, Justin, Veronica, Thom, Ian, Mum and Dad, you cared for me when I felt I could not complete my study. Thank you.

To the staff of the institution where I work, I thank you for your support throughout the study.

To Paul Watson who assisted me during the writing of the thesis, sincere thanks.

To my Supervisor, Charmaine Hamilton, who shared with me her knowledge and who encouraged me and kept me motivated, to you I owe my accomplishment, and special debt of thanks.

KEY TO TRANSCRIPTIONS

The following is a key to the presentation of material in the following chapters.

<i>Italics</i>	the words as spoken by the participants are presented in italics
.../...	Text omitted
[]	Researcher's note
()	Researcher's transcribed words
(Pseudonym, Int. p.)	Source of text, indicating pseudonym of the participant, interview number, page number
...	Pause within the original transcription

TABLE OF CONTENTS

ABSTRACT	ii
ACKNOWLEDGEMENTS	iii
KEY TO TRANSCRIPTIONS	iv
CHAPTER ONE:	
INTRODUCTION AND OVERVIEW	1
Background to the study	1
Older people in New Zealand	3
The transition into long-term care	5
The family and long-term care	6
Family nursing	6
The medicalisation of long-term care	8
Visiting in a long term care facility	11
Study setting	12
Nursing practice in the geriatric area in New Zealand	13
Relevance of the study	15
Structure of the thesis	15
CHAPTER TWO:	
LITERATURE REVIEW	17
Current relevant literature	18

New Zealand studies	18
Literature from other countries	19
Aspects of being a visitor	20
The biomedicalisation of aging	20
Chronic illness and disease in older people	21
Assumptions about family involvement	23
Family members and stress	23
Family members and nursing staff	24
Family members in the community setting	25
Family members in the long-term care setting	25
The importance of visits from family members for residents	28
The importance of visits from family members for staff	29
Family nursing	30
Summary and implications of the study	37
 CHAPTER THREE:	
STUDY DESIGN AND METHODOLOGY	39
 Research approaches in nursing research	39
Choice of phenomenology as method for the study	41
The nature of phenomenology	43
The relevance of phenomenology for nursing	45
Research activities fundamental to the hermetic phenomenological method	48
Data collection methods	49
The research process	51
Transformations in the interpretation of text	52
Assumptions of phenomenological research and explicating assumptions and pre-understandings of the researcher	53
Adequacy of the study	55

Trustworthiness of the study findings	55
Ethical concerns	57
Risks to the participants	57
Informed consent	58
Anonymity	59
Researcher ethics and researcher and participant relationship	59
Accessing participants for the study	60
Description of the study findings	60
Presentation of the study findings	62
Summary	63
CHAPTER FOUR:	
PERCEIVING-VISITING	64
Lived space	65
Insider-outsider-insider	65
Loss-of-privacy	69
Perceived-loss-of-some-control	75
Keeping-the-continuity-with-home	78
Summary	81
CHAPTER FIVE:	
LEARNING TO LIVE WITH VISITING	83
Lived relation	83
Learning-changes	84
Learning-to-communicate	88
Learning-to-communicate-with-relatives	88

Learning-to-communicate-with-residents' families	95
Learning-to-communicate-with-health care providers	96
Summary	109
CHAPTER SIX:	
CONTINUING-WITH-VISITING	110
Lived body	111
Adjusting-to-continuing-the-visiting	111
Letting-go-of-the-primary-care-role-but-continuing-with-visiting	120
Summary	128
CHAPTER SEVEN:	
VALUING-COMMITMENT-TO-VISITING	129
Lived time	129
Rethinking-what-is-valuable	130
Planning-for-the-future	141
Summary	145
CHAPTER EIGHT:	
DISCUSSION AND CONCLUSIONS	147
Findings	147
Support from similar research	155
The qualitative researcher and what I learned	158
Implications for practice, education and research	159

Practice	159
Education	162
Research	163
Trustworthiness	164
Limitations of the study	165
Concluding statement	167
 REFERENCES	 168
 APPENDICES:	
APPENDIX A	190
APPENDIX B	191
APPENDIX C	194

CHAPTER ONE

INTRODUCTION AND OVERVIEW

This thesis developed from my wish to explicate the experience of being a visitor to an older relative in a long-term care facility, the way family members think, feel and act when they visit the person for whom they were the primary carer in the community. The synthesis of the thinking, the feeling and the doing makes for a certain manner of being for the family members interviewed, that is stressful and yet challenging and also valued in their experience of being a visitor. I used a hermeneutic phenomenological perspective to explore the lived experience of family members who are visitors to a relative in long-term care. This methodology has meant that my study is not conclusive of the experiences of all family members who visit a relative in long-term care. Yet it can suggest possible kinds of reactions by family members who have comparable experiences of visiting considering the specific social, cultural, political and historical circumstances of the study participants. Understanding acquired from my study may motivate other qualitative research to relate narratives from family members' own viewpoints instead of narratives that represent the views of researchers or other people. The narratives of the experience of being a visitor may lead to shared meanings and to improved understandings for nurse practitioners and educators and so allow nursing practice and education to be more enlightened and, if considered necessary, changed.

In this chapter, the background to the study is discussed. This includes some information on older people, on long-term care facilities and on the study setting. The reason for selecting hermeneutic phenomenology as the research method is also discussed, as is nursing practice and the relevance of the study. The chapter ends with an outline of the structure of the thesis.

Background to the study

Researchers who study the lived experience of others cannot disregard their own experience of the phenomenon being studied. Van Manen (1990, p. 57) holds that "To be aware of the structure of one's own experience of a phenomenon may provide the researcher with clues for orienting oneself to the phenomenon and thus to all the other

stages of phenomenological research". This study uses van Manen's approach and acknowledges that my experiences of the phenomenon being studied "are the possible experiences of others and that the experiences of others are the possible experiences of oneself" (van Manen, p. 58). My interest in the subject of this research grew over a period of years. My experience as a granddaughter of a person in long-term care has given me helpful insight into the experiential narratives of the study participants and has helped to identify the themes and structures of the participants' experiences. Further, I met many family members while working in clinical practice in a long-term care facility. I have observed that nurses may have little understanding of the context of these persons' lives aside from their relationship to the person in long-term care. My wish to discover more about the meaning of being a visitor and its effects on people's lives also derived from my conviction that understanding is vital for nurses to assess need, to make practical treatment plans, to encourage therapeutic relationships and thus to improve the care received by family members and by their relatives.

The present health care climate in New Zealand strongly emphasises consumer involvement and also quality in health care provision. To provide such a service, we need more understanding of the lived experiences of family members of residents in care facilities as well as of residents themselves and of nurses. Many health care policymakers view the role of long-term care as a residual function to undertake when medical care has failed, rather than as an essential and ongoing element of health care (Beck & Chumbler, 1997). This role of long-term care could have negative ramifications for older adults and society. Richmond, Baskett, Bonita and Melding (1995) state that in New Zealand, the cost of long-term geriatric care can be a drain on limited health funding and that service providers need to ensure that public money is wisely spent. However, they also need to ensure that optimal quality of life is available for older people (Richmond et al.). Information from family members on their experiences of being a visitor may give greater insight into consumer needs and wishes and thus help to meet the twin needs of containing costs while providing optimum quality of life for older people.

This study attempts to develop an understanding of the lived experience of family members during actual visits to a geriatric ward. There is research conducted in this area in America, for example, by Bowers (1987; 1988), Long (1997), Kelley, Swanson,

Maas and Tripp-Reimer (1999); in Britain, for example, by Nolan and Grant (1989) and Twigg and Atkin (1994); and in Australia, for example, by Nay (1995; 1997) and Tilse (1994; 1997). However, this study recognises the importance of context and so gives a New Zealand perspective of being a visitor to a relative in a care facility. There are relatively few studies concerning this subject especially in New Zealand, so phenomenological research can be used, according to Oiler, (1986) to help nurses discover what is there in the world, to name it, and to capture some meaning and understandings.

Walters (1994) holds that phenomenology, as a philosophy, is relevant to nursing, especially if a study centres on the phenomena of people's everyday lives, trying to cope with illness or distress. A phenomenological viewpoint can enhance nurses' understanding of the lifeworlds of the people they wish to work with and care for, by emphasising the meaning of the lived experience (Crotty, 1996). Van Manen (1990) considers that other people's experiences and thoughts about their experiences are 'borrowed' so that a researcher can better understand a new meaning or an important dimension of a person's experience. The narratives of the family members in my study reveal the everyday experience of being a visitor to a relative in a long-term care facility. The philosophical underpinnings which guide my choice of method and situate the relationship of the participants and myself as researcher in this study, are discussed fully in Chapter Three.

Older people in New Zealand

Older people are a diverse group of individuals with a wide range of skills, experience, knowledge and needs (Age Concern, 1996). Ageing is complex and varied, and is influenced by life stressors, lifestyles and social support systems (Koch & Webb, 1996). Yet negative ageist thinking is the norm in Pakeha New Zealand society (Maidment, 1996). 'Oldness' is associated with dependency and a loss in status (Maidment). In such a society, older people often acquire low expectations of themselves and when they move from the community into a long-term care facility that devaluing of their role tends to increase (Koch & Webb).

Falling mortality rates leading to increased life expectancy has intensified population ageing in New Zealand over recent decades and will probably continue to do so in the

future (Statistics New Zealand, 1998). Older people were 11.6% of the New Zealand population in 1991 and are expected to be 19% by 2031 (Age Concern, 1996). Their high rates of chronic, degenerative, disabling conditions are the main causes of illness and death and will increase demands on health and welfare services (Statistics New Zealand). In 1996, relatively few people under 85 years of age were in homes for older people, but this rose sharply to over one-quarter among those aged 85 years and over (Statistics New Zealand). As the number of people in the oldest age group rises, the demand for this type of facility can be expected to increase significantly (Statistics New Zealand). It will pose challenges for nurses and shape their contribution to society in the coming decades.

Over the last two to three decades, the health care system in New Zealand has been extensively restructured in order to contain government spending and to encourage people to be more responsible for their health and wellbeing. According to government rhetoric, this is in order to provide a better health care delivery system for people (Age Concern, 1996). Yet many people believe that the changes are occurring for economic reasons rather than for a better health service. Changes to many geriatric hospitals and rest homes in New Zealand include a strong push to both privatisation and provision of a continuum of care, the development of specialist dementia units and more professionalisation of services such as meeting accredited health care standards and adopting quality assurance programs. Such programs have led to a marked improvement in standards of care (Richmond et al., 1995). Unfortunately, some hospitals and rest homes have not yet met these standards or even adopted these programs. Furthermore, there is some apparent devaluing of the skills required to work in the long-term care sector as older people are being increasingly cared for by staff who do not belong to a profession.

Two levels of institutional care for older people are available in New Zealand: geriatric hospital care and rest home care (Statistics New Zealand, 1998). Geriatric hospital care caters for older people who are very dependent and need substantial help with personal care; nurses are on duty at all times. Rest homes cater for a less disabled group. Nursing staff are not necessarily provided, and most residents are reasonably independent in personal care, though all domestic care is provided. Mental confusion, particularly where agitated or disruptive behaviour occurs, or frequent nocturnal disturbance,

together with urinary and faecal incontinence, are the most common reasons that family members relinquish care to institutions (Richmond et al., 1995).

The transition into long-term care

Considerable evidence exists that a move into a long-term care facility is usually stressful for both older people and their family members (for example, Maas, Swanson, Specht & Buckwalter, 1994; Maidment, 1996; Rosenthal & Dawson, 1993; Townsend, 1990). Most older people would prefer to receive help in their own homes if they are unable to care for themselves (Caron, 1997; Long, 1997). Studies indicate that residents in care facilities are segregated from other age groups and have little privacy and autonomy (Sharp, 1990; Waters, 1994). Studies also indicate that positive events, for example, visits from family members can have a powerful beneficial impact on the wellbeing of residents (Engen, 1994; Grau, Teresi & Chandler, 1993; Shultz, 1976, cited in Laitinen, 1993). However, few studies have examined what the meaning of being a visitor is for family members of a person in long-term care. Family members have been relatively ignored compared, for example, to the body of research on long-term care and older adults themselves. As a result, there is scant understanding of how family members experience being visitors to relatives.

Traditionally, the family, especially its women members, has been expected to care for older relatives who are ill or disabled (Bonita, 1993; Kriseman & Claes, 1997; Maas, Swanson, Specht & Buckwalter, 1994; Statistics New Zealand, 1998). Further, research consistently shows such older adults have a strong preference for assistance from family members especially from female spouses and adult daughters (Travis, 1996). However, caring for such older adults can be an enormous burden and may extend over a long period of time. Further, families commonly do not get the support they need from the formal domiciliary support services (Baum & Page, 1991; Bull, Jervis & Maher, 1995). For these reasons, and because of the growing number of older people, their greater longevity and increasing incidence of chronic health problems, as well as changes in the configuration of contemporary families, for example, dual earner couples, delayed childbearing and blended families, more families are facing the need for long-term care for their older relatives. Thus the number of people living in long-term care facilities depends, to a certain extent at least, on such currently dominant cultural attitudes and practices. Simultaneously, nevertheless, the present public policy of ageing in place

makes the option of placing a relative in long-term care more problematic for family members. Further, current government policy demands that a single person in rest home or hospital care has to pay bills from realised assets until they have just \$15,000 left (Sheeran, 1999). This means that many older people have to sell their homes to meet the costs. Currently, continuing hospital level care costs approximately \$985 per week; rest home care \$525 per week (Bedford, 1999). Further still, most people believe that staying at home provides a better way of life for older people by conserving permanence and continuity and it has a monetary benefit in limiting the use of long-term care institutions. Nevertheless, long-term care placement is given consideration as a viable option by many caregivers, especially for relatives with dementia, because caring at home can be so stressful (Dekker, 1999; Long, 1997).

The family and long-term care

Long-term care boundaries were historically maintained by visitation policies that discouraged close family involvement with relatives in long-term care, thereby shifting the family's role to that of observer. Policies today are more encouraging of the family's presence, if not necessarily of their close involvement.

Family nursing

Until recently, scant attention has been given to the family of an older person as a subject of systematic nursing study despite growing recognition of the importance of families in nursing practice (Friedman, 1992). Further, Wright and Leahey (1984; 1994) indicate that while being aware of the relevance of family centred care, nurses still mainly focus on patients. The patient receives care and attention as an individual while the rest of the family will typically remain outside the nursing team, possibly in a supportive role. The traditional hospital-based approach to care by nurses has reflected the service needs of institutions. The centre of concern was the health (or more likely the illness) needs of individuals. Therefore, care was mainly based on the medical model and aimed towards the preparation of nurses able to give care to individual patients. An increasing awareness of the relevance of the family in nursing practice is shown by the growing number of nurse authors, for example, Friedemann, Montgomery, Maiburger and Smith (1997), Friedman, and Wright and Leahey, who are adding to the knowledge base of family nursing.

Family nursing aims to care for the whole family as a unit (Friedman, 1992; Wright & Leahey, 1990; 1994). Wright and Leahey (1989, p.1) state that “nursing considers the family as the primary unit of health care”. However, it may be difficult to identify who is part of a particular family unit. To be effective in this area nurses need to interact with the family unit, regardless of its composition. According to Astedt-Kurki, Paunonen and Lethi (1997) by providing care to the entire family, all members of the family will ultimately benefit.

Thus the primary concern is with the health of the family and with ways nurses are able to facilitate the health of the family. Patients, or residents as they are referred to in my study, are part of the family. A resident's status influences the family who in turn influences the resident's status. Thus when family centred care is provided, the effect of the resident's status on the family is considered, as well as the effect the family has on the resident. So nursing assessments, interventions and evaluations need to include all key members of the family group, with the consent of the resident if possible. By understanding family dynamics and supporting the family unit, nurses can optimise outcomes for residents and for their families.

Family involvement is advocated as a goal in the holistic care of residents with dementia who live in long-term facilities (Anderson, Hobson, Steiner & Rodel, 1992; Long, 1997). Residents with dementia pose a challenge to nurses delivering care as they frequently encounter communication difficulties, behaviour problems and feeding problems. Nurses can readily identify and address physical needs because cues to pain, discomfort and nutritional deficits can often be detected by observation or physical assessment. However, psychosocial needs are less obvious and if residents cannot express their needs, nurses may need to seek other means of collecting psychosocial data in an effort to meet these needs. Incorporating family members and the wealth of information they possess in the care of residents with dementia (hands on experience and personal knowledge) provides a means of collecting pertinent psychosocial data about residents. This would be of much benefit to residents in determining their psychosocial needs.

The family appears to be a major factor in the quality of care of residents. If the family receives support and guidance, family members are more able to contribute to patients'

wellbeing and quality of life (Anderson et al., 1992). Many nontechnical interventions may prolong and enhance the quality of older people's lives (Clark, 1987). These "buffers of old age" are more psychosocial than medical and include such factors as the individual's emotional and cognitive status and the extent of his or her social and familial networks (Clark, p.69). Berando (1985) also emphasises that social and familial networks are very important to enhancing longevity and quality of life. Family members can provide social stimulation with psychological and emotional support to older people. Greater involvement of family members in caring might facilitate a closer relationship between nurse and family member, with improved communication to benefit all. Some of the nursing literature indicates that many family members seek to increase their participation in patient/resident care but are prevented from doing so by the obstructive attitudes of nurses (Laitinen & Isola, 1996). Conversely, Sharp (1990) indicated that most nurses wish to involve family members, though family members express satisfaction with a minimal role in resident care.

Essentially family nursing requires a relationship of mutual respect between family and nurse, however far apart they may be in terms of ethnic origin, educational background or social class (Whyte, 1994). In family nursing both parties are committed to the welfare of the resident but also to the wellbeing of the family as a whole. The situation requires "...prolonged and reliable attention" from the family and from the nurse possibly over some years (Whyte, p.195). It needs to be a reciprocal relationship in which the family can consult the nurse to talk through a problem and come to a decision and the nurse can alert the family to a problem that she or he perceives.

The medicalisation of long-term care

Ageing has been medicalised (Bonita, 1993; Lyman, 1989) and, as well, many long-term care facilities have adopted the medical model to guide their organisational structures, processes and therapeutic programming (Koch & Webb, 1996; Maas, Buckwalter, Swanson, Specht, Tripp-Reimer & Hardy 1994). A medical model of institutional care views residents as 'patients' who need medical and/or nursing care and family members as 'visitors' who are not necessarily seen as important to a resident's wellbeing, let alone in need of care from nurses for their own wellbeing. Consequently, the characteristics of the medical model emphasise the pathology, illness and physical aspects of care rather than function, daily living and quality of life. This viewpoint adds

to the low esteem in which older people may be held, reducing them to objects in beds, and inhibiting understanding of older people as human beings who want to control their own lives. When nurses devalue residents by using stereotypes, they simultaneously devalue themselves. Nurses need to explore ageing in order to extinguish its negative perceptions and instead to emphasise the importance of the individual person's health status rather than their chronological age.

Using the medical model in long-term care also means treatment tends to emphasise the use of drugs to control behaviour and other symptoms. The residents' daily lives tend to be determined by what suits the providers of care, and concerns for legal liability mean the residents' autonomy and freedom may be curtailed to provide added safety and prevent risk, as for example, when physical and chemical restraints are used to prevent falls. Further, for persons with chronic illnesses the medical model often is unsuitable, because there is no 'cure' or medical treatment other than some symptom controlling drugs.

Reed and Bond (1991), for example, report on a study comparing nursing practice in long and short-term wards for older people. In both settings the concept of cure was a reference point by which nurses evaluated their work. However, its seeming inappropriateness in long-term wards led nurses to seek satisfaction primarily from giving "good geriatric care" which was attainable within their own terms of reference (p. 62). This involved investment in rapid and efficient execution of ward routines that precluded the assessment of, and so also the addressing of, the needs of individual residents (Reed & Bond) let alone those of their family members.

Yet the Horsnell Report in New Zealand (1994) recommends changing the way geriatric hospitals and rest homes are run from hierarchical, medical models to a team approach to help reorient staff toward seeing residents not as patients with disabilities, but first of all as valued people with different abilities and interests. Further, current socio-political philosophy in New Zealand promotes the belief that consumers of health care should exercise choice. In association with this philosophy, nursing is undergoing radical reform. The concept of partnership, also referred to as participation, collaboration and involvement between nurses and clients is a key aspect of the reform movement "the new nursing" (Salvage, 1992, p.9). Such an ideology is a central tenet to the

philosophies of individualised care and primary nursing which advocate the sharing of decision making between client and nurse. Nurses focusing on people's holistic needs instead of orienting their care around procedures and tasks, give residents and family members more control over and more active involvement in resident care for greater resident and family member wellbeing.

According to Jewell (1994) research has reported the possible positive effects of partnerships. Partnerships promote personal choice and responsibility for older adults that can result in better health status, quality of life and life expectancy. In contrast to this psychosocial model, the predominant medical model of care for older adults may actually promote disability and erode residents' ability to make health related decisions, so encouraging iatrogenic conditions associated with dependence (Clark, 1987). Thus, according to Cox, Kaesar, Montgomery and Marion (1991) the traditional medical model is wholly inadequate in long-term settings. It is questionable, however, whether the philosophy underlying the psychosocial model is widely expressed in clinical practice. Studies reviewed by May (1990) conclude that nurse-patient interaction is task-oriented, superficial and routinised. Also there is insufficient evidence to support the assumption that patients/clients wish to participate in decisionmaking. Furthermore, many nurses have been socialised within a hierarchical and bureaucratic organisation. The emotional demands of nursing labour within such a context, where nurses may be inadequately supported and lack information and autonomy to make decisions, is not conducive to involving residents and their families in decisions about their nursing care.

The psychosocial model of care, as opposed to the medical model, emphasises the whole person. Resident safety and treatment of disability are important, but the psychosocial model focuses more on optimising functional abilities so that individuals can participate in social activities and have as much independence as possible. Some risks are considered necessary for individuals to maintain optimum function and quality of life. Care is given at the individuals' pace, and activities are guided by the goal of maintaining dignity and quality of life. Though technically the facility may be a hospital, for residents the facility represents their home.

Nurses in long-term care facilities play a key role in caring for people with chronic illness and in helping them maintain quality of life (Funk, Tornquist, Champagne &

Wiese, 1993). Wright and Leahey (1984) stated that nurses can assist families in adapting to chronic illness and can provide essential support to the family system. Chronic illnesses are by definition beyond the realm of traditional medical science which has focused on 'cure' (Funk et al.).

Visiting in a long-term care facility

Family members continue their relationship with their relatives through face-to-face visits. Often it is only through visiting that family members are able to sustain interaction with their relatives (besides phoning or writing). Some families telephone their relatives infrequently, however, because of the problems of having a conversation with many relatives due to poor hearing or dementia. Writing can also be problematic. Visits from family members are of benefit to older people in long-term facilities (Jacques, 1992). Interaction on a consistent basis with family members may lessen any distress of the older people. For older people with memory loss and limitations in communication, visits may reinforce some of the memories which they are losing. Even if those older people do not remember their family members they will undoubtedly benefit if they receive love and positive regard from their families. Nursing staff may also benefit from family members' visits to their relatives. Family members can tell staff about their relatives, such as their wishes and needs, so that suitable care is given to enhance the quality of life for residents.

Many family members have been caregivers in the community for their relative for an extensive period of time before they consider placing their relative in a care facility. Caregiving often becomes increasingly important to caregivers' sense of self as their responsibilities for their relatives have increased (Jacques, 1992). This means that when their relative is institutionalised, there are changes to family members' identity as well as some loss of their role as active caregivers. When a relative enters a long-term care facility, nursing staff assume the everyday care instead of the family members. Family members may then feel outsiders, bereft and shut out. This tends to be primarily determined by the nursing staff's attitude to them and to their involvement in the care facility. The relationship between family caregivers and nursing staff as formal carers is often difficult. In principle, these people need to collaborate so that the residents receive the best possible care. However, research on community care has shown that collaboration between family members and health care professionals is limited

(Patterson, 1997). There seem to be similar problems in creating collaboration and partnership in long-term care settings. This may be because the long-term facilities as the givers of everyday care hold much more power than family members as informal carers. As well, the stresses associated with visiting and the medical model of long-term care tend to proscribe family members' full participation in the lives of their relatives. For partnerships to work there needs to be a commitment to sharing the various aspects of care in a way that suits residents and their family members.

Study setting

I explore the experience of being a visitor within a private hospital providing long-term continuing care and terminal care, as well as respite care, mainly for older people. The hospital is seen as an extension of the local community and the primary health care team, giving local people access to nursing and low technology medical intervention. At this hospital a preadmission assessment is compulsory to ensure the individual can be adequately cared for. On admission, a person's dependency levels are established. Individualised care is planned, though not always delivered, along with reality orientating devices and activities with professional support from residents' General Practitioners and others.

The philosophy of care reflects the personal beliefs of the hospital's management. They developed their philosophy as one that recognised that nurses work with people rather than do things to people. Care is thus centred on the individual and is planned in partnership with the resident and family and other staff. This philosophy can only be practised when staff are committed to this concept of partnership and when residents are given the opportunity to determine their own needs. When this commitment exists, residents and their families maintain control of their lives.

A questionnaire based on activities of living is sent to the potential resident and family. This is followed by a nurse visiting the family to meet the potential resident, to discuss the questionnaire and to make his or her own assessment. The questionnaire provides a focus from which the potential resident and family can state their perceived needs, in a situation in which a trusting relationship is in an early stage of development. Allowing the older person and the family to state their own needs through a questionnaire and at initial assessment means that care can be provided in various ways which is responsive

to the individual situation. The ongoing nature of assessment and emphasis on older people's holistic, social and cultural needs mean nurses also focus on older people's families and their social environments.

I had been working in this hospital as a nurse for five years before I undertook my study so I was conversant with it. However, Field and Morse (1985) consider that researchers should not undertake observations in a place in which they work or have worked as this prevents the collection of valid, reliable and meaningful data. On the other hand, Smith and Heshusius (1986) argue that the claim that data, rather than its analysis and interpretation, can be invalid is rationalist. Such a claim exemplifies a viewpoint based on the premise that there exists an objective reality or external truth for the researcher to discover and which can best be obtained by keeping an objective distance. I did not hold such a viewpoint. Carrying out the research in this hospital enabled me to gain access to the research setting because of the accommodating stance of the nurse managers and medical staff.

Nursing practice in the geriatric area in New Zealand

While this study does not attempt to define the lived experience of all family members who are visitors, it has uncovered some patterns in the responses of eight adults who are visitors, and suggests strategies that nurses and other health providers could consider when working with this group of people. Nurses play an important role in the care of older people within institutional settings and will continue to do so as the population of older adults with complex care needs continues to grow. Registered nurse expertise is required to assess residents, plan and document their care and to supervise formal careworkers. These workers usually have no formal education concerning the needs of older people but they provide most of the 'hands on' care of residents. They are called formal careworkers or formal caregivers to distinguish them from informal caregivers, such as family members of residents who have cared for and may be continuing to care for their relatives. Registered nurses are also required to liaise with residents' families and with other health professionals; participate in quality assurance, manage infection control and health and safety issues; and assist the organisation to meet its goals and objectives. Furthermore, the public today expects nurses to be highly educated

professionals who can work with people in a knowledgeable, ethical and sensitive manner.

Salvage (1992) states that the new climate in health care has the consumers of health care as its focus and nurses as “enablers” rather than as “decision makers” (p.21). Yet many registered nurses working in the field today probably trained in the narrow medical model and bureaucratic institutional mode, which are incompatible with the collaborative, partner role associated with holistic care. Continuing education for nurses is one way to reduce the gap between expanding gerontic knowledge and its application to clinical nursing practice. Besides minimal education in the needs of people requiring long-term care, issues that negatively influence the ability of nurses to adapt to the needs of residents and their family members include inflexible hospital routines, functional institutional environments and a heavy nursing workload. Robertson and Cummings (1996) advise the importance of having enough qualified, caring staff; supportive and competent administration; functional, attractive facilities; a caring, supportive environment; realistic regulations; progressive nurse practice models; and opportunities for educational advancements and career growth. Long (1997) suggests that all health providers working with older people need education on matters concerning ageing, health and illness. Some material on family relationships and family members’ needs after a relative is institutionalised would also be of benefit, such as the importance of establishing effective partnerships with family members.

Nurses in New Zealand face many challenges because of reforms to the welfare state and the rise of a market ideology. The health care system appears to be driven by efficiency and profit margins, and so the people for whom the system exists are in fact unlikely to be of paramount concern. Nurses have a mandate to care which is the moral imperative of nursing practice (Watson, 1985). This imperative is difficult to realise in a health care system that requires increased throughput of clients with little time for nurses to give quality, holistic and individualistic care. Such a system values residents in long-term care facilities as economic units rather than as people. Thus the health reforms may well conflict with high standards of ethical, professional nursing practice which on the whole, the public, as well as nurses would like to see implemented.

Relevance of the study

I contend that to understand more fully what it is like to be a family member who is a visitor to a relative in long-term care requires qualitative interpretive research as well as more traditional quantitative research. Phenomenology allows for the study of people within the setting of their run-of-the-mill experience. The aim of this study is to obtain an understanding of family members' experience of being visitors to an older relative in a long-term care facility. Family members' experience of being visitors embodies personal knowledge that could become public knowledge to enlighten nurse practitioners and educators and, if deemed necessary, could lead to changes in their practices. Thus it is important that nurses appreciate family members' experiences. Through explicating the stresses, challenges and coping of family members, moreover, my study may result in more understanding of what family members think, feel and do when they are visitors in long-term care. Understanding is an important need on which the therapeutic relationships wanted by residents, their families and nurses are based. It may help nurses to assist these clients to live their lives in the way that is most meaningful to them.

The research is timely in view of the increased emphasis on consumer involvement in care and on family centred care in the geriatric setting. While the results of the study will not be able to be generalised, the understanding gained from it may enable nurses to be more attentive and empathetic when working with families. Because of the lack of published data on family members' experience of being visitors to older members in long-term care, this study will contribute data of interest. Future studies of the family's experience of being a visitor to a relative in long-term care based on this study may provide the momentum to develop interventions that promote the quality of family life.

Structure of the thesis

This thesis is presented in eight chapters.

In Chapter One, the background of the study has been outlined and the purpose of the research presented.

Chapter Two reviews the literature containing issues relevant to this study and which generated the knowledge context within which this study was undertaken. The inclusion of the literature continues in the data chapters.

In Chapter Three the selection of the phenomenological method for this study is justified. This chapter also includes a discussion on research methodology, especially hermeneutical phenomenology which follows the work of Heidegger (1962/1927). Van Manen's (1990) approach to phenomenological research is given particular emphasis as his method has guided this study. The way the research was conducted is described, including an outline of the study participants, ethical considerations and methods used to obtain and analyse data.

Chapters Four to Seven describe and interpret the study findings. From the main theme continuing-the-commitment-to-care, four themes evolved: *perceiving-visiting*, *learning-to-live-with-visiting*, *continuing-with-visiting*, *valuing-commitment-to-visiting*. A theme entitles each data chapter. Each theme has a number of subthemes which help to reveal the lived experiences of the eight participants.

Chapter Eight summarises the main study findings, discusses these with regard to the current literature and details the implications of the study for nursing practice and education. The trustworthiness of the study is examined, its limitations are identified, and areas for further research suggested. A concluding statement finishes the thesis.

CHAPTER TWO

LITERATURE REVIEW

This chapter gives an overview of the literature related to being a visitor to an older relative in a long-term care facility. Although there has been increasing research into residents' experiences of long-term care and of their family members' experiences as informal carers in the community, research, especially of an interpretive nature, of family members' experiences of being a visitor in a long-term facility is relatively scarce. In this chapter, the focus is on family members who have been their relatives' informal carers in the community. The family members recount their lived experience through language and so they have spent some time reflecting on their actions in order to share them with another person. There is interpretation (van Manen, 1990) as people make meaning of their experiences to tell another and so the experience as it is told to another has sustained a first transformation (Reinhartz, 1983). In this way experience is able to inform through heightened understanding after the event.

The experience of being a visitor is a topic of relevance for nursing practice, education and research. Nurses working in the geriatric area often do not know what family members experience in visiting a relative in long-term care. Without this information, it is not possible to implement or even plan individualised care for the resident and family. Furthermore, without such information, nurses may function on the basis of a personal value system to determine what the family and resident should do or be in relation to each other irrespective of their needs and wishes. Whereas nurses who have insight and competency could make an invaluable contribution to this aspect of health care.

The purpose of this chapter is to evaluate literature pertaining to the study and also to reveal the knowledge context in which the study is placed. I looked at relevant literature and incorporated it during the entire study. The literature reviewed is mainly by professional people, very little was found in the lay press. There was also a dearth of New Zealand material available. This New Zealand material is reviewed first. Most of the material reviewed was by health care providers-principally nurses, but also some

doctors and social workers. I evaluate that material next, and conclude with a discussion of the implications of the literature for this study.

Current relevant literature

New Zealand studies

A paucity of New Zealand literature was found at the time this thesis was undertaken of the experiences and needs of family members who have been informal carers. Exceptions are Opie's (1991 and 1992) books, Schofield's (1996) study and Patterson's (1997) study, all from the perspectives of social workers. A study by Stewart (1997) on families' experiences of assisting a member into residential care was the only study that I found to have been undertaken by a nurse.

Opie used a qualitative, feminist, postmodern approach to study the everyday lives of 28 New Zealand female and male caregivers. Her books recorded the experiences of the caregivers she interviewed who looked after confused, mostly demented, older relatives at home. These caregivers' comments portray the harsh reality that many of them face. The caregivers' texts provided a range of different caring relationships so revealing a variety of situational, gendered and structural patterns of involvement in caring. Opie suggests that caregivers have been taken for granted and have mainly been invisible. Caregiving is often exhausting and stressful and caregivers can become cut off from former social contacts. However, she also described how caregivers can get some relief by way of hospital intermittent care, home visits from district nurses and day care centres.

Patterson's (1997) master's thesis was prompted by her experience of dealing with elder carers and seeing formal resources available to this group diminishing. Like Opie (1991; 1992), she studied community caregivers and used a qualitative feminist method. Patterson interviewed eleven women caring for older relatives. Her aim was to discover how the women came to be in the elder care role and to explore the impact of this role on their lives. Again, like Opie, major themes throughout her study were the issues of elder care being unrecognised and the isolation of the care role. Other themes in Patterson's study were the lack of choice in becoming carers and the lack of financial remuneration.

Schofield's (1996) doctoral thesis, in contrast, concerned the everyday experiences, including visiting, of primary caregivers once their relative with dementia has moved into a long-term care facility. She used a feminist research approach and interviewed twenty-five caregivers individually over a period of more than a year. She described and analysed the social and psychological forces that encourage disengagement from a close relationship and the strong paradoxical forces that kept these ties intact. She used the word "careguardianship" (p.2) to describe the special phase of caring by family members that she found to mark the period once a relative entered long-term care. Schofield drew on anthropological theory to analyse careguardianship as a time of liminality. Liminality was a transitional phase of being "betwixt-and-between" (p.2). Family caregivers or careguardians entered a time of liminality when they moved between the social positions of home caregiver and past caregiver. Their contribution to their relative's wellbeing was often disregarded by nursing staff because it was mainly imperceptible and outside the commonly accepted definition of caregiving. Nursing staff also gave low priority to family members' own wellbeing.

Stewart's (1997) master's thesis concerned the relocation into residential care from the perspective of families of older relatives. She used a phenomenological approach to interview five people, twice each, to uncover the meaning people attached to the phenomenon of relocation. Nine themes emerged which gave insight into the lonely and stressful nature of the relocation experience. However, the families remained committed to caring for their relatives and retained hope for their futures. Like Schofield (1996), Stewart suggests relocation is poorly managed by health professionals. She recommends that they support families in their commitment to care, in sustaining their hopes and in helping them find meaning in what may be a depressing experience.

Literature from other countries

While there is a serious lack of New Zealand research literature relating to being a visitor to a relative in long-term care, there is, however, a large amount of overseas literature about dimensions of visiting. Similar to New Zealand, nevertheless, there is little about the subjective experience of people who are a visitor to an older relative in long-term care. In the material that follows I place my study in the context of

contemporary research trends and findings and discuss research about the experience of visiting, especially nursing literature and research and other writing which is concerned with the subjective experience of being a visitor. As well, research into other dimensions, for example, chronic illness and disease in older people, community care and family centred care are part of the context from which understanding of the intricacy of being a visitor can advance, while they also have an effect on the nature of enlightened nursing practice. An outline of these dimensions is included.

Aspects of being a visitor

When family members visit their relatives in a long-term care facility they have to deal with the beliefs and practices of the staff. The staff's constructions of old age may well be dominated by the medical model. Family members also confront the reasons for the institutionalisation of their relatives, that is, their relatives' chronic illnesses and diseases. These two aspects related to visiting are discussed next.

The biomedicalisation of ageing

The biomedical construction of ageing affects the way older people are viewed and also affects the organisation and practice of health (Koch & Webb, 1996). Descartes, in his book "Discourse on Method" (cited in Sorell, 1987) introduced a model of the mind-body split which gives a mechanistic perspective of people. According to Wilkin and Hughes (1986) the Cartesian duality implicit in the medical model comes from positivism. A mechanistic view of people is maintained by Cartesian metaphors of the 'machine' and the 'container'. In the machine metaphor, the machine consists of parts which can be examined individually though they are considered to perform as components together. This metaphor seems to be a conceptual fit with the scientific method. There is an emphasis on people as biomedical objects. The container is another Cartesian metaphor in which the body is viewed as a container for the mind and it is in the mind that symbolic representation occurs. These ideas lead to the belief that phenomena taking place outside the container are objective, while those taking place inside the container are subjective. Experience is thus viewed as a subjective phenomenon. Symbols designating the world are constructed in the mind and these manipulations allow the outside world to be brought into internal consciousness by mental processes. Thus structures and functions can be separated and studied.

Gibb (1990) argues that biomedical science together with dualistic thought and the scientific method have affected the way patients understand their bodies and also the way nurses care for patients. The patient becomes a biomedical object liable to medical intervention. It can lead to depictions of ageing which conform to a perspective of humans as machines. This depiction includes the notion that the human machine comes to a standstill when parts wear out. This perspective in health care has been important in specifying ageist attitudes and depersonalisation. The care of older people in nursing is often closely tied to geriatric medicine and to the concept of Cartesian duality. The nursing profession tends to be influenced by the medical model and it has yielded to negative stereotyping of old age by associating it with decay and deterioration (Koch & Webb, 1996). Benner and Wrubel (1989) state that this pathological model puts helpers in a superior position and those they help in an inferior one. They add that to be in need of help means that one is incompetent, helpless or hapless. Thus the pathological model creates categories and labels for people who are ill or disabled which lessen the understandings that nurses may develop, and the model negates the person's history and personal meanings. People tend to adapt to the label and are likely to be passive and not ask for help. Nursing practice in the geriatric area has been, and often continues to be, based on Cartesian duality, a reductionist approach to care, where only basic needs are attended to. In a study by Jewell (1994) nurses perceived that though there were some older patients eager to collaborate in their own care the idea was not regarded as important for older people by the nurses concerned and so this mode of caring was not implemented by them.

Chronic illness and disease in older people

There is a vast amount of literature available on chronic illness and disease in older people and the reasons for the institutionalisation of older people (Happ, Williams, Strump & Burger, 1996; Mattiasson & Andersson, 1997; Nay, 1995; Phinney, 1998). These authors generally agree that people in long-term care facilities are there because they have reached a point in their illness trajectories where they need partial or complete assistance in one or more of the following activities of daily living: bathing, toileting, eating and transferring. Many have urinary and/or bowel incontinence, mental impairment, respiratory, skin and nutrition problems and multiple chronic illnesses. However, Fries, Scroll, Hawes, Gilgen, Johnsson and Park (1997) report comparative statistics representing institutionalised residents in seven nations. They found significant

differences in age and length of stay and in summary measures of physical and cognitive functioning and case-mix. Countries also differ in their homogeneity across nursing homes (Fries et al.). Ikegami, Morris and Fries (1997) also found that care settings differ, making comparisons by country difficult.

There is general agreement among the authors reviewed that chronic illness is a multidimensional experience which involves living with one or more long term, incurable diseases that cause disruption and disability in many areas of human functioning (Corbin & Strauss, 1988; Price, 1996; Shaw & Halliday, 1992). Cameron and Gregor (1987, p. 672) maintain that chronic illness is a lived experience, involving “permanent deviation from the normal, caused by unalterable pathological changes”. As well, illness is a human experience involving loss or dysfunction and is a reality all of its own (Benner & Wrubel, 1989). Chronic illness involves a long-term change in a person’s way of life, and a reevaluation of what they may hope for in terms of function and health (Jerrett, 1994). It often entails managing complex medical treatments or regimens, and the more difficult these become to cope with the greater the likelihood that people will not adhere to therapies (Becker & Maiman, 1980). Bleeker and Mulderij (1992) emphasise the impact of chronic illness on living when they discuss discomfort. They note that in illness the body “loses its silence”, calling attention to itself (p.15). People’s usual habits of disregarding the body become impossible and instead they are obliged to cope with the physical functions and inconveniences in a manner that would seem peculiar and finicky to healthy people (Bleeker & Mulderij).

Some authors add that although the individual is diagnosed with a chronic illness, a heavy responsibility is placed on the family who experiences life with the illness (Newby, 1996; Shaw & Halliday, 1992; Wright & Leahey, 1984). The trajectory of an illness in an individual may be relatively stable or be affected by exacerbations and remissions, however, chronic illness within the context of a family is typified by long-term coping with illness demands adding to the stresses of every day life. In this way, the two-way relationship between the chronic illness and the family may vary. It depends on the specific illness, the stage in individual and family life cycles, coping mechanisms, feelings about the situation, beliefs about the illness, as well as the contextual social, political and economic variables (Shaw & Halliday).

Assumptions about family involvement

There is much research on the experiences and needs of older adults who reside in a long-term care facility, for example, Byrne and MacLean (1997); Daley (1993); Grant, Reimer and Bannatyne (1996); Happ et al. (1996); Koch and Webb (1996). Much research also exists about the experience and needs of family members in their role of informal carers for chronically ill or disabled community dwelling older adults (Baum & Page, 1991; Chesla, Martinson & Muwaswes, 1994; Erlanger, 1997; Long, 1997; Opie, 1991; 1992). However, research, especially interpretive, into the experiences of family members who place their relative in a long-term care facility is relatively scant. Exceptions are Bowers (1988); Chenoweth and Spencer (1986); George and Gwyther (1986); McCarty, 1996; Smith and Bengston (1979). Despite a long-standing interest in the family as a focal point in nursing care, nurses have not accorded a high priority to the experiences and needs of family members with relatives in long-term care. Perhaps this neglect reflects an assumption that following institutionalisation, families cease to be important because paid health providers take on the caregiving role. An additional assumption may be that people in institutions have families that do not care about them or abandon them. Both assumptions belie the findings of some research that family relationships continue beyond institutionalisation and that family contributions to caregiving in long-term facilities are impressive (Friedemann, Montgomery, Maiberger & Smith, 1997; Maas, Swanson, Specht & Buckwalter, 1994; Rosenthal & Dawson, 1993). Various studies have suggested that the provision of formal services to older people in long-term care does not preclude family involvement through, for example, visits to their relative or contact with a member of staff (Ade-Ridder & Kaplan, 1993; Bonnel, 1996; Bowers, 1988; Duncan & Morgan, 1994; Engen, 1994; Friedemann et al., Moss, Lawton, Kleban & Duhabel, 1993; Rubin & Shuttleworth, 1983; York & Calsyn, 1977).

Family members and stress

Research suggests that many caregivers are tense and stressed both when their relatives are still at home with them and when they are in a care facility (Caron, 1997; Chenoweth & Spencer, 1986; Coughlan, 1993; Kammer, 1994; Long, 1997; Pratt, Schmall, Wright & Hare, 1987; Zarit, Todd & Zarit, 1986; Zarit & Whitlatch, 1992). The degree of stress can alter at the transition from community to institutional care and

also during the period in which a relative is in institutional care. However, studies vary concerning the amount of stress experienced by family members when a relative is in long-term care and if it compounds or eases. Ade-Ridder and Kaplan (1993) and Zarit and Whitlatch suggest that family members tended to have a higher level of physical wellbeing once their relatives are institutionalised; conversely Nay (1997) suggests that most family members are pleased to no longer have all the work associated with being the primary carer, but unfortunately stress sometimes grew. For some family members their stress was also related to their relatives' decline in health and other problems which emerged over the period of long-term care (Pratt et al.). These authors add that stress could also be caused by feelings of discontent with the care given by formal caregivers.

The family's emotional reaction to long-term care placement has been described most commonly as guilt and grief (Matthiesen, 1989; York & Calsyn, 1977). In fact, once their relatives was institutionalised some family members experienced increased feelings of guilt (Coughlan, 1993; Pratt et al., 1987) and they experienced concern about their loss of control over the care their relatives received (Caron, 1997; Willoughby & Keating, 1991). Conversely, some studies, for example, Montgomery (1982) and Smith and Bengston (1979) described the relief from the burden of caregiving as a family response to long-term placement which may result in improved family relationships. Cutillo-Schmitter, Rovner, Shmueli and Bawduniak (1996) and High and Rowles (1995) considered that the transition into long-term care can free family members of overwhelming duties and provide 24 hour care for the relatives that would not be possible at home. Gubrium (1991) suggested that family guilt was due to ambivalence relating to feelings of relief that they no longer shouldered the entire burden of caregiving and yet they simultaneously felt the pain of loss. Stephens, Kinney and Ogrocki (1991) found that family members experienced relief in terms of the effect of placement on their own social lives, but they also felt increased emotional distress. Similarly, Johnson (1990) described daughters' emotional reactions as varied and diverse and related to a wish not to upset anybody.

Family members and nursing staff

As stated previously, family members stay involved with their relatives even when they are in institutional care. Kitwood and Benson (1995) nevertheless revealed that the

family members they studied believe that overall their help is no longer predominant for their relatives. Some studies concerning the families of residents in long-term facilities aimed to explain divisions between activities which were primarily undertaken by formal carers and between activities which family members might provide (Rubin & Shuttleworth, 1983; Shuttleworth, Rubin & Duffy, 1982). These studies found that formal carers undertook virtually all the technical activities required by residents, such as the administration of drug therapy. Family members helped in the provision of non-technical activities such as socialising with their relatives and seeing to their comfort. However, other studies since that time have transcended the division of labour and instead reveal how the activities of both sets of caregivers can mesh and how care can be coordinated and combined (Bowers, 1988; Duncan & Morgan, 1994). Family members wished for an effectual relationship with staff. This was to guarantee care of the best standard for their relatives. It was not necessarily to meet any needs of their own. In fact, family members own needs were not really considered in these studies.

Family members in the community setting

Studies on community caregiving show a mainly negative view of caregiving and that, to a significant extent, family members have had their way of life upset and inconvenienced by their obligations to their relatives. Caring for another person, especially one with cognitive as well as physical impairment, can be a heavy burden, although the research shows much variance in the stress felt by various caregivers (Astedt-Kurki, Paunonen & Lethi, 1997; Coughlan, 1993; Jacques, 1992; Long, 1997). Many family members look forward to long-term placement. Yet many others do not do so and this is indicative of the many and complex issues that affect caregiving by family members.

Family members in the long-term care setting

While there is an abundance of literature on family members giving care in the community, there has been far less research on family members after a relative enters a long-term care facility. Discussion on family involvement after institutionalisation has been mainly as an addition to community caregiving and has given a reduced view of this stage of family involvement. Further, the material available tends to give direction to health providers on achieving good relationships with families primarily in order to benefit residents.

The literature on caregiving in the community not only reveals that family involvement is considered to be less relevant once their relative enters a care facility. It also reveals, as does the literature that is available on institutional caregiving, that the support which family and friends still may feel obliged to provide, such as psychological and social, has received far less attention compared to that given to the physical or practical dimensions. Yet family members conceive of their caring as purposes rather than tasks, according to Bowers (1987; 1988). The duties which families perform when a member has a chronic illness especially one where there is cognitive impairment include prevention of harm to the relative, anticipatory care, supervision and physical care tasks (Bowers). Thus undertaking physical care tasks is just one part of caregiving. Laitinen and Isola (1996) and McCarty (1996) also found this to be the case and stress the importance of the relational dimensions of caregiving for families. They add that with the placement of relatives in long-term care, family members have much less say over everyday care, and their chances to give practical help dwindle. The other duties observed by Bowers still need doing, however, as they are important for residents' wellbeing. Laitinen and Isola suggest that being no longer obliged to provide everyday care does not lessen family members' feelings of emotional attachment and involvement for their relatives which have accumulated usually over a period of years. Engen (1994) indicates that effective visiting by family members is more than just sitting next to their relatives. She argues that visiting requires family members to communicate effectively with their relatives where possible, and that the way this can be established is as important as the frequency of visits.

As discussed earlier, the institutionalisation of a relative is very stressful for most family members. Traditional research methodologies are not suitable to study the meaning of institutionalisation and human aspects of it, such as the experience of being a visitor to a relative in long-term care. For example, in Motenko's (1989) study of frustrations and gratifications of informal carers of people with dementia, what it means to experience frustration was predetermined by the researcher and thus carers' stories were circumscribed by what the researcher believed frustration to be.

Vourlekis, Gelfand and Greene (1992) found that health providers agreed that residents and families needed emotional support in coping with institutionalisation. Yet this study

as did many others, seemed to focus more on the experiences and needs of residents than those of their families. Further, family members themselves were not interviewed and as with most studies reviewed, it was the perspective of health providers that was given. Exceptions to this were the studies by Zarit et al. (1986) and Tilse (1997a). Zarit et al. undertook a study of the subjective burden of wives as informal carers following the placement of their spouses. The study indicated that wives reported they received limited support only from health providers. Although the number of persons studied was small, the thought that some family members are isolated and unsupported after placing a spouse should be considered as it is often perceived that the needs of family members are adequately met at the time of and following the cared-for person's admission to long-term care. Tilse conducted in-depth interviews with 18 spouses aged between 62-79 years who had placed a partner in a long-term care facility. An analysis of the interview texts revealed that visiting was embedded in the relationship, role and history of the long-term marriage. Visiting provided a focus for daily life, continuity in history and identity, help with avoiding loneliness, and was a means of expressing attachment to their partner (Tilse).

The studies overwhelmingly show that when families can no longer cope at home they relinquish the primary caregiving role to institutional caregivers. Yet the placement of an older relative in a long-term care facility is often disapproved of by society (Dellasega, 1991). This is related to the notion that home care is "best" and a long-term care facility a "last resort" (Smallegan, 1981, p.282). The growth of an ethos of community care has led to the censure of institutional alternatives as being invariably dysfunctional (Aneshenshel, Pearlin, Mullin, Zarit & Whitlatch, 1995). Yet, as Willcocks (1986) maintains, the case against institutional care is incomplete and is based more on historical failure than a realistic evaluation of current potential. The institutionalisation of an older relative thus is stressful for many family members, as previously stated (Bowers, 1988; Matthiesen 1989; Schultz, Smyrnios, Grbich & Pruchno, 1993). Family members' distress is particularly intense when visiting in the early months after admission (Buckwalter & Hall, 1987) although these authors do not discuss the possible reasons for this. This argues for better understanding of the meaning of the experience of being a visitor to an older relative in order to inform nursing practice and to ensure the quality of this experience. For many people do, and

will continue to, experience the institutionalisation and so very likely the visiting of a relative in long-term care.

The importance of visits from family members for residents

For most people, admission to hospital is stressful. The person is isolated from loved ones and familiar surroundings, perhaps feeling lonely and vulnerable. The literature suggests that the effects on older people can be particularly damaging. For example, Tolley (1997) found that the move to a long-term care facility often stripped older people of self-control and decision-making, leading to feelings of powerlessness and low self-esteem. Life is measured day to day (Tolley). Similarly, Wilson (1997) found that life in a long-term care facility was associated with a loss of independence and threatened the residents' quality of life. This was especially so if their admission had been unplanned. The residents that she interviewed said they made a conscious effort to protect their families by hiding their feelings about admission to avoid causing any worry to their families. Most of her participants added that they very much missed their families and friends. However, some of their distress was alleviated by visits from loved ones (Wilson). Sharp (1990) found that older people spend 80-90% of their time in hospital doing nothing. This, in turn, has been likened to sensory deprivation (Chadwick, 1984) and may be due partly to lack of nurse-patient interaction or attitudes of health providers towards older people. Sharp suggests that family members may here have a role in reducing the effects of these problems by, for example, providing social stimulation with psychological and emotional support for their older institutionalised relatives.

Campbell and Linc (1996) also found that interaction with family (which tends to be most often through visiting) is important to residents in long-term care facilities. Family ties are valued in themselves and provide important links with earlier life experiences (Rowles & High, 1996). In this way residents can retain their former identities and familiar contact with the outside world. Interaction with family is an important predictor of the psychosocial wellbeing of residents (Greene & Monahan, 1982). These authors demonstrated that people visited more frequently showed significantly lower levels of psychosocial impairment. Furthermore, residents whose families visit them regularly receive better treatment from staff (Rowles & High), feel less alone and have more personalised living quarters (Rosenthal & Dawson, 1993). The presence of visitors has

the additional benefit of decreasing the institutional atmosphere of long-term care facilities and increasing the quality of life for residents. When family members are able to provide continuing emotional support to relatives, these residents' survival rates increase (Clark, 1987; Tennstedt, 1992). Whitehead, (1971, cited in Sharp, 1990) contends that patients are more likely to respond to treatment if they keep contact with the outside world through family members and friends.

Thus these studies indicate that for residents, visits from family members are a positive experience. For the family members involved, however, the experience of being a visitor may have a different meaning. Certainly less is known about this experience from the perspective of the visitors.

The importance of visits from family members for staff

The importance of visits from family members for staff was explored in a recent study by Karner, Montgomery, Dobbs and Wittmaier (1998). They found that contact with family members provides information on the resident's prior life, making it easier for staff members to develop more meaningful relationships with residents in their care. The staff interviewed thought that such types of interaction between them and residents resulted in greater satisfaction among family members and residents with the care provided, which, in turn, can lead to greater job satisfaction for staff. Staff also thought that more family involvement with resident care reduced their work load (Karner et al.). In contrast, other studies have found that policies promoting family involvement were not seen positively by staff members. Shuttleworth, Rubin and Duffy (1982) and Vinton and Mazza (1994) have suggested that family contact and participation are often viewed by staff members as interference with their work rather than supportiveness of it. Staff members have distinct ideas about how they prefer to have family involvement channeled (Vinton & Mazza).

In another, but more recent study, Turkel, Tappen and Hall (1999) used a phenomenological approach to explore the experiences of five long-term care nurses whose roles were reconfigured. This was in order to include home-based care as well as institutionalised care and to include more time and opportunity to get to know the older people well and to establish relationships with them. The nurses moved from a narrow focus on residents' immediate physical needs to a broader, more holistic perspective.

This included family-oriented care which made the experience more rewarding for the nurses according to Turkel et al. These authors did not comment on the experience for residents or for their family members.

Family nursing

The increasing emphasis in nursing on individualised care and holism means more nurses working in long-term care facilities are advocating a resident centred orientation (Happ et al., 1996; Wilson, 1997). This emphasis on residents, however, places families at risk of being limited to resource and ancillary caring roles. Most studies imply that families may be viewed as clients and that they may also be viewed as resource persons, but studies emphasise that facility staff mainly view the family as a resource for the care of their relatives (for example, Anderson, Hobson, Steiner, & Rodell, 1992; Buckwalter & Hall, 1987, Rosenthal & Dawson, 1993). Viewing family members as resource persons means valuing families primarily for the contributions they can make to their relative's care. Family nursing, conversely, aims to care for the whole family as a unit (Friedman, 1992; Wright & Leahey, 1990). The prime concern is thus with the health of the family and with ways of supporting the family's health by means of nursing. Older adults are part of a family. Older adults' status influences family members who in turn influence older adults' status (Mace & Rabins, 1992). Thus when family centred nursing care is provided, the effects of the residents' status on the family is considered, as well as the effect the family has on the resident to ultimately benefit all family members. Family centred care requires nurses to respect families' needs and to utilise these people's knowledge and experiences. However, in practice this can be problematic as it requires nurses to move away from the traditional paternalistic approach to care. According to Vosburgh and Simpson (1993), nurses, as the professionals who have the most interaction with family members, are the health providers in the best position to assist families experiencing the illness of a loved one but sometimes nurses lack the skill to do so.

Information on the meaning of being visitors for family members who have been residents' informal carers in the community could help to illuminate the experience and help to develop nursing care in such a way that it will contribute to the wellbeing of the whole family. This could be particularly so if the information was elicited in the early

months after admission as it is then, according to Buckwalter and Hall (1987), that family members' distress is especially intense.

When health providers emphasise the needs of family members of a patient as well as the patient, they are seeing the family member as a client. Some research has acknowledged that family members of institutionalised persons have needs of their own to which health providers should attend and suggest various approaches to meet family members' needs. Montgomery (1982) argues that family members need to be actively served as clients to facilitate sound family relationships. Other suggestions include involving families in care planning, providing specific activities and meetings for family members and instigating practices that make family members feel welcome in the facility. Brody, Dempsy and Pruchno's (1990) study provided evidence of the need for long-term facilities to have a family focus. Attention to mitigating the strains for family members is important for them but also for residents to whom emotional currents flow (Brody et al.).

Most studies focus on the role of the family as a resource and offer advice accordingly. Shuttleworth et al. (1982) contend that a close partnership between families and health providers may rely on the extent of clarity concerning subdivision of their tasks and the extent to which health providers encourage and support family involvement in dimensions of care. Rubin and Shuttleworth (1983) suggest orientation sessions to define the subdivision of tasks between staff and family in five areas: personalising care, monitoring and ensuring the provision of care, clothing needs, grooming and providing reading material. They also advocate that conferences occur from time to time between staff and family.

Smith and Bengston (1979) in one of the first studies considering family relationships following institutionalisation, consider that the role of the family as resource would be improved by the inclusion of children and grandchildren into programs within an institution. They indicate that this could be undertaken through the inclusion of families in activities, instruction in the ways they could give care, and the provision of orientation sessions and education programs. Laitinen and Isola (1996) state that involvement by families could prove difficult in that it sometimes led to conflict with

staff. Shuttleworth et al. (1982) show that some of this conflict derives from uncertainty about whether the family or health provider should take responsibility for various tasks.

The literature confirms the continued participation of families in task performance following the admission of a relative to long-term care. Families participate in care in various ways. They monitor patients and notify nurses when something untoward happens, they carry out tasks, for example, providing comfort measures and offer advice concerning treatment. This conceptualisation of families as resources highlights their substantial contribution to the provision of care for relatives following institutionalisation. Buckwalter and Hall (1987) addressed the need for families and residents, if possible, to share in the caregiving process on a regular basis. They proposed involving family members in the planning of care, as support persons and adjunct therapists within the facility and as community and public relations liaison officers. They suggested that this involvement was beneficial to both the long-term care setting and to the residents as they adapt to this new phase in their life but give no indications as to why this might be so nor do they mention how this involvement might be affecting family members.

Carter (1991), in contrast, found that family members' involvement with nurses was minimal and mostly unplanned with family members usually taking the initiative. Family members' main source of information was the resident, which most found both insufficient and unsatisfactory. Nurses' notes and handover reports showed few references to family members other than next-of-kin and nurses' contact with and knowledge of specific family members seemed to be superficial. Individually, nurses were more perceptive of family members' needs, but there was scant suggestion that the recognised need was necessarily followed by a nursing response. The findings suggest that the needs and concerns of family members were largely unmet because the focus of care was patient centred. Carter stressed the need for nurses to include family members in their plans for total patient care but she emphasised that this was in order to meet the patient's needs rather than to meet any of the needs that family members might have.

In a similar vein, Tilse (1997b) interviewed spouses of residents to explore the purpose and meaning of visiting and the relationships they sought with staff. Her research concluded that many families wished to act as advocates for very dependent residents

but were in a weak position to do so. Reasons included a limited ability to remove the resident from the facility, little knowledge of the facility as an organisation, the potential power staff have over residents' quality of life and visitors' lack of a collective identity which could foster the expressing of group concerns (Tilse).

An earlier study by Tilse (1994) indicated that most of the nursing staff expected spouses to participate in the care of their partner by providing socio-emotional support (82%) and continuing some tasks, for example, care of clothing, transport, feeding (68%). Observations on the units that Tilse studied suggested that their ancillary caring roles tied family visiting to organisational needs and routines. However, most of the spouses interviewed also continued their caring role by monitoring the quality of care and trying to maintain the identity of the partner. They were advocates for their partners as well as ancillary carers. Yet although being formally acknowledged as an important role for families, advocacy was rarely identified by nurses as a suitable activity. Families who acted as advocates were more likely to be described as difficult visitors and as interfering with nurses' roles (Tilse).

Efforts by nurses to enhance the quality of life in long-term care facilities have included increasing awareness of the need to individualise care. However, the mental incapacity of many residents means that their personal histories, values and preferences which need to be considered in providing individualised care remain inaccessible to nurses (Rowles & High, 1996). Conversely, their knowledge of their relative prior to admission means family members have intimate awareness of their relative's life circumstances, personal history, values and preferences (Rowles & High). Such "local knowledge" could enhance sensitivity of decision making to specific characteristics of individual residents (p.20). Rowles and High's research affirms that by assuming various decision making roles, family members invest themselves in a process of individualising and personalising care to maximise their relative's quality of life and maintain links to his or her past. In these roles family members provide the kind of support nurses have neither the time for nor knowledge of residents' life and personality to provide. According to Laitinen (1994) nurses can readily identify and address physical needs. But psychosocial needs are less apparent. Especially when residents cannot express their needs, nurses have to find other ways of collecting psychosocial data in an attempt to

meet these “higher-level needs” (Laitinen, p.75). Family involvement in the care of older people could be one solution in order to benefit residents.

Sharp (1990) found that many family members were satisfied to play only a minimal role in the care of their relatives. She argues that this may be because people in long-term care are there because of progressive illnesses (Sharp). Thus family members’ caring role lacks the reward of seeing their relatives benefit from their care in the recovery from illness. Secondly, family members may suffer from burnout which may cause them to reject their relatives, wishing no further involvement in their care. Mental illnesses such as the dementias may also engender feelings of bereavement in which the family members experience the grieving process of having lost the people they once knew (Taylor, 1987, cited in Sharp). This could lead to feelings of ambiguity towards the relative resulting in family members’ withdrawal from involvement. Studies by Laitinen (1992; 1993) on participation of family members in hospital care were concerned with the involvement of family members of older people and with the assessment of quality of care. The results showed that there was little active involvement by the family members in their relatives’ everyday cares. However, other literature seemed to suggest that many family members sought to increase their involvement in resident care but were at times prevented from doing so (Engen, 1994; Tilse, 1997b). This was sometimes due to the obstructive attitude of nurses.

Studies which advocate the importance of family involvement in long-term facilities also show how this involvement can lead to difficulties. Rosenthal, Marshall and Shulman (1982) explored how families are seen as problematic by staff. They showed that families and nurses do share the overriding objective of facilitating the wellbeing of patients, however, they might view the means needed to reach this objective in widely different ways. These researchers developed a typology of problems that spans from mild to severe.

Bowers (1987) found that priorities differ for family members and staff. Her comprehensive study showed that family members tend to view caregiving as protective and that they assess quality of life by how well staff protect the dignity and individuality of residents. Conversely, nursing staff largely view caregiving as doing tasks for residents and often judge quality by how well tasks are performed (Bowers). In a study

of perceptions of family members of the care received by relatives with dementia, family members were the most dissatisfied with not being asked by staff to help with residents' care (Maas, Buckwalter, Kelley & Stolley, 1991).

Gubrium (1991) discussed families as interlopers and strangers to long-term facilities. This can happen even when they visit frequently, possibly every day for several hours. Family members can encroach on ward activities and routines that otherwise have their own social rationale. They look around and survey the facility for what seems right or wrong. He also described how family members can be seen as potential advocates for their relatives. Although not all family members will want to be advocates, they are in fact at first taken by staff to have a special bond with their relative, indicating loyalty and protection. The vigilance and concern of a stranger together with advocacy, can lead to the interloper becoming a warden of care, a potentially daunting encroacher. Conversely, Karner et al. (1998) found that staff members were generally more satisfied when family members assisted with resident care as it took the residents off the staff's hands for a while.

Although the nursing profession has been interested for a considerable period of time in the family as an important focus for intervention (Whall & Fawcett, 1991) there are few studies on useful clinical strategies for intervening with families. Gonzalez, Steinglass and Reiss (1989), for example, found that there are "few psychosocial interventions focused on family issues, needs and stresses during the chronic phase of illness" (p.70), though the importance of including family members in caring for people with chronic illness is well established (Corbin & Strauss, 1988). There are few studies on supportive and educational interventions for families of residents though some material in the social work literature has described support group interventions to help families manage contradictory and adverse emotions which resulted from placing a relative in a long-term facility (Brubaker & Schiefer, 1987; Cox & Ephross, 1989).

Using observation and interviews with staff, Tilse (1994) explored the ability of long-term care facilities to respond to family needs. She found that there was a strong value placed on family visiting. Unfortunately this was generally not reflected in the provision for family members of staff time and a private place to be with their relative in the facility. Family needs were included or marginalised by roles expected of them, by the

space made available and by the time, attention and attitudes of staff members. Most nurses in Tilse's study described their contact with families as resident focused. A minority (18%) acknowledged the need of families for support but most said they had little time to give it. Senior staff members were more likely to report offering families time and emotional support. Within six units only two programs (a support group and an activity program) were specifically concerned with the needs of families. Yet the study also found that most of the spouses interviewed had feelings of grief, guilt and sadness. As most spent considerable time in the facility, staff were in an important position to offer emotional support and practical assistance (Tilse).

Some authors wrote about the differences in the emphases and viewpoints of family members and health providers. Bowers (1987) would like health providers to understand stress and tension from the viewpoint of informal carers, that is, from the purpose of caregiving activities rather than the nature and frequency of the tasks themselves. Matthews (1987, cited in McLeod & Schwartz, 1992) found that older people are likely to bring their own 'team', consisting of family or other support persons, to negotiate with the health team, thus guaranteeing some control as well as input into decisions concerning them. Matthews suggested that there is some evidence to support the finding that what older people and the family see as problems with living arrangements are redefined by health providers as medical problems and by receiving agencies as management problems. It remains unclear how their various views are accommodated, nor which group has the most impact on the final outcome (Matthews, cited in McLeod & Schwartz).

It was implied some years ago that attention to informal carers has not been accorded a high priority by nurses (Nolan & Grant, 1989). Bibbings (1994) contends that the situation may have improved somewhat, nevertheless she adds that assessments and interventions with family members too often remain arbitrary and subjective and based on attitudes and assumptions of particular professionals. George (1994) states that knowledge of family caring has grown, yet there remains much to learn about the conceptual and operational bases of caregiving research before the factors which affect family care can be properly understood. If interventions to support family carers are to work, then how success is defined will largely depend on how situations are viewed and understood by carers themselves (Schultz & Williamson 1993). Thus to progress nurses

need to centre their conceptual and practical efforts on the “interactive, contextual nature of the caring relationship” (Opie, 1994, p. 44).

Finally, a recent quantitative study by Kelley, Swanson, Meridean, Maas and Tripp-Reimer (1999) concerns family visitation on special care units. These authors discuss the meanings family members attached to their experiences of visitation to relatives on special care units. They found that with the placement of a relative with Alzheimer’s disease on such a unit, the family does not relinquish the caregiving role, rather they take on different roles in relation to their relatives. Further, the authors found that family visitation is a fundamental part of family involvement in the care of individuals with Alzheimer’s disease, as well as special care unit functioning. Within the context of changing relationships with their relatives, family members visited their relatives as a sense of duty to “be faithful”, to monitor care by “being their eyes and ears”, and to foster a sense of family through ongoing relationships and family rituals (p.20). The authors concluded that nurses have critical roles in promoting physical, emotional and interactive environments which foster family visitation on special care units (Kelley et al.).

How the findings of some of the above studies compare with my study is discussed in Chapter Eight.

Summary and implications for this study

The review of published research shows a lack of qualitative studies that have examined, from the family members’ viewpoint, their experience of being a visitor and the way this experience influences their wellbeing. Thus our understanding of visiting is limited. The literature reviewed about visiting has been mainly from the point of view of residents and health providers. A paucity of literature on the experience of residents’ family members who visit, identifies a need for further research, supporting the aim of the present study, to explore the experience of being a visitor to an older relative in long-term care within a qualitative paradigm.

The next chapter focuses on the hermeneutical phenomenological method used in this study to describe and interpret the way the participants experienced being visitors in a long-term care facility.

CHAPTER THREE

STUDY DESIGN AND METHODOLOGY

Phenomenological research is primarily about wanting to know the world in which we live. As such the world's secrets and intimacies that form the experience of the world are questioned and examined. Wanting to do this research becomes a "caring act": we want to know what is most essential to being (van Manen, 1990, p.5).

In Chapter Two I reviewed the writings of others concerning visiting older relatives in a long-term care setting. I showed that there has been little research in this sphere especially from an interpretive viewpoint. Thus knowledge about how family members interpret the experience of being visitors is limited. The prime purpose of Chapter Three is to describe and discuss the reason for the choice of the design and methodology of this study. The chapter begins by examining three research paradigms used in nursing research in order to highlight the worth of the interpretive paradigm for examining lived experience. This is followed by a discussion on my choice of method, the nature of phenomenological investigation, the researcher and participant relationship and the relevance of the method for nursing. Next I discuss premises related to phenomenology, research activities fundamental to the hermeneutic phenomenological method and the research process including data collection methods and transformations. My assumptions and preunderstandings about the participants' experience of being visitors are explicated. This is followed by a consideration of the issues of reliability and validity in qualitative research. Attention to ethical issues related to the conduct of the study is given as well as a description of the study participants and access to them. The chapter ends with an outline of the use of lifeworld existentials as constructs to reflect on lived experience.

Research approaches in nursing research

The three main approaches in nursing research are positivism, interpretivism and the critical theory approaches. Positivism is based on 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 (Cohen & Manion, 1985). Historical, socio-cultural and personal dimensions of a situation are stripped away and subjectivity is viewed as a private and personal reading of reality given to error (Oiler, 1986). Knowledge created within this quantitative approach is viewed as being factual, verifiable and generalisable. The main criticism of this approach is that different people may experience many subjective truths which may not be wholly generalisable. To a certain extent, nursing has adopted this research approach in order to compete with those in more powerful positions, in particular the medical profession (Playle, 1995). He adds that the acceptance by the nursing profession of these rules and definitions may have much to do with the fact that power is invested in the medical profession as guardians of the gates to the world of research.

Discontent with positivism led to the evolution of interpretivism and to qualitative research perspectives which include phenomenology. The goal of interpretive inquiry is to understand meaning not 'truth'. Interpretive inquiry stresses the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry (Denzin & Lincoln, 1994). It seeks answers to questions that stress how social experience is created and given meaning. Things are studied in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Interaction with participants using interviews and/or observation creates the research data and it is given by description and interpretation of the experience being researched.

The critical theory perspective transcends positivism and interpretivism. Knowledge is socially constructed. It examines underlying structures and processes and the way they contribute to power relationships. Its aim is personal and social change rather than scientific description (Wilkes, 1991).

Nurses hold differing perspectives concerning the value of qualitative as opposed to quantitative research. Qualitative research methods which began in nursing about thirty years ago enabled nurses to consider questions from a different viewpoint and allowed for the exploration of new dimensions of nursing practice. Until then, scientific methods

were often considered to be quantitative, and conventionalist researchers have contested qualitative researchers' assertion that a scientific method has been employed. However, nurses' concern with clients in the humanistic area can make the study of clients' experiences of health and illness difficult using quantitative research methods. Trying to reduce people to sub-units that can be counted negates the complex and holistic nature of health and illness and the manner in which people experience it.

Qualitative approaches are generally more holistic than quantitative approaches and try to capture the complexity and diversity in human experience (Liehr & Marcus, 1994). However, qualitative research does not require justifying but rather the reason a particular method has been chosen to respond to the question asked, requires justifying. With reference to my study, the limited research on the experience of being a visitor suggested the appropriateness of phenomenological research. The question, "What is the experience of being a visitor to a relative in a long-term care facility?" is phenomenological, and so this methodology is best able to respond to it. For the methodology is inductive and exploratory and aims to give understandings of the meanings of a given experience.

Nursing knowledge is aimed towards practice, many parts of which are not receptive to the reductionistic methods of positivism (Stevens Barnum, 1998). The methods of interpretivism are suitable to explore the lived experience of being a visitor in a long-term care facility because they mirror the intricate character of the event through the weaving together of beliefs, feelings and actions that make up a person's lived experience. As a qualitative methodology, phenomenology uses exacting methods to capture experience as people live it. My study uses a Heideggerian hermeneutical perspective of phenomenology which describes and explains people's way of being.

Choice of phenomenology as method for the study

The literature about visiting reviewed in the previous chapter has been mainly from the viewpoint of health providers while the subjective experiences of people visiting relatives has been comparatively neglected. The dearth of material about what it is like to visit relatives in long-term care and how people are affected by this phenomenon means the suitability of current nursing practice for people visiting relatives in long-

term care is uncertain and how nurses may advance their practice in this sphere is not yet ascertained. A phenomenological method seemed to be an appropriate one for a study which attempts to understand human experience. If nurses are able to comprehend the lived experience of people who are unwell or upset then their regard for their clients may be enhanced. Likewise, knowledge acquired from narratives of being visitors by family members increases nurses' understanding of the way family members experience being visitors.

Hermeneutic phenomenology studies persons (van Manen, 1990) and derives from the Heideggerian perspective of the person (Leonard, 1989). As a research approach, hermeneutic phenomenology permits a researcher to both describe and interpret how a family member experiences being a visitor to a relative in a long-term care facility. Van Manen states that hermeneutic phenomenology tries to take into consideration both terms of its methodology. It is a descriptive (phenomenological) methodology because it wants to be mindful of the way things appear, it wants to allow things to speak for themselves. However, it is also an interpretive (hermeneutic) methodology because it maintains that such things as uninterpreted phenomena do not exist. Van Manen adds that the contradiction which is hinted at may be resolved if people acknowledge that the (phenomenological) "facts" of lived experience are always meaningfully (hermeneutically) experienced (p.181). Furthermore, even the "facts" of lived experience need to be captured in language (the human science text) and this is inevitably an interpretive process (van Manen). Consequently, phenomenology permits the experience of family members to shift from a hidden stance to one of illumination. In my study I tried to gain a perspective of the ordinary experience of family members as visitors to find out the meaning of that experience in the context in which it happens.

Hermeneutic phenomenology is an interpretation of people as self-interpreting, thus revealing that interpretation is the appropriate way to study people (Dreyfus, 1991). As a research perspective, hermeneutic phenomenology aims for explicit understanding. So Heideggerian or existential hermeneutics may appear rational. Hermeneutics is an involved, intense manner of observing through looking and listening for an understanding to mould our interpretation of what something is really like. People live as self-interpreters, that is, hermeneutically. The taken-for-granted world is found in language as people live within their circumstances and as they interpret their experience

with regard to their temporal concerns. It is assumed that understanding is affected by previous knowledge experiences and also that understanding will influence future understanding. Central to the research process is the method known as the hermeneutic circle. The whole, for example, whole experiences, is interpreted and understood with regard to its parts, for example, particular events, and the parts are interpreted and understood with regard to the whole. This occurs in a circular manner (Heidegger 1962/1927) to guarantee understanding which is deep and in context.

The nature of phenomenology

Phenomenology is a philosophy as well as a research method (Oiler, 1986). It emerged from a need to understand that human science differed from natural science and needed interpretation and understanding (Liehr & Marcus, 1994). The growth of phenomenology has been characterised by three phases: preparatory, German and French. The following discussion about these phases is founded on the writing of Holloway and Wheeler (1996).

Phenomenology emerged in Germany in the nineteenth century. The preparatory phase included the writing of Bretano (1838-1917) and Stumpf (1848-1936). Bretano gave two concepts fundamental to later phenomenology: inner perception or awareness of one's own psychic phenomena as opposed to unreliable introspection, and intentionality or an interconnectedness of humans to the world. Stumpf contended that knowledge could be derived from analysing empirical material and he demonstrated the scientific precision of phenomenology.

The German phase involved primarily Husserl (1859-1938) and Heidegger (1889-1976). Husserl was, and is, considered to be the primary philosopher of the phenomenological movement (Cohen, 1987). He connected phenomenology to the issue of knowing. He promoted pure subjective consciousness as the requirement for all experience and emphasised essences or roots of knowledge. Phenomenology was a perspective that tried to describe the way the world is constituted and experienced through conscious acts. Husserl also presented the concepts of intersubjectivity and the lifeworld or the everyday world in which people live. Intersubjectivity holds that plurality of subjectivities constitutes a community sharing a common world, that is the

intersubjective world. The lifeworld holds that people take for granted much of what is familiar so that frequently they are unaware of it. Phenomenology starts in the lifeworld which has been described by Husserl as the original, pre-reflective, pre-theoretical attitude that we naturally assume as we live in the world of everyday life. Heidegger moved the focus of phenomenology as established by Husserl from contemplating problems of epistemology to questions of ontology.

Heidegger, who was mentored by Husserl, was concerned with asking questions of the nature of being. In this way he was interested in ontological ideas. Heidegger's concept of Dasein is an explanation of the nature of being and existence and as such is a concept of personhood. Leonard (1994) makes five points about a Heideggerian phenomenological view of the person. These are: 1. The person has a world. The world comes from culture, history and language. Frequently this world is so inclusive that it is overlooked and taken for granted until people reflect and analyse. 2. The person has a being in which things have value and relevance. In this way, persons can only be understood by a study of the context of their lives. 3. The person is self-interpreting. A person is able to make interpretations about knowledge. The understanding acquired becomes part of the self. 4. The person is embodied. This is a different view from the Cartesian, which concerns possessing a body. The concept of embodiment is the view that the body is the way people can potentially experience the action of themselves in the world. 5. The person 'is' in time. Heidegger had a different idea from the traditional idea of time which is viewed to flow in a linear way with an awareness of 'now'. According to Leonard, Heidegger used the word 'temporality' which indicates a new way of viewing time in terms of including the now, the no longer and the not yet.

Heidegger's phenomenology influenced the French phase of phenomenology which was dominated by Marcel (1889-1973), Sartre (1905-1980) and Merleau Ponty (1908-1961). Marcel viewed phenomenology as an introduction to analysing the concept of 'Being'. Sartre held that a person's actual consciousness and behaviour (existence) comes before character (essence). In this way research would centre on real and concrete thoughts and behaviour before imaginary or idealised qualities or essences. The concept of intentionality features in Sartre's writing. Merleau Ponty's interest in phenomenology centred on perception and the development of a science of human being. Like Sartre, he proposed that consciousness is of the world and that there is always consciousness of

something, for example, remembering, judging, dreaming, all of the world, external (Oiler, 1986). Thus a person's body is an access to the world (language, speech, sensation, sexuality). Pure consciousness 'I am' lacks meaning. The meaning comes from 'I am' a nurse or 'I am' interested in knowing about the nursed (Wilkes, 1991). Merleau Ponty (1962) developed the notion of perception stating that it is a person's access to the truth, the basis of all knowledge and that a person's perceives nothing without the world, that is, the lived experience. His phenomenology is concerned with experience, body, time, space and human relationships as people live them (Ray, 1990).

This study uses the research process as described by van Manen (1990) to find out what was important in the experience of the family members I interviewed. I chose van Manen's method as it gives a phenomenological approach which exacts a relearning to view the world as it is encountered in immediate experience. Van Manen indicates that phenomenology describes the way a person orients to lived experience, hermeneutics describes the way a person interprets the 'texts' of life. It tries to explicate the meanings as we live them in everyday existence, our lifeworld. Themes which suffuse all human lifeworlds regardless of their social, cultural or historical situation are lived space, lived other, lived body and lived time (van Manen). These are mainly pre-verbal in that we do not usually speak of them or think about them. Lived space (spatiality) refers to felt space and it explains why the spaces we find ourselves in influence how we feel. To understand the nature of a specific phenomenon it is constructive to inquire into the nature of the lived space that gives an experience its quality of meaning (van Manen). Lived other (relationality) refers to the lived relationship we have with other people in the interpersonal spaces we share with them. Lived body (corporeality or people's corporeal and mental experiences) refers to the fact that we are bodily in the world or embodied. Through our bodies we experience the surrounding world and give meaning to that world. Lived time (temporality) is subjective time rather than clock time. It has past, present and future aspects (van Manen).

The relevance of phenomenology for nursing

Nursing suits holistic approaches to show the knowledge that is hidden in practical activity (Bennner & Wrubel, 1989) rather than the positivist or empirico-analytical paradigm as discussed earlier in this chapter. Hermeneutic phenomenology is being

increasingly used in nursing research as it is suited to the study of many nursing phenomena (Annells, 1996) as a research methodology for exploring many of the questions nurses ask. For example, it has been used by Benner, (1984); Benner and Wrubel; Diekelmann, (1992, 1993); Koch, (1995); Madjar, (1991); Plager (1994); Rather, (1992); Taylor, (1994); and Walters (1995). During the 1970s a small number of phenomenological studies were published in nursing journals. However, in the following ten years many more studies were published and this course continues today. Swanson-Kaufman and Schonwald (1988) discuss the way “knowledge of lived experiences of health and healing are legitimate topics of nursing inquiry” (p.97). Beck (1994) notes that phenomenological research has been undertaken with young and older people alike and in varied branches of nursing.

According to Benner (1985) nursing needs recourse to tangible problems concerning health, suffering and illness and an understanding of the power of practices, skills and relationships that give hope and encourage healing. Phenomenology can give a framework for realising such an understanding. It can explore intrusions to everyday ways of being relevant to illness. Oiler (1986) maintains the objective of phenomenology is a deeper understanding of patients. I consider that phenomenology also has relevance in trying to understand more fully the families of patients. Understanding people using a phenomenological viewpoint gives nurse researchers the chance to understand the rich and varied lifeworld of their clients (Leonard, 1994). Benner (1994) describes the goal of phenomenology as being to “understand the lifeworld, critically evaluating what is oppressive, ignorant, or troublesome from the perspective of the participants and identifying sources of innovation and liberation within everyday practices” (p.123). Benner’s (1984; 1994) work uses interpretive and Heideggerian phenomenology. However, it has been severely criticised by English (1993). He disputes Benner’s claim that one component of expertise is working from an intuitive base. Darbyshire (1994), conversely, endorses Benner’s writing and notes that nurses in many countries are making some changes to nursing education and practice to appreciate the clinical and practical knowledge as advocated by Benner. Annells (1996) holds that critique about the use of hermetic phenomenology is only meagre as yet. She advises that researchers should take note of this fact and so be aware of the present use of phenomenology in nursing.

Two matters of controversy have emerged in recent years concerning nurses and their use of phenomenology. First, nurses who have used phenomenology have not always been true to the basic concepts of the movement (Crotty, 1996). In reviewing nursing research studies with a phenomenological perspective, Crotty argues that these have more in common with humanistic psychology than with either Husserlian or Heideggerian phenomenology. Crotty considers that nurses who use a phenomenological method are muddled about the character and relationship of experience and phenomenon. For van Manen (1990), phenomenology differentiates between the appearance and essence of a phenomenon. In my study, I have tried to clarify the phenomenon of visiting by looking for the meaning of being a visitor in the way the participants lived it. Crotty also criticises nurses who use phenomenology for being inclined to concentrate on subjective factors instead of on the objectivity that is in the subjective. This notwithstanding, there are no interpretation-free facts according to Dreyfus (1991), as I already indicated in Chapter One of this thesis. Consequently, phenomenologists need to interpret and arrange phenomena to show the understanding of being in which “they already dwell, which lets anything show up as anything” (p.31). In doing this study I found that my experience upholds Dreyfus’ perspective. Darbyshire, Diekelmann and Diekelmann (1999) indicate that Crotty’s critique has tried to persuade nurses that interpretive research in nursing has misunderstood Heidegger’s work. However, according to Darbyshire et al., Crotty took a narrow, existentialist view of Heidegger’s work and this view was often misguided and poorly informed. They show that an alternative understanding of Heidegger’s writing in these areas is possible, and further that this interpretation is strongly supported by a deeper reading of Heidegger’s writing and of the secondary literature of Heideggerian scholarship.

Holmes’ (1996) viewpoint is the other matter of controversy. Holmes considers that phenomenology is inappropriate to understand and expand nursing knowledge and also is prejudicial to the traditional goals of nurses because Heidegger belonged to the Nazi Party. Nevertheless, phenomenology gives a philosophy and research method that appreciate people’s experiences. Studies by nurses using Heideggerian phenomenology have helped me in my nursing practice through becoming more aware of seemingly everyday happenings and what such experiences mean to people.

Research activities fundamental to the hermeneutic phenomenological method

Van Manen (1990, p.30) describes six research activities fundamental to the hermeneutic phenomenological method. These are:

1. Orienting or turning to a phenomenon of interest;
2. Gathering the data- investigating the experience as it is lived rather than as it is conceptualised;
3. Reflecting on essential themes which provide a deeper understanding;
4. Describing the phenomenon through writing and rewriting;
5. Maintaining a strong involvement with the phenomenon;
6. A hermeneutic interpretation-balancing the research context by considering parts and the whole.

The writing of Heidegger (1927/1962) and of van Manen (1990) have been used in this study in the following way:

1. The phenomenon of interest is the experience of family members being visitors to a relative in long-term care. Chapters One and Two report the process of orienting to this phenomenon;
2. Exploring the experience of family members in its entirety as they lived it;
3. Reflecting carefully to bring to speech that which constitutes the nature of the family members' experience. This includes bringing to speech that which is usually concealed;
4. Writing the fundamental nature and interpretation of family members' experience in order to show its richness publicly; I wished to develop a text that included the two aspects of phenomenological inquiry identified by van Manen (1997), the thematic and the expressive. He considers that when people shift from the thematic to

expressive meaning, then the question people ask shifts from asking what the text talks about to asking in what way the text talks. Thus the researcher needs to develop a text that addresses both the intuitive and mental capacities of readers. In developing my phenomenological text, I tried to contribute insight and to enhance understanding of being visitors as the participants experienced it.

5. Upholding the truth of the experience as it was lived and related by the family members to me in the written report;
6. Identifying the parts while keeping a view of the whole in trying to discover the essence of the experience. This needed an engaged dialogue with the text to discover the essence of the experience and to discover the parts that constituted the whole.

Van Manen (1990) makes a number of suggestions for structuring a phenomenological study. I have followed one of the ways that he has suggested. I have divided the main body of the study into chapters. Parts or sections of each chapter elaborate an essential aspect of the phenomenon under study. Each section heading articulates the theme that is being described in that section.

Data collection methods

The main data collection in hermeneutic phenomenological research is undertaken by interview in order to collect first person narratives of experience for the data needed to generate a richer and fuller understanding of a human phenomenon. As well, the interview can generate a relationship of dialogue with the interviewee about the meaning of an experience (van Manen, 1990). The interview is centred by the research question which in this study was "What is family members' experience of being visitors to an older relative in a long-term care setting?" To assist participants to tell meaningful stories, it is advisable for the researcher not to interrupt with many questions and answers.

Structured but open-ended interviews lasting about one hour were conducted individually by me with eight volunteer participants on two occasions each. An exception was one participant who, due to the death of his relative, participated in only one interview. So less data was collected from this participant than from the others. The

first interview occurred about two months and the second interview about five months after the entry of a relative to long-term care. Data collection occurred over a four month period.

Interview data were audio-taped and were then transcribed by me using a word processor. Two interviews with one participant were undertaken without being audio-taped because the participant did not wish this. He allowed me to jot down notes while he was talking to me. Soon after each interview with him was completed I recorded on paper further notes as to the information he had shared with me. Fifteen interviews were undertaken and transcribed to form the text for analysis and interpretation. I checked the transcripts by playing the tapes while reading the transcripts.

After each interview had been transcribed, there was communication with each participant to discuss what they had said and to ask if they would like to elucidate, to add to, or to eliminate any of their experiences. Two family members wanted to eliminate some personal details they had described and three family members wanted to add some details of the experience that they had remembered since the actual interview. I used this time to ask any questions I had to elucidate some of the family members' statements and so to move closer to understanding.

The interviews were conducted at a time and place to suit the participants. Twelve interviews were undertaken in their homes while three were conducted in the hospital in a quiet, private setting, free from everyday distractions.

The interview began with an open question such as "Tell me what it was like for you to be a visitor on your most recent visit to (your relative). What was it like for you?" Interviews moved along in a conversational way with questions evolving to explore the experience more profoundly as participants described this phenomenon.

Field notes were documented after each interview to help me to remember when it came to the time for analysing each interview such factors as the nonverbal behaviours of the family members and also to record tentative thoughts.

All participants were offered a copy of their transcripts with two participants accepting this offer. Participants overall seemed to feel comfortable with the research method and with me. I learnt that they were keen to talk to someone who listened empathetically.

My aptitude to listen to the family members seemed to improve as I became more familiar with the process of interviewing. At first I had thought I was unable to hold the participants to what I considered as the subject of discussion.

The research process

The data analysis for this study was undertaken using the methods of phenomenological research described by van Manen (1990).

The study participants' descriptions of their experience were read and reread a number of times to capture a sense of their entirety. Data analysis included reading the whole of each transcript to identify themes and next to look for both similar and dissimilar themes in all transcripts through reading and rereading.

Patterns of text using specific words, phrases or ideas that seemed to be connected to a particular theme were separated from the text through a line by line analysis which led to the emergence of essential themes. To apprehend essential as opposed to incidental themes a researcher asks if a phenomenon remains the same if the theme is imaginatively changed or deleted from the phenomenon. A researcher also asks whether the phenomenon loses its fundamental meaning without the theme (van Manen, 1990). To give structure to the essential themes that I uncovered, subthemes and supporting components were identified. I tried to use participants' own words if these appeared to describe the themes in order to stay near the experience, as it is lived and described by the participants (van Manen).

The evolving themes were considered as to their meaning for the participants which required asking frequently: "What does it mean to this family member and in this context? Do other family members share this experience and meaning?" Asking questions and going back to the transcripts created the dialogical process between the researcher and the data.

I also used van Manen's (1990) approach of taking the four lifeworld existentials of lived space, lived relationship, lived body, and lived time to guide the reflective process. I looked for references to each of these existential themes in the interviews, and included a number of subthemes. Comparing these themes across interviews in the

process of comparing parts and whole (van Manen) led to the development of other themes from which the themes from the text could be generated.

The themes taken as a whole reveal the experience as to their meaning. Interpreting the text exposes the knowledge within it which leads to insight, shared new meanings and understanding which merely taping and describing events does not achieve. The essence of the merged experience of the eight participants was written to produce the thesis. The essence of the experience, continuing-the-commitment-to-care evolved as the main theme and so was used to entitle the thesis.

To check credibility, the overriding thematic scheme of the interpreted experience was shared with each family member. Each person consented that the data had been interpreted appropriately to represent their experience of being visitors. This research can give one interpretation of the phenomenon. This may not be the definitive interpretation. Van Manen maintains that no single interpretation of human experience will exhaust the possibility of another possibly richer or deeper description.

Transformations in the interpretation of text

Phenomenology aims to transform personal lived experience into consensually validated knowledge. This meant that only people who had experienced being a visitor to an older relative in a long-term care facility could participate in my study. Thus the depth of the data obtained relies on the family members' skills to voice these and on my ability as an interviewer to reveal their knowledge. I used in my study the five steps outlined by Reinhartz (1983) in the phenomenological transformation of experience to knowledge.

1. A person's experience is transformed into actions and language that is made available to him or her through a special interaction he or she has with another person(s). In this study each family member's experience was transformed into actions and language which was made accessible to him or her through their communicating with me. I developed a situation in which each person's experience became accessible to him or her in language. This was the first transformation.
2. The researcher transforms what he or she sees or hears into an understanding of the actual experience. Thus next I transformed what each family member saw and heard

into an understanding of the actual experience. I depended on data he or she gave about that experience and I developed my understanding. This was the second transformation.

3. I transformed this understanding into themes which I consider grasp the essence of the experience. This was the third transformation. If there is no such transformation, a researcher is merely recording which is insufficient to give understanding.
4. The researcher transforms those themes that are in his or her mind into a written account which captures the essential meaning of particular experiences. I transformed the emergent themes into a written account which grasps the characteristics that made the experience what it is. This was the fourth transformation.
5. The last transformation has to be undertaken by people 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 experience. Phenomenological understanding elucidates present knowledge and may endorse it or lead to valuing the world previously just assumed to be true or valid.

Assumptions of phenomenological research and explicating assumptions and pre-understandings of the researcher

The main assumption of phenomenological research is that knowledge of phenomena can be secured from explicating the lived experiences of study participants (Annells, 1996; Oiler, 1986). My study takes this assumption to gain a better understanding of what the experience of being visitors is like for family members. Understanding the experience partly depends on the interpretation, sensitivity and thoughtfulness of the researcher, as well as the researcher's scholarly tact and writing talent (van Manen, 1990). However, it also depends on the participants' ability and willingness to adequately relate their experience to the researcher.

Scientific knowledge and people's 'common sense' pre-understandings and assumptions incline them to interpret the nature of a phenomenon before they have dealt with the importance of the phenomenological question (van Manen, 1990). Van Manen believes in explicating people's "understandings, beliefs, biases, assumptions, presuppositions and theories" (p.47) in order that people can try to acknowledge their assumptions so as to hold them off and to try and reveal their shallow or concealing nature. As a nurse working in the geriatric area, I have many interactions with people visiting a relative in long-term care and I chatted to them about their experiences long before I began my study. So I had made some assumptions about the experience of being a visitor to a relative in long-term care and I explicate these.

My assumptions are:

1. that family members have much knowledge and many skills about their relative and caring for him or her but the knowledge and skill may not be accepted by nursing staff.
2. that the relation that exists between family members and nursing staff is mostly satisfying, but also, on occasions, tense and uncomfortable.
3. that family members could undertake familiar tasks they had assumed at home, for example, feeding, equally well within the different setting of the facility.
4. that family members may experience emotional responses such as guilt and grief while visiting.
5. that family members let go of the primary carer role with feelings of loss and distress.
6. that the experience of this phenomenon will differ for individuals but will reveal some basic commonalities or 'essences'.

A helpful way in which my assumptions were shown to myself in the course of the study was through questions, comments and challenges from people to whom I spoke about it, including my study supervisor. The recognition of my prejudices helped me to concentrate on my role as a researcher rather than as a nurse. It also helped me to concentrate on the stories as told by the participants.

Adequacy of the study

Adequacy is attained in various ways so that the interpretation of the text correctly represents the experience and its meaning for the participants. Confirming the interpreted text with the participants as to its accuracy can facilitate the adequacy of a study. In my study I showed the participants how I interpreted the text when I had completed the study. They all found that the findings reflected their common experience. As well, in the four data chapters of my study I incorporated numerous quotes from the participants to help readers to consider my interpretations and in this way readers can participate in the confirmation process.

An interpretive approach is more than a description of a phenomenon because it is always about some failure in human concerns (Leonard, 1994). So the definitive standard for assessing whether an interpretive report is satisfactory is the extent to which it clears up the failure and develops new possibilities for engaging the problem (Leonard). I consider that the findings of my study meet that standard and shows a perspective that has been hidden-the reality of being a visitor to a relative in long-term care. Thus family members' experiences formerly not described have been revealed. This may increase understanding, and nursing care could be adapted to meet the needs revealed.

Trustworthiness of the study findings

Lincoln and Guba (1985) discuss trustworthiness in qualitative research. Lincoln and Guba and Sandelowski (1986) criticise quantitative criteria of reliability and validity as inappropriate for qualitative studies and propose an alternative framework for examining studies in the naturalistic paradigm. They give four criteria with which to evaluate the trustworthiness of qualitative studies. These are credibility, transferability, dependability and confirmability.

Credibility is attained when the participants concur that the findings and interpretations of the text sincerely represent their lived reality. Further, that the findings and interpretations can be valued by other researchers who rate the interpretations as faithfully representing the data. Credibility was attained in this study when the participants saw the research as truly representing their reality, of their experience as it

was lived. This will be confirmed if other researchers judge the interpretations as being true to the lived experience of being a visitor to a relative in a long-term care facility.

Transferability or fittingness relates to the researcher giving enough particulars of the method so that another person can take the study design and use it in a similar circumstance and draw similar inferences. Another researcher should be able to independently study the phenomenon and find similarities with themes as they are expressed in my study. Transferability of my study was enhanced by selecting participants with two to five months experience of being visitors and who could verbalise those experiences. Having two interviews with each participant meant emerging findings could be validated with each participant. When the findings were concluded they were discussed in detail with several of the participants, who endorsed the findings as characterising their experiences. Feedback was requested if participants felt that the themes/interpretations did not reflect their experiences. Two participants indicated disagreement. This was minor and concerned the use of some words in my interpretations of their narratives. We then found words which they considered more accurately interpreted what they were saying.

Dependability relates to the auditability of a study. Supervisors who have undertaken their own research and are familiar with undertaking phenomenological research have monitored this study, from the formulation of the research proposal through to its completion.

Confirmability relates to the findings of a study rather than the stance taken by a researcher. It is attained through an audit trail that gives enough proof in the data chapters to permit the reader to endorse the findings described by the researcher. In the data chapters of my study excerpts from the participants' transcripts are linked with my interpretations. Thus another reader can substantiate the interpretive process.

I tried especially to be faithful to the text, as advised by Benner (1994) as this is important for the trustworthiness of a study. This is shown when the researcher's perspective of the research aim is challenged. Benner indicates that in phenomenological interpretation that if the interpreter's views have not been "challenged, extended or turned around, the quality of the account is questioned and the

danger of just reading in preconceptions must be considered" (p.101). Some of the views I had about the subject of this study have been substantiated. For example, that the relation that exists between family members and nursing staff is mostly satisfying, but also, on occasions, tense and uncomfortable and also that family members may experience emotional responses such as guilt and grief while visiting, although I was not aware of the depth of these responses. Other dimensions concerned with the experience of being a visitor, however, of which I mostly lacked understanding are now apparent to me. For example, that family members could not always undertake familiar tasks they had assumed at home, for example, feeding, equally well within the different setting of the facility, nor did I realise that most family members were so committed to being involved in the care of their relatives. Thus by the time the study was completed, my assumptions had been contested and I felt increasing respect at the care and devotion seen in these family members as they gave of their time and energy to the wellbeing of their relatives.

Ethical concerns

This study involved human subjects so their dignity had to be guaranteed in addition to the pursuit of knowledge. Formal approval for the study was gained from both the Human Ethics Committee of Massey University and the Otago Ethics Committee. All requirements have been observed.

The principal ethical concern identified at the outset was the researcher's potential conflict of interest between the roles of nurse and researcher in the geriatric area. This was managed as explained in Chapter One. The following ethical concerns were also addressed.

Risks to the participants

The participants were informed that although I am a nurse I would not regard them in this capacity. For this study I was a post graduate student with the Department of Nursing and Midwifery (now the School of Health Sciences) at Massey University. I realised that during interviews I might be asked for my professional viewpoint so I emphasised my role as a researcher rather than as a nurse. No conflict of roles occurred during the interviews.

There was no likelihood of lasting drawbacks to participants as long as anonymity and confidentiality were upheld but there was a possibility of transient upset when thinking about the degree to which being visitors had affected their quality of life. I advised participants of this and made arrangements to cope with this if necessary. As a nurse with experience in dealing with people in stressful situations, I could support family members if they became upset during interviews. If participants show signs of distress they were appropriately comforted and reminded that the tape could be turned off at any time. The need for this arose only on one occasion. The researcher was also able to inform the participants of support services such as a counsellor if a need was established. The need for this did not arise.

There are, however, known benefits from the sharing of experiences. Bergum (1991) states that the process of sharing can make a difference in the life of participants because it raises their awareness of what they are going through. As well, the participants feel affirmed because they consider that they are making a valuable contribution on a social issue. Hutchinson, Wilson and Wilson (1994) found that participants in qualitative research may experience positive outcomes such as empowerment, a sense of purpose, and catharsis. I did not try to determine if the family members in my study felt such advantages. However, several family members commented spontaneously on the helpfulness of being able to discuss their situation. Two other family members said it pleased them to share their experiences with me in order to add to nursing knowledge.

Informed consent

Informed consent is an ongoing negotiated process. Each volunteer was given a consent form outlining the study and what it meant for them (See Appendix C). The study was discussed and questions answered before the volunteers gave consent to participate in the study. Participants were clearly told that their willingness to participate in the study or withdrawal from the study at any time would not adversely affect their relative's or their own future care, so that they would not feel obliged to participate to guarantee the continuation of their care. The participants were given an Information Sheet (Appendix B) and any questions they had about the research were answered. All participants were given the name and contact telephone numbers of both the researcher and supervisor so

that any ongoing concerns could be addressed. I stated these points prior to all interviews.

Anonymity

It was important for the collection of the data that the family members felt secure and able to share their experiences with me. All details of the interviews, tapes and transcriptions were kept in a locked drawer at my home. Access to the tapes and interview transcripts was only given to the supervisor and myself. At the completion of the study the audiotapes will be destroyed. If the participants wished to retain a copy of the tape of their interview or a copy of the transcript, it was made available to them. Only two participants took up this offer.

In the final report pseudonyms were used and details that might allow identification of participants were edited. Details of the research site were not published.

Researcher ethics and the researcher and participant relationship

A trusting relationship between the researcher and participant is necessary in order to undertake phenomenological research. Otherwise, participants would probably not share their experience. The researcher and participants relate to each other in a conversation from which the research data emerges. The researcher needs to be able to both communicate and to listen well. Swanson-Kauffman and Schonwald (1988, p.101) state that to gather data well relies on "the researcher's ability to engage with the informants' reality" which needs empathy, intuition and attentiveness. However, such relationships have their own ethical problems. My experience as a nurse in the geriatric area and as a granddaughter of a relative who has been in long-term care was of value in being non-judgmental and in knowing how to approach and converse with adult children, partners and other family members of residents and in knowing when it would be most ethical and tactful to stay silent and unobtrusive. Yet it also meant that our sharedness of having a relative in long-term care could prejudice my interpretations of the data. Thus to undertake this study I examined my assumptions and pre-understandings as discussed earlier in this chapter, section, "Assumptions of phenomenological research and explicating assumptions and pre-understandings of the researcher". The preunderstandings I held were mainly created by my being a nurse.

Accessing participants for the study

Study participants were recruited from a geriatric ward of a private hospital. Notices (Appendix A) informing people of the study and inviting them to contact the researcher were displayed in the foyer. People who contacted the researcher by phone were invited to meet the researcher to discuss the reason for doing the study and what it would involve for them as outlined in the information sheet (Appendix B). Informed consent of the potential participants was obtained on the form provided (Appendix C). The eight people interested in participating ranged in age from about the early forties to the late seventies.

Participants may be chosen with reference to the needs of the study when undertaking qualitative research. Researchers may interview people with a wide, general knowledge of the topic or those who have lived the experience and whose description is considered typical (Morse, 1991). To explore the experience of being a visitor, potential participants had to meet three predetermined criteria. These were: 1. only persons who had been the relative's primary caregiver in the community and 2. who had been visitors for only about two months were considered eligible for inclusion in this study. 3. All participants were to be competent in the English language, both to ensure informed consent to participate and to enable their stories to be understood by the researcher.

A phenomenological researcher tries to prevent inclinations towards developing preestablished procedures, techniques and concepts that could rule-govern a study (van Manen, 1990). I could not estimate before beginning the study the number of people that I would need to interview. The narratives of the eight participants became data which has been used as part of the examination and illumination of the phenomenon shown throughout Chapters Four, Five, Six and Seven.

Permission for access to potential participants for this study was initially obtained from the manager of the hospital in which my study was to occur.

Description of the study participants

The participants in this study came from a variety of backgrounds and social situations. All met the three predetermined criteria (as noted above).

Chris is in the late seventies. Chris's partner who is several years younger has had a number of physical illnesses for many years. Care was required from Chris at home for about seven years. The couple have no children and contact with other family members has become less frequent. After retirement from paid work Chris hoped to extend old interests, but instead found life becoming restricted.

Jim is in the mid seventies and his wife is a few years younger. They have been married for many years. They have several children. Jim was retired from paid work and looked after his wife who had a stroke for some years before her entry into long-term care. Jim has been determined that his own needs and interests were necessary to him and he tries to manage an active social life. Involved on the periphery of the care of his children, he had no prior experience of dependency.

Gloria is in the mid seventies and her husband is a few years older. They have been married for nearly fifty years. They have two children who give Gloria much support. Gloria's husband has dementia, is nearly blind and partially deaf. Gloria looked after him at home for some years before his entry into long-term care. Her physical health is poor.

Barbara, a middle aged woman, cared for her mother-in-law who has an Alzheimer's-type dementia, for two years before her admission to continuing care. She is divorced and has a son living at home with her. She works fulltime. Other family members could only give limited help in caring for their relative.

Sally, a middle aged woman, cared for her grandmother who has dementia, for two years before her admission to long-term care. She is single and unemployed. She has a mother and a sister who play a significant role in helping with the caring.

Evan, a middle-aged man, cared for his mother who has dementia, for six months before her admission to long term care. He is married and works part-time. His wife gives him much support. Other family members were only able to offer limited assistance in caring for their relative.

Jane, a middle-aged woman, cared for her mother who had a stroke for about a year before her admission to long-term care. She found the support she received from family very helpful.

Margaret is in the late seventies and her husband is several years older. Margaret cared for her husband who has dementia for a few months before his admission to long-term care. Her children were a source of support but problems with her own health meant Margaret could no longer cope at home with her husband.

Presentation of the study findings

Phenomenological researchers may structure their texts in different ways (van Manen, 1990). My study is structured around the four basic lifeworld themes: lived space, lived other, lived body and lived time (van Manen). These themes guide the exploration of the experience of being a visitor. The concept of the lifeworld came from Husserl who described it as the world of immediate experience. Van Manen (p.101) maintains: "Our lived experiences and the structures of meaning (themes) in terms of which these lived experiences can be described and interpreted constitute the immense complexity of the lifeworld". The four themes have been held apart from one other in order to communicate the findings of my study though in fact they cannot be kept apart. They create what van Manen describes as "an intricate unity which we call the lifeworld-our lived world" (p.105). The next four chapters show the lifeworld of the eight persons visiting their relatives, lifeworlds that have been substantially changed by being visitors.

The main theme of my study is continuing-the-commitment-to-care. This consists of four essential themes: *perceiving-visiting*; *learning-to-live-with-visiting*; *continuing-with-visiting*; *valuing-commitment-to-visiting*. These themes are emphasised in italics; the subthemes title each related section as they are submitted. While discussing the themes and subthemes, components arose which are fundamental to the experience and these are specified and incorporated into the discussion. Each of the essential themes, supported by the subthemes and components, is the focus of the following four chapters.

This is a master's thesis and so has to meet the requirements of Massey University. As well, I wished my study to be readable for nurses and for others who would like to

understand the experience of family members who are visitors to a relative in a long-term care facility. I have tried to fulfill both aims.

The participants' words are given as they were recorded with small alterations to help understanding.

Summary

In this chapter, the study design and methodology have been outlined. The reasons for phenomenology as a choice of method and data collection methods have been explained. Hermeneutics and the hermeneutical interpretive process have been described. The research process was explained and a statement of the relevance of the phenomenological method to nursing was given. Implications for the researcher, a description of the study participants, ethical concerns in qualitative research and issues of trustworthiness of the study were also given.

The participants who shared their experiences with me have contributed to my understanding of the experience for family members. I have tried to bring to speech the reality of their visiting. The next four chapters present the findings and the thesis has been formulated from them, inviting the reader to share in the creative epistemological transformation process as the outcome of the hermeneutic phenomenological method. In doing this the reader shares in the validation process which is a fundamental part of the research process.

CHAPTER FOUR

PERCEIVING-VISITING

If Gus is in the lounge and there's patients who are noisy, calling out, you know, or wandering over right to where we are sitting and butting in, and, well, I won't say I like it but I'm not so upset as I used to be. I've got more used to it, I guess, and just knowing that they can't help it has made me more accepting (Gloria, Int.2, p.4).

Hermeneutic phenomenological research gives sound perceptions to what appear to be common, ordinary events so that people are able to interact in a more unequivocal way with the world (van Manen, 1990). Five transformations make possible these perceptions (Reinhartz, 1983) as reviewed in Chapter Three. I submit the four data chapters as my written transformations of the family members' stories, built on these understandings. These chapters are my current interpretations of the data. Each chapter centres on one of the four essential themes, *perceiving-visiting*, *learning-to-live-with-visiting*, *continuing-with-visiting* and *valuing-commitment-to-visiting*. The last transformation is the reader's interpretation (Reinhartz) and consequently people reading this study could make it into a piece of work that has some relevance for them.

This chapter will discuss how the study participants perceive being visitors to their older relatives in a long-term care facility. The participants as family members have been their relatives' primary carers in the community. Most have lived with their relatives for a long period of time in their own homes. All the family members experienced *perceiving-visiting* as gaining knowledge of the hospital environment but for most it also involves experiencing changes in status. Perceiving is described as a gradual awareness of the implications of being a visitor. The family members' awareness is influenced by the environment of the long-term care facility which, in turn, is very much influenced by the attitudes and behaviour of the staff with whom the family members interact. Awareness is also influenced by the family members' own wellbeing and that of their relatives when visiting. Throughout the family members' narratives,

certain statements were reiterated. From these statements four subthemes developed related to *perceiving-visiting*. These subthemes are insider-outsider-insider, loss-of-privacy, perceived-loss-of-some-control and keeping-the-continuity-with-home. Insider-outsider-insider is supported by two components: figuring-things-out and giving-and-taking. Loss-of-privacy has the component making-the-best-of-it. Perceived-loss-of-some-control has the component having-no-other-ways-out. Keeping-the-continuity-with-home has two components, appreciating-cosiness and wanting-the-comfort-of-pets.

Lived space

From a phenomenological perspective, this chapter can be interpreted within the concept of lived space. Lived space or spatiality is described by van Manen (1990, p.102) as “felt space...we become the space we are in”. It is the way in which we interpret and experience the space in which we exist. Lived space is not just the physical surroundings. It is a person’s perception of the effects of the surroundings on the experience of existence as part of those surroundings. According to Van Manen there are cultural and social practices related to space that give the experience of space a qualitative aspect. Lived space will be open to interpretation and individualised to the family members. Lived space is important to family members who must leave their usual home surroundings when visiting their relative to meet new experiences in unfamiliar surroundings. In this chapter I will discuss the themes uncovered in the study relevant to the existential of lived space.

Insider-outsider-insider

The first subtheme in this chapter is the experience of having been an insider, becoming an outsider and then becoming an insider again. Family members had all considered themselves as insiders when they were the primary carers for their relatives in the community. They considered themselves insiders in the sense of having been closely associated with the health care team who were involved with their relatives’ needs and also because of having had in depth knowledge about their relatives’ wellbeing and state of health. Feelings of being outside the health care team and no longer being the primary carers were expressed during the first interview by all participants when describing their most recent visit to their relatives. This was part of a process of having

been an insider and then being an outsider. They held these perceptions because they knew little about how the staff and the facility function. For example, they did not know the names of some of the registered nurses, careworkers, doctors and management staff and their various roles, and they had little understanding of the practices, policies, procedures and everyday routines. They seemed to have little knowledge about what resources were available and how best to access these resources. Family members described being aware of their unfamiliarity with the staff and the facility and having insufficient knowledge to meet new or unknown expectations which made them somewhat anxious, uncertain and ambivalent about being a visitor. These thoughts and feelings suggest unsatisfactory role relationships.

By the second interview most participants described their most recent visit in a way that indicated that they had furthered the process of change by becoming part of the health care team again (insiders), though in a different and lesser way than experienced previously in the community. It related to getting to know staff and routines in order for them to continue to be involved in the care of their relatives. For family members this was perceived as becoming insiders again. Acquiring knowledge about the facility, for example, the various people in it and its layout was described in expressions such as “learning the ropes of the place” and “trying to figure things out up there”. Thus figuring-things-out is the first component of insider-outsider-insider. Chris’s narrative captures this.

I don't know too much about what's happening. It feels rather strange, that, not being the one talking to the doctor when he comes to see her. I get the information now about how she is, ah ... second hand through the staff. She's their concern now, but mine still too. But in a way I'm on the outside—like a guest. I guess that in some ways I'm no longer the most important person in her life. And that's after all the years we've been together ... And Jean has been sick off and on for the last, oh, about 25 years. She didn't require much help at first, it gradually built up ... You know, they just didn't really discuss it with me, what they expect me to do. So I guess it's alright with them me still doing certain things for her. Today I cut her fingernails. Other days I help her in and out of bed, up to the toilet, pour her drinks... No-one, no staff has actually said anything

to me as to whether they're happy for me to have that level of involvement...though the way a few look at me... (Chris: Int.1, p.6).

Knowledge about the facility was very important to all family members. They would have liked more information about daily routines and activities for their relatives, especially ones that affected them as well as their relatives, and in particular, the time and place of activities in which they could be involved. Also important to family members is information on their relatives. They wished for personal information about their relatives: their relatives' progress (physical, emotional, social and psychological); medical treatment; care needs; acute changes in relatives' wellbeing; anecdotal incidents of everyday happenings; visitors and mail; items required, for example, clothing. The information the family members wished for depended in part on the mental status of their relatives. If their relatives did not have the mental capability to inform family members themselves, the range of information which family members wanted was greater. However, such information was not always readily forthcoming. Several family members perceived themselves as being secondary to caring for their relatives because of negative staff attitudes and behaviour towards them when they request information. This is shown by Chris and Barbara in the following narratives.

I usually feel the staff are so busy that I don't want to trouble them. But when, today, I saw them sitting down and chatting, I went to talk to them. ... I find it, ah, annoying when they just casually say, "Oh, she's fine" when I don't really think that's the case at all ... Having known her for so many years I feel that she isn't alright at times when they keep insisting she's fine. I expect they think I'm a, oh, a fusspot [laughs]. But it's just that I want the best for her and it makes me feel so useless that I can't provide that any more... [tearful] (Chris: Int.1, p.8).

[Staff] like to think they know best. Like, when I brought in some new toiletries for her including her favourite soap they said, "Oh no, we don't use soap for Anne," and they showed me this pot of, a kind of cream that they said is less drying for her skin. Well, Anne's ... never complained of a dry skin. When I told them that they said that had now changed, the skin gets drier the older you get and in a tone of voice, we

don't mind you showing an interest in Anne, but please don't be in our way (Barbara: Int.2, p.3).

The predominantly medical model of care probably added to feelings of being outsiders to the facility. For instance, the facility had a policy of unrestricted visiting, but some family members said that they learnt to avoid visiting at times when staff were considered to be busy with physical activities of daily living such as washing and dressing. The time for being with their relatives was thus curtailed. The family members and nurses in the facility had to establish a rapport with one another in order for family members to become insiders again. The family members talked of how being assisted, being involved and being valued made them feel welcome and feel like insiders. There developed a reciprocal give and take in relationships between most family members and staff. Giving-and-taking is the second component of insider-outsider-insider. One family member's remarks show that she appreciated that staff allowed her to have continued input into her husband's care. Gloria explains.

The nurse said ... "Don't worry, um, he's getting fed, that he's clean and such things". That made me feel good in the sense, ah I didn't have to do those things any more after such a long time, yet... ... I told them that I still like to do some of the things that I used to do. And they said, "Alright". Um. So though I can't feed him at the moment because of my hands I feel reassured that I can take that up again when I can (Gloria: Int.1, p.10)

Once they were familiar with the routines most family members felt some control over the self and the situation and felt some sense of affinity with the other people in the facility. This led them to feel more comfortable. However, most family members perceived that the ideal of working individually with people, such as doing things with and for residents and family members when it suited them rather than staff, was given less weight by staff than adhering to routinised procedures and tasks. Chris and Gloria illustrate.

I had, had thought that she would have a shower every day. That's what she had at home. And that seemed reasonable to me. However, they told

me it was policy up there that each person is showered only twice a week as that's all that the staff have time for ../.. We had just assumed... It's taking me a while to adjust to, to the reality of institutional life for Jean. She loved her showers at home and used to look forward to the home help who helped shower her. But I must accept, Jean herself has, she doesn't complain though I know how she must feel (Chris: Int.1, p.5).

It takes some getting used to... being a visitor, not that important to Gus anymore../.. I'm learning that the staff's priorities for Gus are different from mine. I don't like some of the things... I did think that they would get him up every day... But not to worry too much about it, as ../.. he seems contented (Gloria: Int.1, p.11)

The subtheme insider-outsider-insider and the two supporting components figuring-things-out and giving-and-taking were but one part of the experience of *perceiving-visiting*. Of much concern to all family members was the loss of privacy and the meaning that held for them.

Loss-of-privacy

The concept of lived space will be shown here in the way that visiting requires personal space for most participants. Changes to lived space occur with the loss of privacy which results from the institutionalisation of a relative. Many family members perceived that the spatial design of the inside of the building such as the number of occupants per room, influenced their relationship with their relatives. Family members visiting a relative in long-term care experience a new and different physical environment that includes the relative's bedroom, the communal lounge, kitchen and bathroom. Most family members commented that the lounge and bedroom areas look clean, comfortable and inviting which they perceived as a deliberate attempt being made to provide a relaxed and homely setting. The large lounge is perceived to help some people to socialise and to promote the sharing of experiences and also to cultivate an environment where residents and families are supported by one another. This is discussed further in Chapter Five in which the lifeworld existential of lived other is presented and discussed.

Being in a long-term care facility is different to most individuals' usual living arrangements. The sharing of facilities with people who begin as strangers, and having only one room that is the resident's own private space, or perhaps even sharing that space with up to three other people as is the case for most residents in the facility in which the study was conducted, are changes which require some adjustment not only for the resident but also for the family member visiting. They perceived that a care facility lacked some of the attributes of a domestic residence. For example, the lounge and most of the bedrooms are shared with other people which was different from going into the relative's home. Communal living gave little privacy and yet privacy was very important to most family members. Intimacy and anonymity were perceived as particularly appropriate by most family members when visiting their relatives. Gloria and Margaret explain.

We have to tell him, ah, like his sister is not well and we haven't told him. And she's to have an operation on Monday. But we haven't told him about the operation and that's the sort of things. The things we talk about are the things that anybody can hear. So then I don't sort of worry about the other people there (Gloria: Int.1, p.1).

I now take him to his bedroom if I want some time alone with him. I've worked out the times his room-mates are likely to be out of the room so then we can have some time to ourselves (Margaret: Int.1, p.4).

In spite of residential separation, most spouses wanted respect for the marital boundary. When the staff provides for privacy, meaningful rituals between spouses can be maintained (Gibson, Bol, Woodbury, Beaton & Janke, 1999). Unfortunately, the family members in my study who spoke on this topic perceived that the lack of adequate privacy as well as the moral milieu of the facility meant that chances to show fondness and devotion through certain physical interactions were inhibited. This finding is similar to the study of Gibson et al. In their study about expressing sexuality in a long-term care facility, they found that lack of privacy was the primary deterrent to sexual expression. In my study, many family members did feel, however, that they could hold hands or embrace lightly in the facility.

One spouse acts as an advocate for his relative with staff. For example, the relative prefers to remain in her room to eat meals in privacy rather than in the large dining room which seats about forty people. When staff members encourage her to eat in the dining room, the spouse intervenes and requests that she be allowed to eat in her own bedroom.

Family members sometimes could not find a private place to sit with their relatives. For example, one family member described both visits that I interviewed her about as lacking somewhere to sit in peace and enjoy her relative's company. She told of all visitors being "shepherded" into the communal lounge. Further, although some of their relatives had their own rooms, these were not necessarily perceived as suitable places for more than two family members to visit at a time because of the lack of space. Tilse's (1994) study set in an Australian long-term care facility found that a pleasant and private place to visit is an important provision for families. This was also the case for the participants of this study. The component making-the-best-of-it supports the subtheme loss-of-privacy. Family members were perceptive of the space they were limited to. The only options for most family members were a bedroom or a lounge. Except in the few cases where a relative had a single room, these spaces had to be shared with other residents and their families and friends. There was little room available where family members could gather in privacy or where nurses could speak privately with them. They were generally dependent on staff to be set up a place to sit and to be offered refreshments. This meant families sometimes competed with others for a quiet place to sit. This also meant nurses had considerable control over the location of visits and access. Gloria illustrates the latter.

She [nurse] even told about a little area around the far corner of the ward which nobody much uses. So Gus can be wheeled there in his chair and we can have some time to ourselves and I don't have to worry about talking so loud, everyone else hearing and being annoyed by the noise (Gloria Int.2, p.6).

To be on their own with their relative when visiting was experienced as particularly meaningful when there were problems in communication concerning the hearing of the relative or of the family member. Some family members complained of the noise in the

lounge from the radio and television. However, their relatives' preferences and the extent of their illnesses also influenced where family members sat when visiting their relatives. If their relatives were very ill or close to death then they would spend most of their time in the bedroom where there was more likelihood of some solitude. If their relatives were comparatively well, conversely, most visits took place in the lounge which suited those family members who wanted the diversion of others: residents, staff, visitors. However, the other residents and their visitors were perceived as a nuisance if they behaved in a way which caused upset. Chris illustrates this.

When Jean and I try to talk they're (residents with dementia) likely to come up and want to talk with us. ../.. it's upsetting ../.. Ah, I worry about how Jean copes with it all when I'm not there... [sighs]. (Chris: Int.1, p.11).

Thus not all family members seek privacy for visits. Privacy may mean enforcing isolation particularly for families who visit a relative unable to communicate or respond. Private visiting for these family members was perceived as limiting the chances for social contact, consultation with staff, support for themselves and participation in the daily life of the facility. Margaret shares her feelings.

...I sort of feel very lonely up there ../.. if Harry is in his bedroom especially if he keeps dropping off to sleep ../.. We haven't got much to say... It gets me down being there. Sometimes he spends nearly all the time I'm there in the toilet [laughs a little] (Margaret: Int.1, p.4).

Some sights, sounds and smells were perceived as alien by family members. The dis-ease of being a visitor experienced by some family members is countered primarily by the hope that it is in the best interests of their relatives to be in the facility. Also they accepted that residents were ill and were not responsible for their behaviour. Family members learnt to be patient and to allow for or endure the behaviour even though they remained uncomfortable with some of the sights, sounds and smells. This was especially notable at the second interview. Barbara shares this experience of the first visit I interviewed her about.

All that noise in the lounge, the TV and that... She's never liked noise. The staff have to keep it on because some patients want it. Ah, well, it's their right too. And...but I have noticed in the lounge there, you know, ah, it's fairly close if you're talking. And if I tell you something not really funny... I was holding her hand. And she's so sick and I said, "Anne, hang on, hang on," and I was ... talking to her and saying what a lovely, neat person she's been and... Then I said if she really wanted to let go, if it was time to see George now, then she should just let go ... And this little old lady said, "Yes, yes, I will". And I thought, huh- [frowns]. (What was that like for you?). Well, the truth is I don't want to know if one of the patients there has died [laughs a little]. When this old lady said, "Yes I will," it was so awful, I didn't realise she was so close. But they often do that, there's so many of them, I'm just scared to relax (Barbara, Int.1, p.6).

In the following passage Barbara talks about the second visit I asked her about, five months after her relative entered long-term care.

What I still can't take is the noises some of them make, and the smells! One old man who often sits in a chair close to Anne ... makes the most awful moaning sounds, he goes on and on and on... It drives me mad. I asked the nurse could she do something about it, and she said, "He's not in pain," in a tone of voice, and why don't you mind your own business. ... But... by and large the home smells clean, she's clean, and she will know she's clean and looked after. I think that's why she's looking so settled now. And, you know, that's what matters to me (Barbara: Int.2, p.3).

The small personal space and lack of privacy was a problem for most family members. Family members sometimes met residents with inappropriate behaviours, such as repeatedly calling out to them or frequently hovering near them, and they were unsure of the best way to respond. Resilience was more notable on the second visit described, thus probably learnt with the passage of time. It was of concern to some family members that some staff did not make efforts to respect family privacy by knocking on

doors before entering the relative's room. Furthermore, they thought that if their relative had to share a room with other residents then staff needed to make efforts to have compatible room-mates for their relatives. Kane, Caplan, Urv-Wong, Freeman, Aroskar and Finch (1997) in their study also found that cognitively intact residents attach importance to choice and control over matters such as roommates. The staff they interviewed also viewed such control as important to residents but to a significantly less extent than residents did. What residents' family members viewed as desirable was not explored by these authors. In this study Chris and Jane discuss their feelings.

Being in the four-bedded ward is of concern, uh, to me ... She would like a single room ... and I'm not surprised because ... the other three in the room, they're not really all that... They're such different people. They seem to get on but she finds the radios and TVs of Lilian who's in the next bed and Molly in the bed opposite quite intrusive. I find that, too, when I'm there, visiting ... It's just how people feel about company isn't? I guess you can get quite tired of it. They're nice people. But on the other hand, Lilian is so close, though the other two are further over the other side of the room. But ah, it's the use of equipment and the curtains, it makes it hard to keep the privacy. Though I don't think it bothers Jean that much, but she and I would both prefer for her to have a room of her own (Chris: Int.1, p11.).

And now she's in a single room. And that has been a God sent. That was my thing when we were told it had to be hospital care, you know, where do we go? I mean, don't get me wrong, the ladies she was in with were really lovely and she enjoyed that company but that's fine ... but not over a long time. And with Mum at her age it could be years. She's got her own things round her in here and it looks really good. And you couldn't really talk in that other room. It was very, very small. We [self and husband] work full time. The only time I can come is after work or first thing in the mornings which was not really visiting times. All the staff were busy doing things. But of course, at night time when we came in all the people in the room were in bed. To me, I felt it was invading their privacy as well as Mum's (Jane: Int.1, p.1-2).

Perceived-loss-of-some-control

The experience of being a visitor was perceived as stressful by most family members as they sought social contact, inclusion and involvement and also some control in the care of their relatives, as well as time with relatives. Callery and Smith (1991) undertook a study of nurses involved in the care of children on a children's ward. These authors asked the nurse participants about whether they chose to negotiate roles with the parents of the children in the ward. Callery and Smith found several environmental factors that work against family member control. They emphasise that problems of loss of control or unequal power relationships are, in part, territorial, caused by family members visiting in the nurses' workplace, with attendant lack of privacy, facilities and control. According to the authors this could be counteracted by the provision of an informal family-centred environment, but this is difficult if the ward is organised to suit the medical model, with all residents including those with cognitive and also those with physical impairments, sharing space on the same ward as was the case in this study. Chris and Gloria explain what some loss of control mean to them.

I feel ... they're happy for me to be there doing little things, like helping with feeding and toileting, to show interest in her care and yet at the same time let them make the decisions and for me to be considered a nuisance otherwise. We're reasonably capable of making up our own minds about treatments and things as long as we're adequately informed about the pros and cons... (Can you say a bit more about that?)

I feel they like me to be involved but only up to a certain point. ... I feel they keep control. Despite ... me knowing her better and for longer by far ... I want to be there for her as long as I can. I'm aware, I'm 79, and ... that the time will come I can't drive in to see as often as I'm doing now. I'm probably not much younger than a lot of the patients! I've still got some worries, particularly with regard to the vomiting. ... She's never without a kidney dish right at her side. And of course she can hardly eat... No wonder those wounds are not healing, I say. Yet, all in all, the nurses seem to do their best. Some of the nurses seem to want the, what I can tell them about her, others not (Chris: Int.2, p.3-4).

...he [husband] had some mouth ulcers. I'd been on the look out for them because he's on antibiotics for a chest infection and he's prone to a sore mouth when he's on antibiotics. So I went to find the nurse and she said, "Thanks, I'll look into it". I just hope she doesn't forget. I've learned that they say they like you to be involved and interested but sometimes I think, um, that's words. They've hinted, some of them, that I'm overanxious, overprotective about him. I don't think they can understand just how hard, when someone to whom you've been married to for all those years and whom you've cared for because they're sick, how hard that is, to let them take it all over just because you can no longer on your own do the physical work. I sometimes think they're happy, the staff that is, they don't mind you being there as long only as you're not in their way [Sighs] (Gloria: Int.2, p.5).

The component having-no-other-ways-out supports the subtheme perceived-loss-of-some-control. Having-no-other-ways-out revealed the participants' mixed feelings about their relatives' placements. The institutionalisation and visiting of their relative represented some losses for family members, especially the perception of a loss of some control over their relatives' wellbeing. However, the facility also represented safety and security for their relatives and of respite for family members when they could no longer cope with their relatives' physical and /or mental illnesses. As Margaret points out:

It was good there was a place like that, I wasn't feeling so good ../.. Mind you, no one would ever want their husband to be in that kind of place. It's not home, after all, is it? (Margaret: Int.1, p.4).

Most family members valued the facility with regard to the standard of care provided, the friendliness that most of the staff showed them and the cleanliness of the facility and its beautiful garden setting, but their mixed feelings regarding their relatives' placement were shown in their stories. For example, Sally said, *"It's not home but there's probably no other place for old folks"* (Sally: Int.2, p.2).

Speaking of the facility as a “place like that” and “it’s not home” were frequent, comments on the facility’s institutional character. The comments emphasise the importance to family members of a homelike setting as will be discussed in the next section, keeping-the-continuity-with-home. Yet they simultaneously realised that for the facility to be a supportive one for their relatives, it also had to be a restrictive setting. One family member referred to the facility as a “holding pen” for “old fuddyduddies”. Family members perceived that the institutional character of the facility meant they found it difficult at times to think of the facility as a home.

Family members’ perception that they had no other ways out concerning their relatives’ care and placement was the foundation of their understanding that they had lost some control. In this way family members saw their relatives’ placement in the facility and their own visiting there as having to adjust to these changes. They related how their relatives required long-term care and could no longer live with them in the community because of their relatives’ poor physical and/or mental health. By the second interview, approximately five months after their relatives entered the facility, most of the family members were resigned to the fact that their relatives had to be in the facility because of deteriorating health and frailty. Margaret’s explanation was characteristic. *“He is sick such a lot... So that is where to be* (Margaret: Int.2, p.4).

Most family members were impressed by the levels of care that their relatives received and by the overall quality of institutional life that they witnessed. They felt that the facility was a far better place to be in than many long-term care facilities portrayed in the media. Family members felt relieved and reassured that institutions of this type could be run with concern and humanity. They expressed gratitude for the people who worked in the institution and compassion for those who live in them. This notwithstanding, many family members found it hard to believe that some relatives were content to be in the facility. Family members’ attention centered on the loss of freedom that institutionalised people have undergone. For these family members independence meant having control over one’s own life, which, in their eyes, is something that residents lacked. Jane illustrates this point.

I didn't click... how very different it is from having her at home. She has to eat when the others eat. And going to bed... But ../. she is one of so many people ... (Jane: Int.2, p.8).

However, at the same time, independence had a different connotation for themselves. For themselves, having their relatives live in an institution meant freedom from worry about the day-to-day details of food, security and shelter, as well as freedom from having the burden of 24 hour care for their relatives. Thus there arose the paradoxical situation that the family members' perceived-loss-of-some-control over their relatives at the same time gave family members some freedom.

Keeping-the-continuity-with-home

All the family members wanted their relatives to maintain a feeling of continuity with their previous lives. It was important to them that their relatives have bits and pieces from home in their rooms in the facility. Family members believed that this helped to keep the continuity with their previous lives for their relatives and it also helped some family members themselves to begin to feel more at home in the facility. Displaying some of their relatives' personal effects, such as photos, books and knick-knacks allowed the family members to reveal some of their relatives' private past to other people in the facility. Family pictures and other objects such as furniture were also helpful in reminiscing with their relative. However, as Cram and Paton (1993) also found, though a facility might have a policy of giving permission for residents to bring in personal possessions, in practice such possessions are not that welcome. In my study, this seemed to be partly due to the fact that there was so little room in the shared bedrooms and also due to the fact that the facility did not want to have to pay out if possessions were lost or broken. For example, though the facility allowed residents to bring ornaments, a family member related how her mother's had been placed in a cupboard after one ornament had been accidentally smashed. The others were replaced on the locker when she assured staff that she minded any breakages less than her mother being deprived of being surrounded by her treasures. Cram and Paton suggest that being able to keep important, symbolic possessions with them in the facility, may well have aided the residents in their study to adapt to their new environment and may have helped them to maintain a stable and coherent self-image.

Family members in my study, however, also perceived that while the facility was different from home, in another way, it had become their relatives' home. Most accepted that it was where their relatives would live their last years and where they would be visitors for that period of time. Remarks such as "*He'll be here till he dies and I'll be coming in till then*" (Gloria: Int. 2, p.5) were frequent. Family members had to adapt to this change in living circumstance for their relatives, due to their relatives' increasingly complex care needs. This adaptation was especially notable by the second visit. Sally, Barbara and Gloria explain.

I felt [facility] provided what she needed .../. She had been on respite there before, but in a different section. Though that section had all single rooms. She'd never had to share before. I found then and I still find that the [facility] has a welcoming, ah, a homely feel about it. I'd make myself a cup of tea or be offered one and I always felt welcome. They encourage you to bring photos and ornaments and things-and hang them on the walls above the bed and put on top of the locker. 'So I didn't feel I lost her in that sense. .../. However, when all's said and done, it is an institution, of course, though they do make some attempts to personalise care for the patients (Sally: Int.2, p.2).

I like the wee fluffy animals, all those sort of things. It's just, yes, like a lot of old people would like (Barbara: Int.1, p.8).

There's comfort all round. The chairs... The decor is a bit shabby. The carpets threadbare in places... I also really like all the personal things they have .../. Gus has a board behind his bed with photos and some of his medals, he's also got bits and pieces from home on his locker. The nurses said, "They, ah, they might remind him of home" and I find that a comforting thought, but I don't know, I think Gus isn't really too aware, now [Sighs]. (Gloria Int.2, p.5).

This study thus consistently emphasises the importance of a homelike setting for family member wellbeing. Family members spoke of such a setting as making the facility

“cosy”. Therefore appreciating-cosiness emerged as a component of the subtheme keeping-the continuity-with-home. They perceived as appropriate the opportunity for their relatives to sit or walk in the garden, the beauty of which most family members commented on, carpets on some of the floors, and the accumulation of personal belongings in bedrooms because this was both cosier and more like home. Several family members related what they would like changed to the facility’s appearance if they were in charge of it. Changes included curtains and bedspreads that matched, wallpaper and floor coverings which were both attractive and yet functional, an aquarium in the lounge and more large cork boards where residents could display photos, cards and other items of interest to them. Another suggestion made was redecorating the bathrooms which looked cold and institutional. Several family members suggested soothing music to be played as needed. Above all, their wished-for changes included individualising their relatives’ rooms through decorating projects.

Five of the family members commented that the ward had only one pet, a cockatoo in a cage. These family members would have liked at least one other animal in the ward as they believed that their relatives would really enjoy the company of pets. The main reason was that their relatives had had pets at home from which they were very sorry to part when they entered the facility. Another reason given was that pets make a facility seem more friendly and homelike. Wanting-the-comfort-of-pets is the second component to support the subtheme keeping-the-continuity-with-home. Jane and Jim relate.

I'd love to have a cat up there. Because Mum loves them ... So that would be lovely if they could get a nice, soft, lovely cat (Jane: Int.2, p.9).

The bird squawks a bit. But, um, I think you know, some people just like to hear that. The others might. Madge, I don't know. I just don't know how much she takes in. But she just loves our cats. And she would love to stroke one, if there was one, there (Jim, Int.1, p.8).

These findings are supported by research. Research has shown that the presence of companion animals or pets increases the socialisation of residents among themselves, with staff and with family members who visit (Savishinsky, 1985). Muschel (1984)

suggests pets facilitate by being social lubricants. For example, animals affect the dynamics of family visits by providing a focus and something to talk about in situations that can often be tense, awkward or full of silence (Savishinsky). When people speak to animals, they often touch them as well. Touching is a means of communication that can be highly effective in reducing stress (Muschel). She adds that the nonverbal communication and physical contact with animals diminish the negative consequences of the sensory deficits and emotional losses of older people. Furthermore, pets can help older people adapt to life in the care facility. Older people do not have to worry about being rejected in their dependent state, for the animals provide love and reassure them of their value, even in their weakened condition.

Corson and Corson (1983) state that animals are effective 'social catalysts' causing people in a care facility to relate to one another more frequently and effectively. Animals provide a neutral topic of conversation for residents and their visitors. The loneliness and despair many older people experience in care facilities is often increased by the trauma of having to part with pets when they enter institutions. The presence of animals counteract these negative feelings by offering comforting and supportive interactions. Pets recreate an aura of domesticity for residents who have been cut off from their homes and families by age and illness. Francis and Odell (1979) also found that pets provide the warmth, companionship and sense of purpose that many institutionalised older people lack. Crowley-Robinson, Fenwick and Blackshaw (1996) found there was a trend for decreased tension, depression, anger, fatigue and confusion among the residents that they studied but also significant increases in vigour when there were pets in a facility. Lastly, Roenke and Mulligan (1998) explored the characteristics of pet therapy in a long-term care facility. They found that pet visitation promotes positive experiences and improved the wellbeing of residents. Characteristics which contributed to the benefits received by residents included humanness and the ability to facilitate reminiscence. These qualities may enhance the physical, cognitive and social-emotional benefits received by long-term care residents participating in pet therapy.

Summary

This chapter has explored the essence of *perceiving-visiting*, identifying subthemes and supporting components. The chapter was also linked to the phenomenological concept

of lived space as a function of how family members shaped the way they comported themselves in the long-term care context. They learnt to become insiders to the nurse work group, to cope with the loss of privacy in the facility and with some loss of control in the situation. All the family members welcomed and encouraged a continuity with the homes their relatives had left behind and the majority wished for the presence of pets in the facility. Chapter Four in particular reveals the need for more personal space when visiting in long-term care. Family members often lacked a private place in a geographical or emotional sense where they could go if they felt the need for such a space, for example, if they felt especially stressed. They were conscious of the space to which they were limited. For many of the family members, their stress and anxieties about being visitors to their relatives meant that the ward was not a situation where they could feel at home in the sense of being relaxed. Overall, family members perceived that they could show that they cared for and were at times anxious about their relatives but felt they could not give a sense of being over-solicitous or possessive. They could be at their relatives' sides and show interest in their relatives' care but felt they were expected not to be a bother. They could also show that they were prepared to participate in their relatives' care and that they were capable of providing care for their relatives but felt they could not give an impression of usurping the staff's role and felt obliged to concede that formal care providers knew better than them. These perceptions were very stressful for family members.

These observations have implications for nurses in the way they work with people who are visitors which will be discussed in Chapter Eight. The next chapter will discuss how the participants learn to live with visiting.

CHAPTER FIVE

LEARNING-TO-LIVE-WITH-VISITING.

Well, I give her a peck, and ask her, uh, if she... I try to remember, uh, her troubles from the day before. The likes of today, she, uh, had been at war with Lynne [physiotherapist] ../.. And so Lynne is on the 'black list just now. And uh, so I try to cover it, you know. ../.. Anything that I may try for a conversation she either blank-out or doesn't understand. So it is not easy. But so far, you know, for the time she's been there, uh, I've learnt to cope (Jim: Int 1, p.7).

In chapter Four, the family members' stories related their experiences of *perceiving-visiting*. Their stories revealed both positive and negative aspects about being a visitor to their relative. This chapter proceeds to disclose the stories and add another facet to what it meant for participants to experience being a visitor as they sought to continue their relationship with their relative in the long-term care facility. There are four subthemes which support the second essential theme *learning-to-live-with-visiting*. These are learning-changes, learning-to-communicate-with-relatives, learning-to-communicate-with-other-residents'-families and learning-to-communicate-with-health care providers. Learning-changes has the components adjusting-to-loss, role-strain and redefining-and-negotiating-roles. There are components to learning-to-communicate-with-relatives. These are being-family and continuing-the-relationship-in-diverse-circumstances. Learning-to-communicate-with-other-residents'-families has the component finding-others-who-understand. Learning-to-communicate-with-health care providers has the components commitment-to-being-involved-and-sharing-the-care, trusting-staff-to-give-help, expressing-concerns and lastly, stressful-relations-with-staff.

Lived relation

The theme of learning is expressed by all family members. Learning influences and is intrinsic in the four lifeworld existentials as discussed by van Manen (1990) but is of special significance in the existential of lived other or our interaction with others.

Relationships with others is known as relationality, described by van Manen (p.104) as “The lived relation we maintain with others in the interpersonal space that we share with them.” In this chapter I will discuss the themes revealed in the study appropriate to the existential of lived relation.

Learning-changes

Family members had to learn-changes to their usual roles and activities. Lived other concerns the relationality between the family member and the others engaged in the lifeworld. All the family members told of how they developed new relationships with many others and how present relationships sometimes changed when they were visitors in the care facility.

Family members’ roles and obligations varied and were influenced by their life stage and individual circumstances. All family members described the roles they normally undertook. These roles included those of husbands, wives, mothers, fathers, sisters, brothers, workers as well as having had the role of being the primary carer for their relatives in the community. Family members discussed their need to learn to make some changes to these roles and to let go of some of the obligations they held before the institutionalisation of their relatives. Their visits meant to them some changes in the usual activities of living. For some family members it meant trying to fit visiting around work and family obligations. There could also be considerable financial expense involved through factors such as cost of transport and time off work as well as contributing financially for their relatives’ care at the facility.

Institutionalising and visiting a relative affects a family member’s way of life. The family member needs to adjust to a number of changes: being needed less; accepting the current situation; and forming relationships with the relative’s new carers. All family members showed signs of grief especially during the first interview. Grieving may occur due to the loss of the relationship with the relative as the relationship was previously, the loss of identity as a functioning couple if they were partners, and possibly there is also the lost functioning of the person once known. Yet this loss is indecisive. Unlike loss through death which is absolute, the family member is not free to continue with life to the same extent. The participants thus experienced grieving,

adjusting to separation and the challenges of life after placement which included being a visitor. They may need to learn to adjust to the new reality. So adjusting-to-loss is a component of the subtheme learning-changes. Chris and Margaret illustrate this. Margaret's narrative also illustrates her experience of role reversal. She had become the dominant partner in her relationship with her husband, a position he had held prior to his dementia.

It feels so strange. You know, to sit and to just talk and maybe help her up and down to the toilet and in and out of bed, things like that. But no longer moving about doing the big things like you know, helping with washing and dressing... I should be grateful for not having all that work to do any more and I am, ... There's so many changes I'm having to get used to... My life's so different now that Jean's up there... I suppose I'd got used to the way things were There's no pleasing some people is there? [laughs].(Chris: Int 1. p.4)

I feel I've become a mother of a young person. Helping him get into bed, helping him with eating, that sort of thing. ... It hurts that he is like that. He used to be such a strong person. ... Always took charge (Margaret: Int 1, p.2).

It thus seems that the relative's institutionalisation does not eliminate the stresses for family members. Ade-Ridder and Kaplan (1993) noted that though family members may value knowing that their relative's care is excellent, their own specific roles to be enacted once a relative moves to a care facility are ambiguous and vary. This change in roles was also experienced by many of the family members I interviewed. For example, in my study many of the family members found that new roles are added to their usual role set such as becoming 'visitors' to the facility, while other roles are lost such as the role of primary carer. Role change can lead to stress. It may occur because of conflicting demands on a person to simultaneously play various roles. Chris provides an example of role strain because of added roles.

Well, I had a cup of tea with her, and she seemed to really enjoy that. Which then made me feel good, glad that I now make the time to be with

her. Which can be really hard at times, because I've got the garden and house to look after by myself now, and I'm 79 (Chris: Int.2, p.1)

This narrative illustrates both learning-changes and the resulting feeling of role strain. Role-strain is the second component of learning-changes.

The caregiving role did not end on the placement in long-term care. Instead, family members become visitors and most provide services in concert with the facility staff. Thus their roles are redefined. While visiting, family members may offer support by advocating for the relative, feeding and providing other forms of physical, emotional or social care. The change in caregiving roles may change the status of family members in several ways: from primary carer to visitor, from insider to outsider and possibly back to insider again, and from high control to low control over priorities of their relatives' care. Conflicting role expectations between the family members and facility staff may lead to tensions between them. This is consistent with other literature (Bowers, 1988; Duncan & Morgan, 1994; Kelley, Swanson, Maas & Tripp-Reimer, 1999; Rubin & Shuttleworth, 1983; Shuttleworth, Rubin & Duffy, 1982). Difficulties between family members and staff will be discussed later in this chapter.

Schmidt (1987) suggested that pressures between the family member and nurses can be alleviated by validation from both of a continuing family member role. In my study, some family members negotiated new ways to care for their relatives that meet the needs of both their relatives and themselves. As well, these family members accepted the present circumstances and understood that their actions are restricted by the structure of the relatives' present home and circumstances. Redefining-and-negotiating-roles, the third component of learning-changes was part of most family members' experiences when visiting.

Sally shared her experience of the need to redefine and change roles as a consequence of the institutionalisation of her grandmother and thus being limited to visiting her. She explains.

You know she was here [Sally's home] every day, ... it just seems strange. It seems like I ought to go and see what's she's up to or where she's at, but she's got the nurses now (Sally: Int.2, p.2).

Finally, family members adjusted differently to changes they met. Most learnt to adjust to their changed situations by accepting them. This was particularly so by the second visit described. They believe they have cared and are caring for relatives to the best of their ability. They learn to accept the facility in which their relatives is placed and acknowledge that the relatives need to be there. Others do not seem to have adjusted in a way that allow them to achieve integrity. Chris and Gloria accept the need for a facility for their relatives whereas Barbara has not done so.

...we've got a lot out of the time spent together. I used to worry whether I should have kept her at home a little bit longer. And that upset me at first when she went there. But lately, like today, I could see that they're looking after her. And so I'm comfortable with that the staff are doing some of that caring for her. If she wasn't being looked after, then... Then I'd be really upset. I suppose I'd have to have her back home again and I know that wouldn't work. Friends say, "Yes, you've certainly done what's for the best". And you do know yourself that you've done what's the right thing for her. She's being cared for. And I say, "Yes". My head tells me I've done the right thing... (Chris: Int.2, p.3)

Gus seems much more settled in, that's the main thing, and so I'm able to be more relaxed. I've learned that I can be there for about an hour ... and we both like that, after that I just get tired. ... So Gus, I think, knows that too, and he seems to fuss less when I go home (Gloria: Int. 2 p.3).

I could, maybe, have kept her at home a little longer. I could have coped with the nurse and the other people coming in to help ... I didn't think it would come to this. After all those years we've been close, so many good times, it makes me feel so upset that she's up there now (Barbara: Int.2, p.2)

Learning-to-communicate

To be in the world means meeting with other people. Being in the world is a being with (Heidegger 1927/1962). An important factor in the experience of being a visitor is the relationship of family members with others. These others include relatives, health care providers, and other residents and their visitors whom the participants became acquainted with and who affected how the family members comported themselves. In the rest of this chapter I will consider family members' relationships with others. Subthemes in this area fall within the lifeworld existential of lived other.

Learning-to-communicate-with-relatives

Long-term care dramatically changed the nature of family members' responsibilities as informal carers. Yet their relationship with their relative could continue largely unchanged. For example, on both occasions interviewed one wife's visits lasted for hours to oversee her husband's care and bring him the foods he liked. In this way she experienced a sense of an ongoing relationship with her husband. Particularly by the second visit that I explored with them, the feelings of guilt and self reproach that nearly all the family members had felt when describing their first visit were much less severe and the visit gave them a sense of confidence that their relatives were in good hands: *"I stay about half an hour having a bit of a chat. Then it's enough. I know she's alright"* (Sally: Int.2, p.5). No longer facing the strain of round-the-clock caring meant for some family members that they were able to value being with their relative in a way which had been less likely prior to placement. Some watched TV or listened to music together. One family member found that she had more opportunities to be with her partner and just to relax and chat together. On the first visit described both also attempted some knitting; on the second visit they mainly discussed news from their overseas relations.

Family members had to learn alternative ways to communicate with their relatives if their relatives could not remember what they had previously known or anything that was currently happening in their lives or if they could not speak any more. This altered family members' relationship with their relatives. Barbara discussed such problems when wanting to talk with her relative who was becoming increasingly demented.

Ah, she makes sense, at times, but only for a short time. But it's not always easy... Being with someone who's been so close to you for so long and can't say anything much. I don't really know how she feels about being up there, whether she knows who I am, now. She has moments of being lucid... I see it as a gift, of Anne as she was. It makes me sad, too, and it's confusing, though, because it reminds me of how she was... (Barbara: Int.2, p.5)

Gloria also explains how being unable to sustain a conversation with her relative made her visit difficult for her.

I'm coming to terms with all these different ways he is now ../.. Sometimes he's coherent, but only for a short time ../.. On Sunday, visiting him went well till he suddenly said, "Well, you... Go away, then". And then you have to put up with that. You have to learn that that's not really him. You have to speak loudly all the time, else he can't hear you. So conversation is very difficult. I don't know whether he knows me. He never calls me by my name any more, though. He's started to mutter quite a lot. When he does that there's no, ah, sense or logic... I find it's best then just to sit ../.. But, you see, the brain deterioration that Gus has, uh, it seems to be getting worse. It does make talking with him hard going (Gloria: Int.1, p.9-10)

If their relatives could converse reasonably well, conversely, the visit was experienced as much more valuable by family members. Chris's experience of communicating with Jean was quite unlike Barbara's and Gloria's and gave much more satisfaction.

We chat ../.. about anything at all, really... For Jean, that's someone to have a chat with, and I enjoy listening to her (Chris: Int.1, p.3)

One reason that some family members gave for their visiting was showing staff that fulfilling family obligations was very important to them. They considered that not visiting discredited their sense of integrity. Another reason for visiting that several

family members remarked on was that they thought staff would be critical of them if they did not visit on a regular basis. However, all the family members interviewed discussed at length that an important reason for visiting was the fact that they were family. Being-family emerged as a component of learning-to-communicate-with-relatives. Rooted in being-family were the relationships and rituals which gave significance and continuity to the family unit. Most family members enjoyed continuing an intimate relationship with their relatives. Though there were deterrents to visiting for some family members, for example, shortcomings in communication, they still valued being with their relatives. Communication was a much discussed topic by family members. They tried to sustain their relations with their relatives by communicating with them about happenings in their present or past lives. Some family members found that being able to talk with their relatives enabled their relationships to stay intimate. If it was not possible to relate verbally, a few family members did not know how to spend their time when visiting their relatives. Sally relates.

She doesn't identify with what's happening with us, our family... there's not much else, so the visits are not long (Sally: Int.2, p.5).

Two family members discussed how food and the ritual of partaking in food allowed their families to feel a sense of being bonded. For these family members, bringing in a treat in the form of food that they knew their relatives would enjoy, enabled them to do something with or for their relatives and gave them, as well as their relatives, some pleasure. Moreover, participating in the mealtime ritual was meaningful to some family members. Chris illustrates the importance of having the chance to continue the ritual of sharing a meal.

I had dinner with her. ... That's what a family would do is eat together and I was made to feel really welcome (Chris: Int.2, p.4).

Being a visitor was hard if family members thought that their relatives were behaving towards them in ways that were inconsistent with their previous selves. Understanding how to deal with mental deterioration has been found to be hard for family members (Stephens, Kinney & Ogrocki, 1991), especially for women (Ade-Ridder & Kaplan, 1993). The family members I interviewed also found fluctuations in the relationship

difficult to endure and especially hard was no longer being known by their relatives for who they were in relationship to their relative. Evan vehemently described how when his mother addresses him by his father's name, "*I just hate it*" (Evan: Int.2). The difficulty of coping with these continuing and changing relationships combined with the many emotions within the relationships are further described by Evan. By the second interview he felt that his mother had forgotten him and so he felt that he had totally lost his mother. However, that state was easier on him when he actually leaves the facility after each visit than when his mother used to cling to him wanting to go back home with him.

Family members experienced distress and feelings of powerlessness when it became impossible for their relatives to converse intelligibly in part because it meant that these relatives could not indicate if they had unmet wants and needs or if they were dissatisfied in any way. The family members were especially concerned that they might not know if their relatives were having physical pain. This concern is an important one as some authors have shown that nurses undertreat the pain of cognitively impaired older people (Kaasalainen, Middleton, Knezacek, Stewart, Ife & Robinson, 1998). Their study found that it was difficult for nurses in a long-term care facility to determine a painful experience when cognitively impaired older people's ability to communicate declined. As a consequence, some residents suffered pain unnecessarily, according to the authors. In my study Barbara was particularly fearful that any distress her mother-in-law might have might go unrecognised by her and by the staff. All she could do was link what she currently observed about her relative to what she already knew about her from their close association in the past. She describes this experience.

Anne's face was all crinkled up with pain. I said to Min, "Well, she does feel pain, now." Ahh. And you come away, and you're like a big booby and you have a bit of a tear. They thought they had it under control, but, I don't know ../. She always felt pain badly, every twinge../. She can't answer, you... If she could. Her bottom jaw moves at times, as if she's trying to say something. And you say, "Yes. You're trying to answer us, aren't you Anne?" And you know, you just try to talk to her as if she can hear you (Barbara: Int.2, p.2).

Family members needed to adjust their way of interacting when their relatives could no longer speak or understand speech. Some family members learnt to use touch instead of speech. For example, they held their relatives' hands or patted or stroked their hands, backs or hair. Sally's grandmother objected to being touched at times which further decreased for Sally her means of being close to her relative. She realises this.

I gave her a kiss and a hug last night, she said, "Oh, how lovely". And then she has days when, you know, you get the sense she doesn't even want you, you don't come near her, but, um, you just take it in your stride but just try, uh, not to take it personally. But although sometimes it's hard if she's having a bad day (Sally :Int.1, p.7)

Thus the experiences of family members when they visited varied greatly. Continuing-the-relationship-in-diverse-circumstances is the second component of learning-to-communicate-with-relatives. Family members' visits at times were "upsetting", "difficult", "valuable" and "good". Family members experienced concern about their relatives, especially about their relatives' wellbeing and about their relatives' adjustment or otherwise to their placement in a care facility and to a lesser extent, about the progressive memory loss of some relatives. It was upsetting for those family members whose relatives did not know them when they visited. One family member noted that this meant to her that she no longer mattered to her relative, after having felt valued as a beloved daughter-in-law for many years. This made her feel sad and somewhat estranged from her relative. Another family member who described how she would try to get her relative to recognise who she was in relationship to him by talking to him about it, attributed her behaviour to her need of continuing the relationship for them both. She said she did not know why this was important to her but thought it might be because it felt so strange not to have her husband recognise her after about fifty years of living together. Family members with a relative who did not know them had to learn to accept the way their relative currently presented while grieving for that person as he or she used to be. Margaret described the emotional effects experienced when visiting her husband.

I sit there and hold his hand, and it's like holding a cold fish. ../. He doesn't know what he's saying, most of the time. He's working ../. I say,

"You're retired now, dear". ... I can only understand a little of what he says. If I could understand more I could help more and not feel so useless and awful (Margaret: Int.1, p.6)

All the family members whose relatives had dementia experienced grief for the progressive and irreversible change and deterioration in their relatives' health due to the disease process. According to the family members some staff members seemed unable to help them to overcome problems with communication, telling family members or indicating to them to just accept the situation as it was. Two family members who mostly accepted the lack of verbal communication, Sally and Margaret, did feel that adopting such an attitude made visiting less stressful for them. However, others, such as Barbara in particular, and to a lesser extent, Evan, had difficulty with adopting such an attitude. On the whole, those family members whose partners were the persons institutionalised, seemed to feel the most profound emotional effects. However, by the second interview, they seemed to have adjusted to the loss of their partners as they had once been, but strong ties of commitment continued which then prompted them to keep up the visiting. Margaret and Gloria reflect on this.

When I'm there, I'm busy doing things but it's also, you know, a lonely experience. Like, yesterday, I sorted out the clothes that he's to wear today and I took away the clothes that I handwash at home. He had hallucinations and accused people-family, staff, of setting him up and making him crazy. That sort of thing, they're very hurtful... ... That person you've loved isn't there, lost. If you can accept that, it's less hard, I think. There's hardly no response, nothing like we used to have. I find it really hits worst when I'm doing my visiting there to him (Margaret: Int.1, p.6)

I told Gus different things that are happening ... Like things happening in the family, and other things that he might be interested in. Like anything to do with the RSA ... But we don't talk like we used to. You have to be careful what you say. ... I don't tell him about any deaths I know of members that he knew. That might upset him. On Sunday I told him that his brother-in-law ... and his sister, Gus's sister, are thinking

of coming down to see us sometime ../.. He seemed to take that in and smiled and nodded anyway... (Gloria: Int.2 p.1-2)

Yet loss of acknowledgement as a result of cognitive impairment could greatly affect the relationship between family members and their relatives as it negated prior close bonds. However, on occasion, these same relatives showed flashes of cognitive insight. This meant family members experienced some longing and sometimes also some conviction that there was some enduring acknowledgement of them. Family members learnt that acknowledgement fluctuates. On the first visit described, one family member was remembered by his wife to be a member of the family, and yet earlier within the same visit his wife seemed to barely know him. Jim shares his feelings.

I'm apprehensive about what Madge is going to be like when I get there. Um, you know, because some days she's good, and some days, like today, she's ../.. doesn't know me. I'll be there talking to her for a while and she's not quite herself. And I think that because, since she'd that problem with the hip. But, um, I can't explain it really. Yes. And I go out and I think, oh, God. And I try to be as bright as I can (Jim: Int.1, p.2).

Jim continues:

She will say, "You're not really leaving me, are you? Well, what am I going to do? I don't know what to do. You're my husband". You know, but that's a panic thing she gets ../.. So round about teatime I'll say, "I have to go now" and the nurse will say, "Oh, I'll fix her. She'll be alright. You just go". That upsets me though, every time she does that (Jim: Int.1, p.9).

Though overall emotional commitment to their relatives was high, a way of reducing stress which some family members learnt to use during their visits was to keep at some distance emotionally. This kept family members from experiencing too much disappointment and distress especially if relatives no longer knew them. However, moving away emotionally can itself be stressful as it made some family members feel alienated from their relatives. Their ways of coping with such stress were not always

understood by staff which could compound feelings of alienation and unhappiness. Jim describes his feelings.

If I'm there and she's abusive to me, I shut off, anyhow, but the staff cannot understand. I just think of how she used to be... (How does that make you feel?). It makes me feel like a martyr. And I don't want to be a martyr... She doesn't understand me. She doesn't understand her surroundings. And she likes to dominate her presence... But I am there for the simple reason that she is my wife. (Jim: Int.1, p.1-2)

He thus learnt to distinguish his wife as a relative whom he continued to value as such, from the person who because of her condition has changed towards him. This process was a painful one.

Learning-to-communicate-with-residents'-families

Most of the participants in this study had not previously experienced the placement of a relative in long-term care. The visitors of other residents, usually family members like themselves, were an important source of social contact for some of the family members. Several also received considerable support from the visitors of other residents. As described by Aneshensel, Pearlin, Mullan, Zarit and Whitlatch (1995), social support processes modify families' stress experiences. For the family members I interviewed, social support modified the stress associated with visiting their relatives. Support often was recognised as just talking with the other residents' visitors. This kind of social support for family members was described as the act of others sharing the burden of the experience of being a visitor.

The experience of being a visitor is thus shared with other families visiting their relatives. This came about through contact family members held with other families mainly in the lounge. Some of the family members were keen to communicate their own experiences to other visitors. They often learnt that their experiences were similar and they felt understood and this was a source of comfort and support. In this way their visits enhanced the family members' wellbeing. One family member described the relief she felt when a nurse introduced her to someone who had similar experiences to hers.

Through talking to another woman who knew similar stress she learnt that she was not alone. Other family members told of similar experiences. So finding-others-who-understand is a component of learning-to-communicate-with-other-residents'-families as shown in these narratives.

I've made some friends up there ../.. Uh, we talk and they appreciate what's it like, being there (Gloria: Int.1, p.2)

Ah, just knowing. ../.. You're not on your own, that's comforting (Margaret: Int.1, p.9)

What I do really like is the chance to talk to other people there. One woman ../.. Her husband has dementia like Anne and she's been coming to see him for six years! Well, we've talked quite a bit over the last months and I've learned a lot ../.. Like what to expect as far as the physical deterioration is concerned, which staff to best approach, how to get information from them, where to find things in the kitchen and so on (Barbara: Int.2, p.3-4)

Learning-to-communicate-with-health care providers

Relationships with health care providers are complex and to some degree require the handing over of control to others who are perceived to be experts. All the family members valued nurses who gave expert assistance and those nurses who showed genuine interest in the family members and their relatives. Most family members also appreciated staff who worked in partnership with them, especially nurses who shared their knowledge with them but who also encouraged family members, and residents themselves if possible, to make the ultimate decisions concerning residents' wellbeing. Such health providers were seen as a source of support.

The family members mostly had a good relationship with the care staff especially with the charge nurse. They valued this relationship because the charge nurse seemed to appreciate their knowledge of their relatives; she was the health care provider who knew them and their relatives individually. This relationship was perceived by some of the

participants as a partnership in the care of their relatives. The family members spoke of the information communicated to them and some felt well informed, some of the time. Chris and Gloria illustrate.

... some, [nurses] they tell me things ../.. I still felt responsible and I wanted to know what she was doing and everything ../.. They were really good, ah, they helped me a lot by talking to me and explaining things to me... (Chris: Int.1, p.9)

You see, too, with being married for so long and then looking after him for all that time I know him so well, his likes and dislikes. Like food and clothes. Um... And the side he sleeps much better on. Some, the nurse, sister in particular seem to appreciate what I tell her, them, and she will tell me what's been happening to Gus since I was last there. Like the pills. Why he's on antibiotics again. And also why some of the ointments aren't working. That's why he's on antibiotics again. Well, he's my husband. I really appreciate her time ../.. And she'll listen when I tell how I feel about Gus being there, and she understands. And then I don't feel so worried or guilty (Gloria; Int.2, p.6)

All the family members gave emotional support to their relatives, some also gave physical care and some advocated for their relatives. Commitment-to-being-involved-and-sharing-the-care is a component which supports the subtheme learning-to-communicate-with-health care providers. All the family members believed their visits were a means to uphold their relatives' welfare, to continue to have some responsibility for them, to help to protect their relatives from harm, to be kind, considerate and observant. These beliefs constituted a commitment to care. Chris and Gloria spoke of their involvement in their relatives' care which they considered they shared with health care providers.

I prefer it when I know the staff, know their routines and know what they're happy for me to do with Jean. It varies with different ones, you know. With most I'm made to feel welcome and they're happy for me to be involved. I feel as much part of the place as Jean. Though if I query

something, they like to think they know best! Like the fact that she's so nauseated and vomits so frequently. I feel it should be investigated by a specialist but the sister says it's only related to the drugs she's having for her infections (Chris: Int 2, p.3)

I don't find going up there quite as hard as I did then ../.. I think I've just got used to it ../.. And I know he's in good hands. I've got to know the staff really well. Well, the regulars, anyway, and they know me and they'll tell me things. I've got trust in them ../.. I know the routines up there, too, and that helps a lot. I don't go when I know they're doing things to him like showering him because that means I just have to sit there and I may as well not be there. But I like to go at mealtimes because I like to help with feeding him and the staff are more than happy to have me do that. If I go up at teatime then I can help get him get ready for bed too. I know how to coax him to roll so his clothes come off more easily and the aides will take, will listen and do it the way I've found works best when I did it for so long at home. Although it's becoming harder now, he's become more stiff (Gloria: Int 2, p.3)

Conversely, Barbara related how she wished for involvement but felt this was negated by staff.

I'm just genuinely interested in anything to do with Anne, not nosy but concerned for her wellbeing in every way, like I have been for the last few years when she relied on me so much ../.. No-one really tells me what's been happening to her so I don't know. She can't tell me... (Barbara: Int 1, p. 9).

The family members held different perspectives of the help they had been given in the facility. Most found health providers to be usually obliging and friendly. Family members also valued nurses whom they could trust to provide the care they wished their relatives to have. They also valued help for themselves that was of a practical, problem-solving type. An example of such help offered to several family members included a nurse's advice on where to find privacy in the facility. Several family members talked

of how much better they felt when staff initiated communication and appeared responsive to their concerns. One family member still had some worries about the use of medication and restraints, but felt staff cared and could be trusted to do their best. Trusting-staff-to-give-help is the second component to support the subtheme learning-to-communicate-with-health care providers.

Some family members worried about the drugs their relatives were taking. For example, one family member was concerned about the large number of tablets her relative was taking. She wondered if these were contributing to her relative's sleepiness and lethargy. However, most family members said they trusted staff would tell them of significant matters concerning their relatives. Gloria illustrates: *"And there's always staff around ../. There doesn't seem to be a barrier between any of us especially when he [husband] is poorly"* (Gloria Int 1 p.2).

In another example, staff communicated concerns about his wife to one older family member on his visit which he experienced as support. In addition, he learnt to develop a relationship with the staff. They have humorous exchanges and this means to Jim that he looks forward to seeing staff. He believes that the staff care about his wife's wellbeing and this is a relief to him. It makes him feel that he can trust them to take good care of his wife. He also described how when his wife suffered an acute infection and was confined to her room, the staff took time to come in the room to see if he needed anything and to see how he was doing. He said *"the staff look after me"* (Jim: Int. 1, p.6). He valued caring activities, for example, the careworkers bringing him a cup of tea and bringing him a comfortable chair to sit in.

Several family members who wanted to contribute to some of the personal care of their relatives reported that staff viewed them as interfering with their planned care; some family members who suggested improvements in their relatives' care found that their suggestions were perceived as criticism by some staff. Thus in these ways relationships with staff were experienced as difficult. Family members as well as staff may believe themselves primarily responsible for the residents' care, leading to role ambiguity and lack of trust. This sometimes resulted in tensions developing between family members and staff. In Barbara's view, she knew little about professional nursing care but she was well acquainted with the needs and wishes of her mother-in-law.

Well, you know, if someone can't communicate I think you've got to be involved. ... I noticed how the skin was broken [between relative's toes] and she's so prone to infection. ... You have got to do battle for that person so I went and questioned and they didn't like that... (Barbara: Int. 1, p.12).

Some family members met with staff policies and procedures that they did not agree with and they had to decide whether or not to bring their concerns to the attention of staff. When expressing their concerns family members thought they were also involving their relatives and so they learned to consider how this might affect their relatives. Expressing-concerns is the third component of the subtheme learning-to-communicate-with-health care providers. Family members thought that communicating disapproval to staff might result in backlashes such as their relatives' care being compromised or even being told to remove their relatives from the facility. Tilse (1997b), as discussed in the literature review chapter, also found that spouses of residents thought that they might be asked to remove their relatives from a facility if they made complaints. Tilse concluded this was one reason why spouses felt they were in a weak position to act as advocates for their relatives though they dearly wished to be advocates. In my study, family members noted that the possibilities of being asked to remove their relatives from the facility as well as other forms of backlashes would be damaging to them and to their relatives which thus made it hard for them to express their concerns. Barbara reflects on how this affected her.

I try not to say too much, not sound too complaining, about the care she gets, because I'd worry that they might tell me to take her elsewhere. And then what would I do? (Barbara: Int. 2, p.2).

Thus at times the care that was in fact given to their relatives was of a lower standard than the care that family members anticipated would be given. However, some family members said they were selective in the issues which they will tackle with the staff. Margaret was hesitant to express a minor complaint. Yet when she did, it was promptly acted on, and she said it would encourage her to express complaints in the future, if she considered this to be necessary. She shares this experience.

...there was a towelling round his neck that I thought was a bit smelly. He was dribbling, you know. And I said to somebody, you know, it's a bit wet. And straightaway it was off. No hesitation (Margaret: Int.2, p.9).

Robyn Stent, New Zealand's Health and Disability Commissioner, suggests establishing a protocol for communicating with families on matters regarding residents' care (Wenley, 1997). She believes that rather than complain to the care facility, many families move their relatives to another facility and often only then will they complain about the former one. However, the Commissioner has seen many incidences where the new place does not meet people's needs either. She states that care facilities must take positive steps to ensure that they make it easy and non threatening for residents and families to express their concerns (Wenley). If such steps were implemented the quality of care for residents in care facilities could be enhanced.

In my study, although all family members very much longed for a satisfying relationship with staff, some were moderately isolated or outsiders. These family members felt that this was primarily due to two problems. One problem involved their interaction with their relatives. They felt isolated and upset if their relatives' speech changed and deteriorated and so they were unable to have satisfying talk with the relatives. These relatives were also usually experiencing other cognitive problems at the same time, such as some memory loss and this meant that the overall effect for family members was that being visitors grew increasingly difficult and was perceived as burdensome by some of the family members. However, some family members commented that nurses encouraged them to participate in therapeutic activities with their relatives such as music, arts and simple board games. Helping family members to be involved in the type of activities in which they wished to participate was seen as caring behaviour towards them by these family members.

The other problem was that some staff shared less information about their relatives than family members wished for. Nursing staff in long-term care facilities probably have more interaction with both residents and their family members than other kinds of staff. Thus the information that nursing staff have about their relatives may have considerable weight for family members. Nursing staff are the people who could, more than other

staff, tie relatives to the lives of family members (Karner, Montgomery, Dobbs & WittMaier, 1998; Vosburgh & Simpson, 1993). Yet staff sometimes cannot do so because according to the family members they do not adequately grasp family members' needs and/or lack the time, inclination and familiarity with residents to pass on information to them. Such staff probably adhere to a traditional relationship between formal carers and informal carers that minimise role expectations for mutual involvement in caregiving. One family member suggested family conferences with staff be held soon after admission of residents to the facility to give the family a chance to ask questions and to emphasise how important regular information sharing is to them.

Diverse relationships evolved between family members and staff at the facility. A taxonomy of different relationship arrangements between formal care providers and family members has been made by Twigg and Atkin (1994) which applies to community care. Schofield (1996) applied this to the residential phase of caregiving to enhance understanding of family members' caregiving. The assumptions which influence the attitudes and practices of health care providers are different in each arrangement. These encompass active participation to non-involvement and establish family members' role in giving care. The four arrangements in which family members may be situated are those of 'co-worker', 'co-client', a 'resource' or 'superceded'.

As 'co-workers', staff and family members work together to give the most suitable care for a resident (Schofield, 1996). In such a relationship, health providers acknowledge that it is important to preserve the self-confidence of family members to guarantee good support for their relative. This involves family members bringing their expertise to their relative's care. Their past experience in caregiving is appreciated and included in staff practices. In my study, this kind of a relationship, although not infrequent, seemed to be less common than most family members would have liked.

As 'co-clients', family members are a focus of concern for staff and have their needs assessed together with those of the resident (Schofield, 1996). Family members and their relative are assessed as a unit, and family members have an authentic call on the resources of the facility. Some family members in my study seemed to hold this position at times, for example, in the support staff gave to Margaret when her husband was suddenly admitted to an acute hospital following prostate problems.

When family members are seen as 'resources', their past experience and knowledge is noted but they are not involved in the giving of care to their relative (Schofield, 1996). Family members are seen as past caregivers whose role is limited to that of valued kinsperson and a care historian. Staff recognise that family members can contribute with information they give, this notwithstanding, however, the centre of concern is very much the resident. The degree to which family members are of use as a resource depends on the information which staff request to be communicated to them and whether this information affects the giving of care. In my study, some family members held this position. Chris illustrates.

... most of the time it's [the care] very good. ... they do take a suggestion as if they're interested to hear them. They accept that as Jean's carer for years I do know all about how certain things tire her more easily than others and how certain of her pills affect her (Chris Int.1 p.8)

According to Schofield (1996) a common response of care facilities seemed to be to 'supercede' or completely replace families by not involving them in caregiving. In my study, some family members believed that some staff tried to entirely replace family members by not involving them in caregiving. A few family members in my study did indicate that this is what they wished for, though they in fact seemed to be regular, frequent visitors to the facility. However, for others the thought of staff entirely replacing them in caregiving caused feelings of being an outsider and of purposelessness. Overall staff may overlook important information concerning residents and their care, if family members are given insignificant meaningless roles only. Margaret explains.

...you only want what's best for them but ... they [staff] won't give you answers. ... And yet I know what works for him (Margaret: Int.2, p.7)

Staff are responsible for giving information to family members about any changes to policies and practices in a long-term facility (Jacques, 1992). Jacques adds that staff are also responsible for giving information about their relatives' health and wellbeing to family members because it can be difficult for family members to perceive the full

extent of their relatives' wellbeing. This is especially so for family members with relatives with dementia. On the whole, family members in my study who spoke on this topic expressed a strong wish for the registered nurses or medical staff to discuss with them important changes in the health of their relatives but this wish was not always fulfilled and it was at times the formal careworkers who conveyed to them the more important changes in their relatives' health status. This was unlike Tilse's (1994) study which found it was the senior staff members who were likely to offer such information. Furthermore, family members in my study also wanted the more senior staff members to support them during such a period of change. All the family members especially wanted their loss and grief acknowledged. Such a need for support was also strongly felt when family members were experiencing changes in their own lives. For example, one family member related how he could not visit for a period of time because of increased hours of employment but when he phoned daily to ask about his mother's wellbeing, he was often only given the most brief and curt response (Evan, Int. 2). Family members varied as to the level of information they wanted from staff and also the level of participation they wanted in the facility.

One family member reproached herself and also expressed her annoyance with staff because she felt she lacked sufficient knowledge about her relative's wellbeing. She considered that without such knowledge her relative's concerns could not be adequately met by her. Barbara states.

I told them Anne was not simply dumped there, and that I wanted them to tell me things that were happening to her. ... I had the feeling there didn't seem to be anyone around who actually knew who Anne was. When I asked, "How is Anne?" I got, "Well, ah, I only work here part-time so I don't know". But I want to know what's going on. ... The ones that say something like, uh, "She's as good as can be expected", get to me even more. ... I don't even know what is expected! All the time it's they're not sure, they'll tell me. But it makes me feel I'm failing her, I could perhaps do more for her (Barbara: Int.1, p.12)

One reason why family members lack full knowledge on their relatives' wellbeing on which nearly half of them remarked were neutral comments, such as "He's good," as

Barbara illustrates above, which staff customarily gave in response to questions about their relatives. Several other family members experienced uncertainty about the information they were given. The facility seemed to lack standardised policies and procedures for deciding what information family members were to be given and by whom. Gloria and Barbara share their feelings.

I think there's more to it than they tell me, at times. They tell me only the bits that're not too bad. You feel you're intruding as if you've got no rights. I feel like giving one particular nurse a piece of my mind, but I don't want to be seen as a trouble maker. They might resent it. Take it out on Gus even, when I'm not around. And I do of course realise the staff have lots to do (Gloria: Int. 2, p.6).

I also felt the decisions are being taken away from me as to what was happening to her. They [staff] kept saying "We'll let you know... If there's anything of importance". Or, you know, if there's any change in her condition. But I would just so much like to know the little things that are happening in her life for her (Barbara: Int 1, p.9)

There were difficulties for family members in accessing information when they met with staff who did not know their relatives well. Several family members remarked on the fact that if they could only visit at certain times and talked with staff who worked part-time at those times, then family members could receive little information of happenings for their relatives during the rest of the time, when neither the staff they approached or they themselves were present at the facility. One family member identified the social worker as particularly helpful because she was available in the evenings and seemed to know what was happening with her relative better than the formal careworkers. Some family members also noted that there seemed to be so many different care staff. Possibly there were more casual staff than usual when I conducted my first set of interviews as these occurred over a holiday period. Institutional barriers such as frequent changes in staff meant that some family members held negative feelings about the care environment. Another reason the chances for interaction were limited was the strain of work which staff seemed to be under. This factor was mentioned by most of the family members and will be discussed in more detail in

Chapter Seven. Family members did not like to impose if they noted that staff appeared to be constantly busy. Barbara explains.

But then you don't feel like asking in case you're considered a nuisance and the staff seem to be always doing things... (Barbara: Int 1, p.9)

One family member told of her difficulty in deciding the most appropriate way to ask about her mother's wellbeing.

I do ring most days ... but it's always very brief. I don't think the person answering knows too much. I don't consider myself a very assertive person but I did wish on Tuesday that I had some more say ... I feel as though I'm letting her [mother-in-law] down as I probably could be trying harder on her behalf and yet staff seemed to resist the attempts that I made. I feel guilty if I don't try my best for her, yet I also feel guilty and annoyed if I bother the staff (Barbara: Int 1, p.9)

For Heidegger care is our most fundamental way of being in the world and if there is no care, then there is nothing which is of consequence or shows up as a concern. Family members in my study often referred to caring as being a personal and special characteristic, which made some nurses superior to others. Some family members hinted at Heideggerian concepts of authenticity and inauthenticity when they described nurses. These family members told of the way some nurses seemed truly caring as compared to others who were thought to be only doing what they did because their job demanded it. Staff taking the time to explain their relatives' illnesses especially when there had been recent changes in their relatives' conditions was perceived as very caring by several family members. Also perceived as helpful by some family members were comments from staff about how much their relatives enjoyed their visits. Jim told how a nurse emphasised the enjoyment his visits gave his wife which encouraged him to keep coming.

The nurse said, "Just come when it suits, she doesn't even realise. ... but likes it when you are there". Um, ... she's happy to have me when I'm actually up there (Jim: Int. 1.p. 3).

Heidegger (1962) described a solicitude or care, which “leaps ahead” to enable and legitimately give care back to people (p.158). Family members were grateful when nurses facilitated chances for them to participate in the care of their relatives instead of leaving them isolated and dependent on nurses. According to Benner and Wrubel (1989) “caring...means that persons, events, projects, and things matter to people” (p. 1). These authors describe such caring as the most fundamental way of being in the world. Most family members’ stories of when they thought that caring was good was when they considered that a relationship existed in which they felt they were as important as their relatives to the staff. This was of the utmost importance to these family members’ own sense of wellbeing. On the other hand, a few family members felt that at times the staff as a whole did not care about them but focused only on their relatives. This was shown in family members’ stories of when they felt outsiders, lorded over or not understood. Sally relates how she felt that she mattered to the staff, while Barbara relates that her experience was sometimes the reverse.

... most of them [staff] I must admit, make you feel that what you say is of importance and... it will be taken into consideration and you yourself are of importance to them [staff] (Sally: Int. 1, p.8)

Some, most of them [staff] are just so kind and helpful and then there are some, it's ... we do hope you're going home soon and leave us to get on with our work (Barbara: Int.1, p.12).

Family members who express-concern about the care their relatives received or who experience conflict with staff, usually do so because of differing views from staff about what constitutes good care. Stressful-relations-with-staff is the final component of learning-to-communicate-with-health care providers. Family members who feel they are obliged to protect dependent relatives and think they know relatives’ needs better than formal caregivers, feel they must query the care provided by others (Bowers, 1988). Bowers found that formal carers tend to respond in a defensive way to concerns or questions about the quality of their care and interpret such behaviour as uncalled for meddling with their work. This was also evident in my study as several family members remarked upon it. These family members implied that they watched over the care that

their relatives received because they believed that otherwise the care of their relative might suffer. Chris elaborates.

I do think that the staff are all well meaning people who do their best by her. ../.. Well, I do realise that some are not that good, ah, also, what goes on when I'm not there is probably not the same... not as good as when I am there ../.. when I'm there I look around and make sure they do things proper. Like those subcut fluids, not letting them run too fast. One nurse said that's not good for her (Chris: Int.1, p.6).

Bowers (1988), Duncan and Morgan (1994) and Kelley et al. (1999) found that most family members seek to establish shared caregiving roles and collaborative relationships with staff. In my study, family members also sought to meet their own needs for emotional support, social contact and the alleviation of guilt through relationships they establish with nurses. Family members may avoid expressing concerns or using complaint procedures for fear of disrupting their relationships with nurses as discussed earlier in this chapter. Value conflicts arose for family members when the care that was practised in the facility conflicted with what they perceived to be good nursing care, that is the way they had undertaken care as informal carers in the community. Brody, Dempsey and Pruchno (1990) suggest that the coexistence of formal and informal carers is a situation ready for conflict and disagreement. These authors believe that care in an institution tends to be a task-oriented and goal-directed kind of care. Furthermore, the care is given by people who often do not have a strong emotional commitment to the care recipients/clients. Formal caregivers work within a bureaucratic framework and usually give services in a routinised and organised way whereas informal carers at home tend to be on duty 24 hours a day and give more personalised care.

Intentionality is a phenomenological term which is concerned with the way people interact with others in a shared world of relationships and activity (Dreyfus, 1991). The family members of my study needed to transact relationships with health workers as well as with their relatives and other residents and their visitors. The family members needed to adjust to the demands of such relations. They felt that such an adjustment helped them to become, to a certain extent, part of the team of formal care providers, other residents and their families as well as their own relatives. Such interaction was

much valued by most family members. Enjoyable visits were visits when family members felt they achieved something meaningful to both themselves and their relatives. Conditions that contributed to these feelings related to caring for their relatives, having a degree of autonomy in the facility and working with supportive staff. Barbara talks about how important such conditions were for her.

The nurse who's in charge, she's the best to approach, she makes me feel as if I count, still count in Anne's life. And she involves me, like she'll always tell me, I know, if there's a change in how Anne is
(Barbara: Int.2, p.3).

Summary

Lived other involves the relationality between family members and the others involved in the lifeworld. When visiting in the long-term care setting, family members form new relationships with many others and existing relationships continue to change. This chapter has discussed how participants *learn-to-live-with-visiting*. It detailed how family members adjust to the changes in roles that they experience; how they learn to communicate with relatives and others because of visiting. The family members mostly wanted to participate in the nursing care of their institutionalised relatives but their attempts to do so are sometimes discouraged and resented by staff. These observations have implications for the wellbeing of people who are visitors. These are discussed in Chapter Eight. The next chapter will discuss how the participants are *continuing-with-visiting* their relatives.

CHAPTER SIX

CONTINUING-WITH-VISITING

I come every day ../.. the family has had to fit in. Before, Jack [husband] was never comfortable in the kitchen, now he's much better. I know how much she's [mother] looking forward to it when I come and so that's why I visit every day on the way home. But like earlier this week my brother said not to bother going because he'll be going in. And I thought oh, how nice it would be to go straight home ../.. and then I thought, oh, I can't not go in. And I come ../.. and she said, ah, Steve [brother] said you're not coming but I knew you would. See. She just expects me to come. And I'm tired and I'd like to go straight home after work but then I think well, she's spend all day there and she'd like the family to give her some attention (Jane: Int.1, p.3).

In this chapter the importance the participants placed on *continuing-with-visiting* is described. *Continuing-with-visiting* is the third essential theme and reflected the participants' intention to remain involved in their relatives' care which required them to adjust to the stresses, challenges and demands of being visitors to their relatives. They need to accept their mixed feelings and also adjust to their new life circumstances. Family members seemed to value nurses who enabled them to share the caregiving role and who helped them to work through losses and relationship changes. The subthemes are: *adjusting-to-continuing-the-visiting* and *letting-go-of-the-primary-carer-role-and-yet-continuing-the-visitor-role*. *Adjusting-to-visiting* includes the components *emotional-upheaval*, *adjusting-to-some-loss-of-control* and *coping-with-uncertainty-and-change*. *Letting-go-of-the-primary-carer-role-and-yet-continuing-the-visitor-role* is supported by the component *living-with-ambivalence*.

Lived body

Lived body or corporeality refers to the phenomenological fact that we are always bodily in the world or embodied (van Manen, 1990). He adds that "When we meet another person in his or her own landscape or world we meet that person first of all through his or her body" (p. 103). Phenomenologically, this chapter can be interpreted within the concept of lived body. Lived body encompasses how a person looks and also how the body functions physiologically. It thus incorporates homeostasis and major bodily functions such as the physiological stress response. Lived body is the physical body and signs and symptoms of health and illness that are obvious to a person. However, it also includes how a person contemplates his or her own body (van Manen, 1998). Benner and Wrubel (1989) consider the lived body within the domain of stress and coping and emphasise the compensatory devices that the body is able to use as a reaction to stress. Within the existential of lived body the experience of being a visitor has relevant themes as various family members felt, for example, tired, stressed or depressed whereas others felt satisfied, valued and so on.

Adjusting-to-continuing-the-visiting

Family members of hospitalised patients are at risk for health problems (Dellasega & Mastrian, 1995; Hathaway, Boswell, Stanford, Scheider & Moncrief, 1987). Maas, Buckwalter, Kelley and Stolley (1991) also found in their study that family members are at risk for poor physical health and, as well, they use more psychotropic drugs than other groups of caregivers. The study of Maas, Buckwalter, Swanson, Specht, Tripp-Reimer and Hardy (1994) found that it was difficult for families to maintain satisfying relationships with their institutionalised relatives, families experienced feelings of guilt, ambivalence and loneliness. Their study showed that family members' mental and physical health may decline, resulting from changes in the patient, ambiguous family-staff relationships, institutional barriers and conflicts with staff over roles and caregiving priorities (Maas et al., 1994). Most family members in my study experienced various physical health problems, such as problems with sleeping and eating and tiredness. These problems had often first arisen when they became informal carers in the community. Gloria's narrative captures this.

I said to Paul [son] "I have made up my mind. I can't manage any more". "Well, fair enough, Mum, we'll get it sorted it out," he said. So we had to decide what to do. I couldn't manage. Not even with some helpers coming in. I was exhausted, putting Gus into a home, a permanent place was just... something that had to be (Gloria: Int. 1, p. 5)

Like some of the other family members, Gloria's health problems continued when she was visiting her relative. She continues.

My hands are in such a state [holds up hands which are swollen with red splotches]. Its from being worn out, the doctor says. And there is no way I could give... could even put a spoon to his mouth at present. Anyway, the caring is good there .../. I don't feel that I've got to go in and do things to him. I don't think to myself, and he should be getting this and he should be getting that (Gloria: Int. 1, p.2-3)

Sally expresses feelings of tiredness and strain.

When you come, you've been busy, you're on edge because you want to provide, from the outside whether it be news, you're the source of entertainment for the resident. Um, so I think you're a little strained and quite tired when you're there. You know, coming up with different things that will keep them interested (Sally: Int.1, p.5)

Thus some family members experienced mainly physical problems as a result of being visitors. For some, tiredness affected their abilities to work and engage in recreational activities. However, some participants kept well and did not experience physical problems. Margaret describes how she learnt to identify stresses associated with being a visitor that she believes have negatively affected her health.

Visiting's an extra stress on your body and its tires you out .../. the time coming and going from the hospital, and the time just sitting there. But I'm keeping it up. You've got to get ready, get dressed to go, be in the

mood to go ... So I just know to have an early night after I've been...

(Margaret: Int. 1, p.7)

Mental health was also sometimes affected. Some family members experienced feelings of isolation as described in the previous chapter, and they felt the staff as well as the greater community did not understand or care about their stressful situation. Brody, Dempsey and Pruchno (1990) also found that family members' mental health was affected. In their study, both sons and daughters, but especially daughters, experienced an increase in symptoms of depression and emotional problems following the institutionalisation of their elderly parents. Kaplan and Ade-Ridder (1991) describe the emotional pain experienced by spouses because of the split in the marital bond when one partner is in a care facility. The participants of my study described their thoughts, feelings and actions when visiting their relatives. All family members described emotional turmoil associated with visiting their relatives especially during the first interview. The emotions revealed included guilt, sadness, anger, loneliness, anxiety, helplessness, demoralisation, ambivalence, resentment and relief. Jim reveals helplessness and anxiety. *What if she would die before I see her again? ... So you're not knowing...* (Jim: Int.1, p.4).

Some family members experienced much grief when visiting. Gloria expresses her feelings: *"It's better for the Lord to take them than to have them there"* [facility] (Gloria: Int.2 p.2). Several family members felt disappointed that they had been unable to continue to provide care at home. Chris explains.

My goal was always to keep her home ... It makes it so difficult to visit. I feel really guilty when I'm there (Chris: Int.2,p.3)

One family member, while participating in a second interview, stated that emotional upheaval described the feelings she had while visiting. Most family members described dealing with the difficulties of their feelings. Emotional-upheaval is the first component to support the subtheme adjusting-to-continuing-with-visiting. In the following passages Barbara talks about this while Margaret described the ambivalence she experienced especially in relation to her decision to institutionalise her husband.

I went there ... and to me it was really devastating ... Anne was in the lounge with the other people. They were sitting like, like uh, little dummies all around and they didn't seem to be doing anything. And, ah, they just sat there, not interested, as, as poor little people. I think that really hit me, really upset me. She was sitting there in this big lounge. Her head was slumped forward onto her chest ... And I thought what have I done putting her there? (Barbara: Int.1, p.1)

I sit and wonder if I could have cared for Harry longer at home. ... Why should I go and put him away when he has a home? (Margaret: Int.1, p.5)

Two family members questioned whether they should visit. This related to their relatives being unable to sustain meaningful conversation and so they did not know what to do with themselves during visits, they could only sit and be there for their relatives which they did not always find satisfying. Gloria and Evan point this out.

Well, then, we were only there about twenty minutes and then he told us he had work to do and we'd better go! Other times he sits and talks a lot of nonsense. Uh, it makes me feel... really low, to have him say things like that .He used to be ... always kind and considerate. ... But like when I heard him on Sunday I thought to myself how long will this go on for? The doctor says he's got a strong heart. He's 79 ... he might go on for years yet. I don't know if I could stand visiting for all that time, just sitting there, that's what I sat and thought to myself. I haven't ever said that yet to the family because, ah, I don't feel good about the fact that I'm feeling like that [sighs]. (Gloria: Int. 1, p.8)

Evan described how his mother did not know him any more. This limited their interaction and he did not know how to spend his time when visiting her. He mainly talked with staff and other residents and their visitors. He also had difficulty adjusting to the uncertain trajectory of his mother's illnesses. She had twice got a serious chest infection, and both times he went to say goodbye to her. One time when the doctors told him his mother would not last the night, the family actually prepared for the funeral. His mother did not die, however, and Evan felt guilty but also he felt angry. (Evan: Int. 2.).

Some family members felt powerless and vulnerable in terms of halting their relatives' deterioration. Conversely, several family members complained of the reverse situation, that is, what they viewed as a senseless prolongation of their relatives' lives. Barbara explains the effects on her of the second type of situation.

I do wish for her death, deep within me. ... Anne, I just know, would hate to be the way she is now, if she knew. We, just wish she would put her little head down and not wake up. Which makes me feel guilty and you can't not feed her (Barbara: Int. 1 p. 11-12).

Though family members expected the further physical decline of their relatives while in the facility, further mental deterioration was a more traumatic experience. Family members explained how they often needed help to adjust to these changes and wished that nurses would give them more support at such times, especially in setting visiting goals. Visits to the care facility were more stressful for family members when their relatives were mentally impaired. Margaret and Gloria capture the changes in their husbands which, in turn, affected them.

He has such little quality of life ... I find it difficult to cope with his decline... But he enjoys me coming to visit him, well, I think he does ... which make me happy. Which is good because a lot of my feelings about him are sad. ... He can't pick them [greatgrandchildren] up or do anything like that. He's so changed (Margaret: Int. 1, p. 3)

It's just the not knowing what he's going to do or say and I find all the other things associated with visiting hard to take at times. Such as, ah, the noise and some of the people wandering around. It can depress me. But if Gus is having a good day, then it's... I feel a lot of satisfaction in seeing him (Gloria: Int 1, p. 9)

Their relatives' adjustment to or acceptance of the care facility also affects family members' stress. Behaviours that reveal relatives' unhappiness over placement, for example, refusals to eat, crying or emotional withdrawal, appear to strengthen family

members' feelings of loss of control, guilt, anger and grief. This, in turn, could produce physical symptoms of poor health. The more problems family members described with their relatives' adjustment to being in long-term care, the more guilt the family members indicated and the less pleased family members also seemed to be with the care facility. On the other hand, improvement in the relatives' physical or mental health after placement tended to lead to improved family relationships and also to enhanced wellbeing for the family members.

The move from home to institutional care usually involves a substantial loss of control by family members over their relatives' care which adversely affects many family members' wellbeing. Most families have had little or no previous experience with care facilities and so they are an unfamiliar environment to which family members gradually learn to adjust as they learn what to expect and what is expected of them. Adjusting-to-some-loss-of-control is the second component to support the subtheme adjusting-to-continuing-the-visiting. All family members experience difficulty in adjusting to the fact that their relatives are in a facility and the loss of control this entails for them but most learned to come to terms with the situation. This is shown by Gloria and Chris.

Gradually I've got a bit better at realising, well, there's no way I can be there all the time with him. ... The staff, they seem to be caring, that I tell myself I don't need to worry too much. Though I want the best for him and I'll carry on seeing him. I used to really worry whether all the things would be done for him the way, you know, he liked them, the way I used to do them for him. I used to get upset at even little things, like Gus's skin has always been so sensitive and, ah, I would think would the staff remember to wipe soap off properly and to use all the special ointments (Gloria: Int.1, p.7)

You find you're getting used to her, ah, being there... That's whether you like it or, or whether you don't. My doctor did offer to put me on anti-depressants because sometimes I get a bit gloomy... (Chris: Int.1, p.6)

When describing their first visit that I interviewed them about, many family members felt outsiders to the facility and were unsure about what their role ought to be in the new

environment. This leads to an often reported difficulty after placement according to Townsend (1990) which is that family members are unsure of how to occupy themselves during visits. Though this was also the case for some family members in my study as discussed earlier in this section, the opposite seemed to be more true for other family members as Margaret illustrates.

I, ah, spent some time helping him back to bed and then I gave him his tea. They're happy for me to do things for Harry but I had to say I couldn't toilet him any more. ... I hadn't the energy to do such physical work. And I usually sit beside the bed for some time. I talk with the nurses, the head nurse if she's there, before I leave (Margaret, Int. 1, p.2)

Heavy care such as help with activities of daily living is no longer needed after placement, and all family members did less physical tasks by the second visit described. However, a source of emotional symptoms for some family members appears in the form of distress about the facility and their lack of control in it to which they had to adjust. Sources of distress included a perception that their relatives' care was inadequate, that staff numbers were insufficient and perceived negative attitudes of some staff towards them and their relatives. Barbara reveals a perceived lack of control.

This home was recommended by people whose opinions I value ... And I can't really face that I might have made a mistake. ... Then I wonder do I overemphasise the faults? Am I too easily irritated because my nerves feel rather, uh, frayed what with the emotional upheavals of the last few months. I want to be able to leave Anne there and feel I can trust the staff to look after her well. ... She was such a fastidious little person. Anne would hate to see herself with stains on her clothes and food dribbling out of her mouth. Yet... I hesitate to antagonise the staff in case it puts her, ah, care from them at stake (Barbara: Int. 1, p. 3)

Being a visitor influences the whole of a person's being. It impacts on the body as it is lived in a profound manner. Many of the family members felt symptoms such as tiredness, guilt and anxiety as they adjusted to the loss of control they were experiencing. Each one of these symptoms shapes being in the world as a whole. The

participants varied concerning the symptoms which perturbed them most seriously as illustrated by Margaret, Chris and Gloria.

I thought, oh, God, why me... Feeling thoroughly sorry for myself, I guess [small laugh]. I've felt really thoroughly down... (Margaret: Int.1, p. 3)

I do like to know that she's alright. I feel that's about all I can do for her now. She's always pleased to see me. So I usually go every day for a bit... ../.. If I stay too long I, and she, we both get tired. So I leave then (Chris: Int. 1, p.4)

Gus seems much more settled in ../.. so I'm more relaxed. I've learned I can be there for about an hour ../.. and we both like that, after that I get all tensed up (Gloria: Int.2, p.3)

Another way participants are *continuing-with-visiting* is by coping. Coping-with-uncertainty-and-change is the third component related to the subtheme adjusting-to-continuing-with-visiting. Family members had to deal with the uncertainty and change that their relatives' chronic illnesses entailed, as well as with changes in their own lives which could affect their visiting. For example, one family member took up full time work which meant for her that she had less time to visit her grandmother. Despite all the stresses that the experience of being visitors involved and the long-term ramifications of their relatives' illnesses, family members showed remarkable coping skills. They revealed these in their descriptions of the ways in which they passed the time, cared for their relatives and maintained some positive feelings. Chris expressed a positive outlook when she compared how she felt prior to and since her partner's institutionalisation.

I'm not so tired as I was in the last months that Jean was at home. I'm starting to sleep better, too, it's taken me all those months to adjust not having to get up at nights to Jean. For the toileting, you know. By the time I get there, it's a twenty minute drive and the time I get home again that's tiring enough at my age. I still manage to come most days but I'm... ah, more able to say no and not feel guilty if I feel I can't manage

it on a particular day. Then we have a lovely long chat on the phone instead (Chris: Int.2, p.2)

Gloria's coping and hope is captured in the following excerpt.

...when Gus is quiet and responsive I like to think he's settling down to being there. And it does still make me feel guilty from having him away from his own home that he worked so hard for. I say that, though at the same time I know that it isn't possible. And, uh ... I'm not as upset as I used to be ... I've got more energy now to work in the garden, all that tiredness from looking after Gus at home seems to have gone. Though visiting still a bit tiring but not as tiring as caring at home (Gloria: Int. 2, p.3)

Laughing was one of many ways family members developed to cope and *continue-with-visiting*. This is supported by Houston, McKee, Carroll and Marsh (1998). These authors found that people who participated in humorous activity were found to have significantly reduced levels of anxiety and depression when compared to other people who received no intervention strategies which encouraged humorous exchanges, as measured by a General Health Questionnaire.

Overall, most family members experienced satisfaction with most aspects of the facility. Perceptions of care and the degree to which care was valued seemed to be affected by family members' and by their relatives' feelings about placement in the facility. Chris and Gloria discuss this.

I notice how nice they are with the patients... Though they don't spend much time actually talking to them. They seem to be run off their feet ... But it seems to be not too bad. They're very good with Jean. She seems to be, ah, more accepting of the place (Chris: Int. 1, p. 1)

The big boy, Andrew, I think is really good and Jean's commented how good they are, the male nurses. Um, I still haven't got used to the male nurses. But I'm like Jean, she accepts them because they're good. As I

watch Andrew there, he's very good, and he's the one who's always washing his hands... (Chris: Int 1, p.1)

...if he is good then I worry about whether I should have kept him at home longer. But if, once he starts going on about things like his things being stolen then I'm really uptight .../. However, like I said, it's getting a bit easier each time I go up, to cope with. I'm trying hard not to let it all upset me too much. I mean, you see, he's still my husband. And so I want to know, to know that he's being looked after really properly. So I watch what goes on when I'm visiting him, I look at what the staff are doing with the other people there. It varies. A lot. Some are so nice and kind. Others, there's one in particular, who seems a bit of a bully. But... he seems more settled. Doesn't call out so much (Gloria, Int. 1, p. 9)

Letting-go-of-the-primary-carer-role-but-continuing-with-visiting

Interwoven into most of the participants' narratives were references to how they continued to visit while at the same relinquishing some of their previous caring, especially the physical caring, for their relatives. Letting-go-of-the-primary-carer-role-but-continuing-with visiting is the second and last subtheme that relates to *continuing-with-visiting*. However, all family members want to make certain that care in the facility is as good as the care their relatives had been having in their own homes. This is not just basic physical care such as cleanliness of their relatives but a holistic care to uphold their relatives' integrity. Wilson and Daley (1999) also found in their study of families' perspectives on relatives in long-term settings that the primary concern of families was that their relatives were well cared for, which to these family members included more than just physical care. The authors found that spiritual care was important for the family members that they studied. The family members in my study sometimes spoke of spiritual care by nurses being an important component for their relatives' wellbeing, however, they more frequently emphasised that they would like staff to give their relatives emotional care as well as physical care. The difference between my study and that of Wilson and Daley may be due to the fact that unlike their study, none of the relatives in my study were dying at the time I undertook the study, though two were critically ill at the time of the second interview. In my study Chris explained that the

kind of care that she would like Jean to have was the care that Jean physically required but over and above that it was an emotional kind of care. Chris continues.

I looked around and I couldn't help but be impressed at how clean and neat everything looked in the lounge. The patients, the furnishings, and the nurses were polite and cheerful. So though I would dearly love her to be home with me, if she's to be in a hospital I'm glad it's where she is. They get there the care they need, but also the care you would like them to have. I mean in terms of the little extras, friendliness, smiles... while they keep up the pace! Most of the staff show real caring, they tuck the patients up well with rugs over their knees, pillows behind them and at their sides to prop them up before they give them drinks and I've even seen them give patients a cuddle! (Chris: Int.2, p. 2-3)

Caring is a vital element, if not the most vital element of nursing. McMillan (1998) examined the perceptions of residents in long-term care facilities. Residents were asked to describe what they felt were the most important caring behaviours of the paid carers in the facilities where they resided. McMillan found that meeting physical needs, meeting psychosocial needs and meeting the needs for love and belonging were very important to residents. Meeting psychosocial needs received the strongest emphasis as 15 of the 16 residents mentioned the meeting of specific psychosocial needs as important caring actions. In my study, their understanding of the relatives' likes and dislikes and their expectations of long-term care led family members to have a notion of the standard of care that should be given. This had to be changed at times when the reality of the way the institution operates are learnt. For example, as discussed earlier, one participant expected that her partner would have a shower every day. She had to adjust to the reality that this was not possible as it did not fit into the staff's time plan.

The stress of coping with the relatives that they had experienced when caring for their relatives in the community was lessened for family members when long-term care staff had become involved in their relatives' care. The staff had assumed the bulk of the everyday physical caring for the relatives and family members valued letting go of this aspect of their previous role. Most family members considered that most of the staff were kind and caring of their relatives. They also all were reasonably satisfied with the

physical care provided. On the whole their relatives were kept tidy and were fed and dressed, and if necessary, toileted. Physiotherapy and diversional therapy was provided on all weekdays. A hairdresser visited the facility once a week; a chiropodist once a month; checkups for all residents by a general practitioner were once a week. Most family members experienced such a sense of release from tension and of freedom that they talked about how they felt better in themselves and how they were contemplating other pursuits. Physical stress in particular was reduced. However, psychological stress especially in the form of anxiety continued for many family members. This seemed particularly noticeable if they considered that staff would not allow them to participate in decisions about their relatives' care and if they believed that they lacked adequate information about their relatives' wellbeing and about the facility in general.

Kitwood and Benson (1995) and Kelley, Swanson, Maas and Tripp-Reimer (1999) found that families visiting older people in a long-term care facility evaluate the quality of care in such a facility through observing the care being given by the staff. In my study, observing care was somewhat restricted for those family members whose relatives are cognitively impaired as the accounts from relatives are open to question. The physical care given was to a certain extent obvious from the way their relatives looked. If family members noted some lapses in the giving of physical care then these suggested to them that other kinds of care, such as tender loving care, were also lax. This led family members to feel upset. One family member found it difficult to adjust to the way her relative had altered in looks. She described how her relative had lost much weight and consequently her dentures no longer fitted. Furthermore, the staff mixed and matched the relative's clothes in combinations that her mother-in-law would not have liked. Barbara talks about this.

You know, she was always so fussy about her clothes. To see her in clothes with stains and the skirt and top didn't match, yet she's got plenty of clothes... It seems a small thing and yet it annoyed me. They need to use those large bibs they have, each time she has something to eat
(Barbara: Int. 1, p. 10-11)

Her relative now bore little resemblance to the mother-in-law she had known and loved for about thirty years. The family member found this difficult to adjust to and

consequently she toyed with the idea of whether to continue to visit. It also led her to harbour negative feelings towards the facility in general.

...as she's deteriorating, it's sometimes as if she's ... not Anne. I find that hard... She can't wear her dentures any more and with the weight loss she doesn't look like Anne any more. It makes it hard to see her like that. You wonder if it's worth the bother (Barbara: Int.2, p.5)

Being visitors in the care facility as opposed to being the primary carers for their relatives in the community meant letting go of some of their former responsibilities. It also freed up family members' time and energy for other pursuits. For some family members this meant reducing some of the tension and conflict in their families. But despite the fact that these family members are no longer primarily responsible for the day-to-day mostly physical care of the relatives, most experience varying levels of emotional distress and physical complaints.

I've tried [little laugh] to do, to move myself away a bit from... That is the way. It's a bit like divorce. It is. That's what it is. ... And there's an emptiness there. ... It really hurts (Gloria :Int. 1, p. 6)

What I find hard to take is when I try and tell the nurses something which is of importance as far as Anne's concerned and they don't listen. Like they take her stockings off when they get her ready for bed but they never put the bedsocks on Betty's specially knitted for her. Anne, even in summer, gets cold feet. You'd think putting a pair of socks wouldn't be too much to ask. So on the days I'm there, if I'm there late afternoon that is, I'll help to get her ready for bed, put on the socks... ... But it makes me upset when they can't even do a little thing like that. It makes me wonder what other things they do or don't do. I can't be there all the time, but I have to keep on doing things that I'd rather the staff now did as I've got so much else on my plate at the moment. With work and at home. It makes me headachy at times and sometimes I can't sleep at night with the worry of it all. I do realise they're very busy but does that excuse them? (Barbara: Int.2, p.4)

Family members often discussed their relatives' clothing in part because many of them still continued to help care for their relatives' clothing. This is similar to Tilse's (1994) study, which found that 68% of partners of residents in long-term units continued the task of helping to care for clothing. Tilse suggested that such a task ties family visiting to organisational needs and routines. Several family members in my study took more expensive items, such as woolen jerseys, home with them to wash by hand. Another reason why clothes were so often discussed was the problem for staff in monitoring residents' clothes especially those of residents with cognitive problems. These residents could not tell if the clothes in their wardrobes were actually their own and they could consequently be dressed in the wrong clothes by staff without the residents being aware of it. This occurred if clothes were wrongly labeled or if staff forgot to check the labels. Some family members complained of staff's lack of care with clothing. For example, one family member described her distress when her mother mistakenly wore someone else's clothing. Seeing their relatives in other people's clothes, or other residents in their relatives' clothes, was mentioned several times not so much for the material value as for the carelessness this symbolised. Another source of irritation with relatives wearing what family members consider the wrong or stained clothes was that this could indicate to them that staff undervalue practicing individualised and holistic care, and this gave one family member considerable distress. Barbara relates.

...her clothes were dirty right down in front of her. Well, she was just such a spotless little person... that really upset me (Barbara: Int.2 p.1)

Another experience causing upset to some family members was the loss of clothes in the facility. One relative told of clothes "disappearing" though no accusation was made of outright theft. Karner, Montgomery, Dobbs and Wittmaier (1998) found that concerns about issues such as missing clothing are of far less importance to formal careworkers than they are to the families of residents. The care workers in their study stated that they worried about what they considered to be more significant issues. This included providing an advocacy role for residents. The careworkers considered that family members negotiated over the role of health care providers and that this type of negotiation is a burden to the health care providers' time and emotions (Karner et al.).

Thus these two groups of people attached different meanings to various issues and could potentially be in conflict over them. Gloria describes her upset about clothes that seemed to be missing. However, she did not want to confront staff and maybe invite their indignation and denials.

Some of his clothes have gone missing. I mean this is not just one item but four since he's been there! Every time I ask the staff where such and such an item is I'm told not to worry it'll be in the wash! It's been upsetting me because most of his clothes are new, bought specifically when the staff asked could he have some looser fitting clothing and that preferably had some stretch. I've complained but not said too much, just still hoping that staff are right and that they'll turn up in the wash. I don't want to get the staff's backs up over this, I mean it's only clothes, but it still annoys as I'll have to get him some more and who knows it might keep on happening (Gloria: Int.2, p.4)

A frequently cited problem by family members when being visitors was feeling ambivalent and torn about their decision to institutionalise their relatives and between their relatives' and their own and their wider family's needs. Living-with-ambivalence is a component of the subtheme letting-go-of-the-primary-carer-role-and-yet-continuing-the-visitor-role. Though visiting was an important part of the life of the family members, each also went on about the task of living in the community as a family member to their children and others, and as a friend and possibly also as a worker. Nevertheless, some family members found that their visits caused disruptions to wider family relationships and in this way their visits were stressful. Visiting to them meant time away from their other family members as Jane illustrates in the quote at the beginning of this chapter. Family members considered that it was important staff listened to their concerns about such issues. One family member stated sometimes he just wanted to be heard (Evan Int.1).

Further, feelings of ambivalence occurred when family members experienced difficulty with health care providers. Family members then wondered whether their decision to institutionalise was the right one. They would like non-judgmental attitudes from facility staff, open and honest encounters with them, staff keeping them informed about

their relatives, especially when there are changes. Family members appreciated emotional support from staff at all times, but especially when their relatives experienced critical illnesses.

One family member described the first visit that I interviewed her about as experiencing ambivalence about having to place her husband in care and about visiting him in the care facility. "*Gus often cries when I leave, making it difficult for me to accept that I've done right moving him into*" [care facility] (Gloria: Int.1, p.12). However, the second visit she described as having learnt to adjust to these feelings by telling herself that she could no longer meet her husband's physical needs. The family member was able to help nurses care for her husband by offering information about him that allowed them to understand some of his strange and difficult behaviour. This lessened her feelings of ambivalence, guilt and frustration and it enabled her to continue her visiting role and value it. The study of Maas, Buckwalter, Swanson, Specht, Tripp-Reimer and Hardy (1994) also found that when staff provide a partnership role for family members whose relatives are institutionalised, family members experience less stress.

Family involvement in long-term care serves to individualise care. About half the family members became involved in decisions concerning personal care which they found satisfying and which helped lessen their ambivalent feelings about their relatives' placement. For example, deciding what clothes their relatives would wear on any given day, arranging knick-knacks in their rooms, bringing in their relatives' favorite foods from home and bringing their favourite music tapes to listen to. All the family members held an important role for their relatives by comforting them, sitting with them, talking with them, holding their hands, and if their relatives were cognitively impaired, listening to their confused sayings and trying to re-engage them in familiar aspects of their lives such as by looking at family photos.

When speaking about the care given to their relatives by staff, family members particularly liked to see that their relatives are given a tender, loving kind of care. This, again, helped them to deal with their ambivalent feelings about placement of their relatives in the facility and of their no longer being there for their relatives on a continuous basis. Some family members believed staff practised tender loving care when the staff showed caring physically, for example, by sometimes patting or hugging

the residents. One family member noted that she appreciated the fact that one particular careworker kissed her relative goodnight. Another family member felt that staff showed caring when they addressed residents using terms of endearment or used baby talk. Yet another family member experienced ambivalent emotions when she heard a careworker address her relative by using a diminutive of the relative's name which her relative had never liked. The family member was not sure whether to complain about it and risk the careworker's ire.

Yet some studies show that such patronizing communication styles do not uphold the dignity of older people. Ryan, MacLean and Orange (1994) noted that patronizing may take many forms. It includes using simple language, diminutives and baby talk. Ryan et al. found nurses' use of a patronizing conversational style was rated as less respectful, less nurturant and more frustrating by residents of a long-term facility than a neutral style. The recipients of baby talk were especially perceived to be less satisfied with the interaction. O'Connor and Rigby (1996) found the low respect inherent when using baby talk to older people reinforces negative ageing stereotypes and can, in some cases, be related to lower self-esteem in older people.

What care is like is also measured by the care seen to be given to other residents as well as that given to a family member's own relative. Further, family members needed to hold firm to their hopes that the staff gave good care to relatives even in their absence as they perceived this would make up for the nurturing not available to their relatives because the family members are not there. Sumaya-Smith (1995) also found that family members liked staff to act as surrogate family members to their relatives in a care facility. Knowing that staff cared in this way for their relatives, meant that the family members in my study felt less ambivalence about no longer being present for their relatives around the clock and they also felt they could let-go-of-the-primary-carer-role but-continue-to-visit and at the same time lead their own lives.

Thus the change from full-time hands-on care in the home to being a visitor was a cause of distress for some family members. The family members felt ambivalent about institutionalising their relatives, being visitors to the institution, and about disruptions to wider relationships. All the family members also simultaneously described, however, the pleasure their newfound freedom gave them. This was mainly because of the

decrease in their physical work and the joy of having the time to undertake other pursuits, some which were new to them, others which had long been neglected. In the following passage Margaret talks about this.

I'd been reluctant for him to go into care, and yet when he did, it was a tremendous relief, and I was just so tired. And, um, there were quite a few days when I didn't even go and see him. Ah, I had a lot to do, to catch up with at first ../. Also, I have to admit I didn't in the least feel like it. The first times I visited him I had butterflies in my stomach. Now, though, I've got past that though I can't say I actually like it (Margaret: Int. 1, p. 9).

Summary

It is through their bodies that people experience the world about them and give meaning to that world (van Manen, 1998). This theme is shown in Chapter Six with the descriptions of what it means to live with a body that is not its usual self, and of the distress that being a visitor to a relative in a long-term care facility can engender.

This chapter has discussed how the participants strive to continue-with-visiting. Adjusting to visiting and letting go of the primary carer role are ways they find to *continue-with-visiting*. They continue this activity by learning to cope with the physical, emotional and mental demands that their visits to the care facility entailed for them. Family members experience the ambivalence of deep sadness and guilt, mixed with relief that the responsibility of daily care has been handed over. In adapting to the change, they have to come to terms with their mixed feelings and also adjust to their new circumstances. It seemed to help them when formal care providers stood by and were supportive of them and also when these providers balanced their responsibilities toward the family members and the residents.

The next chapter will discuss how the participants value their commitment to visiting.

CHAPTER SEVEN

VALUING-COMMITMENT-TO-VISITING

There's not much conversation possible now. So I look at it as for seeing how he is, checking out with staff how he is. I feel cut off from him, there... Harry, well, I don't think he remembers when he last saw me. But you can't be sure. I mean, I could probably go less often ... But I couldn't do that. Just in case he is aware of something. And I need to know for myself that he's alright. So even though I find it hard... I couldn't not do it. I'll keep on going in ../.. I know he would've done the same for me (Margaret: Int.1, p.6)

In this chapter *valuing-commitment-to-visiting* is described. This essential theme describes how participants continue the ties of attachment and commitment to their relatives while simultaneously also planning for a future without their relatives. It also describes the strategies the participants used to cope with the demands of being a visitor and to maintain their lives as purposeful. The subthemes are rethinking-what-is-valuable and planning-for-the-future. Rethinking-what-is-valuable is supported by three components: distancing-from-relatives, the stress-and-the-valuing-of-visiting and checking-for-wellbeing. Planning-for-the-future has three components: letting-the-past-go, uncertain-duration-of-residency and keeping-a-confident-outlook.

Lived time

This chapter will also continue the description of the experience of being a visitor to a relative in a care facility by exploring the existential lifeworld of temporality. Lived time, our temporal way of being in the world, is subjective time; it appears to slow down when a person is bored or anxious and speed up when having fun (van Manen, 1990). Van Manen describes past, present and the future as the horizons of a person's temporal landscape, a continuous topology within which we are located. The dimensions of past, present and future are constantly brought together in a unique way at any given moment. Time is not at our disposal, rather our relationship with time is the

basis of our living in the world. In lived time, future and past are entwined in the present. The past is that which was, as it presently manifests to us. These three temporal dimensions are unequally present for each individual, and at various times we enter into one dimension more than the others. It is possible that for some of the family members in this study, especially the older members, that the temporal landscape is one in which the past dominates their experience of present and future because the latter may hold little promise or reward.

Leonard (1994) explains temporality as an increment of events that withstand time. It develops before our sense of time and relates to being there, rather than as a linear viewpoint of past, present and future. Benner and Wrubel (1989) compared the Western idea of time as “a linear succession of moments” (p.64) with the existential concept of temporality, which they define as the way a person lives in the present and yet at the same time is both shaped by the past and is projected in the future. This is evident in the stories of the family members in this study. Being an informal carer in the past affects the way being a visitor is currently experienced and affords both hope and anxiety for the future. The life they have shared with relatives influences their way of being in time as their circumstances have changed with the institutionalisation of one member.

Rethinking-what-is-valuable

Caregiving for the family members extended from the home setting to the institution. When describing their first visit that I interviewed them about, most of the family members wanted to continue to be involved in caring for their relatives. This included the giving of physical care. These family members felt that the physical care that they gave was an extension of their emotional caring for their relatives. Their commitment to their relatives was a significant aspect of family role. For some family members the goal seemed to be to maintain the caregiver role as it had been prior to institutionalisation. However, by the second visit that I explored with them, though their emotional commitment remained very strong, there was some lessening of the degree of commitment to physical tasks. Also the frequency of visits, their degree of regularity and the length of time spent visiting had all lessened somewhat for most family members. The first subtheme rethinking-what-is-valuable relates to this. Though family members highly valued commitment and responsibility for care, the stress which being

a visitor could generate led them to rethink the value of their visiting and they decided to be satisfied with a lesser degree of involvement.

However, though relieved of the stress of carrying out or overseeing home care, for some family members any gains from long-term placement were offset by other stresses. Some family members now must cope with similar anxieties to those they had experienced at home and sometimes with the added perception that care for relatives is less than optimal in the facility. Some family members coped with these anxieties and also with feelings of guilt, fatigue, loneliness and inadequacy by emotionally and/or physically distancing themselves from their relatives. The component distancing-from-relatives supports this subtheme. For example, one family member was still learning how to adjust to her role as a visitor five months after her husband went to the care facility. The distress of being a visitor led her to visit less frequently.

I feel the most awful sadness. I feel very strongly that it's my responsibility, my duty to care for him. ... there's no hope for a shared future. It's not that there's anything wrong with [care facility]. But ... I hate going and I've been making excuses to cut down on going (Margaret Int.1 p.5)

For some adult children, perceived conflict between obligations to their institutionalised parent and to themselves, to their family still at home or to their work is especially stressful. The conflicting obligations led them to distance themselves somewhat from their relatives. Barbara shares this dilemma.

And when I had to leave her, I kissed her ... I work fulltime ... But it didn't make me feel good to be leaving her... I felt kind of guilty and yet also a bit resentful. Because I did try and yet it wasn't enough. I now try to shut it out... (Barbara: Int.1, p.9)

All the family members experienced some distress when visiting. This was particularly so when their relatives had cognitive impairments. According to Jacques (1992) cognitive impairments such as dementia and related types of illnesses are usually characterised by contradiction, forgetfulness, unpredictable behaviour and deficient

communication. In my study, family members faced contradictory dilemmas if the state of mind of their relatives seemed to fluctuate. For example, if their relatives seemed more responsive on that particular visit than was the norm for those persons, then some family members tended to rethink their decision to institutionalise their relatives. It led these family members to recall vividly and emphasise the good times they had shared with their relatives prior to placement in the facility. Yet family members were at the same time aware that the improved mental state of their relatives was probably only temporary and consequently they could not, in fact, cope at home with their relatives. The contradictions in these circumstances led to some dislike of visiting though family members still basically valued and felt committed to visiting. The stress-and-valuing-of-visiting is the second component of rethinking-what-is-valuable. Gloria explains.

...when I see him lying quietly in bed .../. I do get those feelings of doubt again, should I have tried harder to keep him at home at least a little longer? I don't think I could have, really, but I do wonder... and, ah, I think if I'd tried to ask for even more help to come into our home. He's a big man. .../. He's lost a lot of weight, but he's got this stiffness (Gloria: Int.1, p7).

Brubaker and Schiefer (1987) and Cox and Ephross (1989) in their studies also found that family members felt contradictory and adverse emotions after they placed relatives in long-term facilities. These authors described support group interventions for families to help cope with these emotions. The groups were claimed to be moderately to highly successful. However, unfortunately, such groups were not available to the family members of my study.

Another factor causing tension for the family members of my study was the forgetfulness of some relatives. For some family members forgetfulness was experienced as a rejection of their shared past. These family members then felt it was difficult to perceive the worth and purpose of the visit to the relatives though there was still some benefit of visiting to the family members concerned themselves. However, the forgetfulness of some relatives could sometimes be considered an advantage to other family members. Evan related in my first interview with him that his mother liked him to come and that was important to him. However, if she no longer knew him he would

come much less. (Evan: Int.1). Thus this person was distancing himself and rethinking the value of his commitment to visit. One family member reasoned that the number of times that she visited would soon be forgotten and thus she need not visit as much as she would have felt obliged to go if her relative was aware of the frequency of her visits to the facility. *"I tell myself she doesn't have any idea of time anymore"* (Barbara: Int.2, p.6). Thus this family member was coping by distancing herself from her relative. Barbara also recalls:

I said to one nurse, "I can't come in next weekend". And she said, "Well, Anne wouldn't know, so don't worry about it." ... So I'm starting to let her go a bit, leaving her more and more in the hands of the nurses. Anyway, I just haven't the time... My life's really busy, ah, what with work and a child (Barbara: Int.1, p.10)

Unpredictable behaviour towards family members was another dimension of dementia-type illnesses which influenced being a visitor. Family members could not anticipate how their visits would affect their relatives. This was stressful for family members. One family member related how she felt she was on an emotional "see-saw" just before both visits. However, by the second interview most family members had accepted that it was hard to plan emotionally for a visit and also accepted the uncertainty of it by learning to anticipate it. Some tried to distance themselves somewhat from their relatives and from visiting. They did this by making changes to their visiting routines. For example, by decreasing the amount of time spent at the facility or by relinquishing more of their previous caring role to the facility staff.

The fourth and last consequence of cognitive impairment was the deficient communication. Being a visitor could mean feeling frustrated and miserable when they could not communicate satisfactorily with their relatives. However, family members' feelings were less intense when I interviewed them for the second time as they were more accepting of the changes in their interactions with their relatives. Whereas at the time of the first visit explored family members were still learning to adjust to the changes. During my first interview with her Gloria described the discomfort she experienced when she visited Gus. *"I'm on edge when I come there. And before and after I see him"* (Gloria: Int.1, p.9). Conversely, for a few family members being a

visitor meant spending time which was agreeable to them despite their relatives' deficient communication. They described valuing doing something with their relatives which could be as practical as assisting with activities of daily living as illustrated by Sally whose grandmother could communicate very little.

It doesn't bother me to feed my grandmother. Or help her. I look at it as helping her to have her tea. But I don't think I would enjoy doing it for someone who's not, ah, family. ... Because, um, it's very invasive assistance for the elderly. When you're a baby its not invasive ... Ah... (Um. Yes? So it's different depending on age?) No, right. But when you're an elderly you're trying to give them the respect that they deserve and not trying to be invasive, um, you know trying to do it how they want. It's kind of a hard line to walk (Sally: Int. 2, p.4-5)

Most family members did not describe their visits to their relatives as an event that they enjoyed, but more as a task they had allotted to themselves as close family members. Jane explains, *"She was there for us, all the years, now I'm here for her"* (Jane, Int. 1, p.6). Jane worked full-time and lived a distance from the facility but added that she came everyday, *"I feel very committed to that"* (Jane, Int. 1, p.6). Overall, most family members learnt to adjust to visiting. Coming to terms with being a visitor was achieved partly, I suggest, by distancing themselves to a degree from their relatives and the situation while simultaneously and paradoxically being committed to continuing their visiting role. As one family member said, *"Visiting can be very stressful."* However, he added that visiting could also be good, especially when his mother indicated that she liked seeing him (Evan: Int.2). One reason some family members continued their visiting was because they so much wished for a visit that made them feel that their relatives enjoyed their time with them, as Sally and Chris reveal.

Nana does have, very few and far between, but she does have days when she wants to instigate conversation. It just makes it all worthwhile. Um, most of the communication, or questions, or discussion, it has to come from me. Um, it does get trying (Sally: Int. 1, p.6)

Jean really appreciates me visiting her ../.. It gives a great deal of satisfaction ../.. Today we played a game of cards... (Chris: Int.1, p.10)

Family members rethought the value of visiting if the amount and type of conversation diminished and they received little gratification from being a visitor. Yet they stressed the importance for them and their relatives of “staying in touch” with the staff and “knowing the staff are doing their best”. In this way family members continued their commitment to what they perceived as their obligation of observing that relatives were being well cared for and of advocating for their relatives if they perceived a need for this. Thus checking-for-wellbeing of the relatives is the third supporting component of rethinking-what-is-valuable. The following anecdotes capture family members’ experiences of checking-for-wellbeing of their relatives.

I just see how she is. May be check out with staff how she is, because she can't say. She's totally different... not Anne any more. I just feel like I've already lost her. She's there but she isn't. (What does that feel like?). It's probably the most difficult thing. Because no-one can be a 100% sure that she really is totally oblivious to what's around her. Well, because sometimes she does open her wee eyes and looks alert and will say a few words. ../.. And I see whether she needs anything, toiletries, things like that. So, ah, I'll tell all that's been happening in the family and that kind of thing...When I went in ../.. She woke up and she moved her hand a little as if she wanted to reach over and hold my hand ../.. I told what the family's been getting up to ../.. I think she'd like to hear that because she's such a family kind of person.... As I say, I don't know how much she takes in, but it's worth a try in case she does and it also helps to pass the time for me. Otherwise it sometimes passes quite slowly. (Um. Sounds a...good way to spend time). Um. Yes. Well, I feel it's something I can do for her that she probably likes. I also gave her a drink ../.. and noticed that her jug had orange cordial. I don't know how many times I've told them, Anne, she hasn't got a sweet tooth and would much prefer filtered water. And then they wonder that she doesn't want to drink much which they assure me they're always encouraging. Anyway, I got that sorted out ../.. I find I have to always be on the look out for that kind of

thing. When she went there first the nurse ... asked me loads of questions about Anne's likes and dislikes ... but I do wonder if anybody takes any notice! (Barbara: Int.2, p.2-3)

I had a talk to the nurse and got some of Jean's problems sorted. There's so many different ones working up there so I wonder how much, how they themselves are fully aware of Jean's different needs. You know, she can only eat certain foods because she gets squeamish so easily...especially since that last operation she's had. Her stomach's always been a problem ... Of course, when she was at home I always saw to things like that, but with all those different staff I do wonder. Jean wouldn't complain (Chris: Int.1, p.7)

Family members sometimes have difficulty establishing contact and communicating with nurses. They felt they were often denied the opportunity to talk about their concerns about their relatives. Some family members perceived nurses to lack time while others were too shy to approach nurses. All the family members talked about how much they would have liked to have had more of the staff's time to tell them about their relatives' interests, habits, likes and dislikes. Several family members suggested staff learn more about what residents did in the past, their life stories. They also commented that staff should recognise that residents with cognitive impairments are not the same people they once were.

Their visits allowed family members to monitor the care their relatives received by being their relatives' "watchdog" (Evan: Int.2). Especially by the second visit described, family members wanted to guarantee their relatives' wellbeing rather than continuing their role of providing the hands-on physical care. Stephens, Kinney and Ogrocki (1991) also found this shift after placement in a facility. The family members in my study felt it to be important that they were seen by staff to be visiting their relatives. One family member continued to visit on a daily basis in part because she thought that "*the nurses have to know you come and see ... that it's important to you*" (Jane: Int.2. p.7). Thus these family members provided help to their relatives, albeit in a roundabout way. Rosenthal and Dawson (1993) also found that visits from family members showed staff that other people care about the residents and Rowles and High

(1996) found that this increases the likelihood that staff give more attention to the residents.

Yet, at the same time, some family members felt self-conscious and awkward undertaking the role of monitoring care. Jane said, *"I look about carefully. I want to get on with the nurses, though, if I can"* (Jane: Int 2, p.5). Some family members observed care very carefully when they were with their relatives. These family members were especially vigilant when they thought that the staff did not realise they were there. This was similar to the finding of Kelley, Swanson, Maas and Tripp-Reimer (1999) in their study of visitation on special care units. The participants of their study believed that just dropping in when the staff were not expecting them would promote better care for residents by keeping staff more alert and on their toes. In my study, too, some family members visited at different times of the day and on different days when they perceived staff were not expecting them. One family member when speaking of her relative said, *"The staff let her join in if she feels up to it. I've seen it when they haven't seen me"* (Chris: Int.2, p.4.). Some family members monitored care by observing not just the way their relatives were being treated but also by the way other residents were being treated. This finding is similar to that of Duncan and Morgan (1994).

Thus the significance for the family members of going to the facility was in part to encourage better care for relatives which they believed was accomplished partly by monitoring the care provided by the staff. Bowers (1988) and Duncan and Morgan (1994) also found in their studies that family members emphasised their role of monitoring care and Stephens et al. (1991) like my study found that guaranteeing wellbeing was of notable importance as to why families visited their relatives. *"I couldn't not go, though I know there's staff, she would be looked after, I don't know, I couldn't not come"* (Jim: Int.1, p.5).

...you being there makes a difference in the care they get. ... I try to come at different times so they don't know when to expect me (Barbara: Int.2, p.3)

Some family members gained little of value for themselves from being visitors. They described their experiences as: *"All I can do is to check he's all right"* (Gloria: Int.1,

p.5). and *"It's not much use coming really because he forgets in no time"* (Margaret: Int.2, p.2). Again, these persons were distancing themselves from visiting yet valuing the commitment to visit in order, for example, to observe their relative's wellbeing. This is similar to two studies which explored daughters' reactions to the institutionalisation of their parents. Matthiesen (1989) discovered that daughters experienced grief related to the loss of the mother-daughter relationship and the anticipation of future losses. As a means of coping, daughters tended to distance themselves by visiting for shorter periods. Johnson (1990) found that daughters experienced ethical dilemmas in terms of having to make difficult choices in relation to time available. They had to choose between the wants and needs of their parent and their own as well as their children's and partners' needs and wishes.

Family members need to unite the ideals of how they themselves cared for their relatives in the community with the realities of nursing practice. Family members' individualistic, holistic care of relatives had to be moderated with the reality that nursing care must meet the needs of a number of persons and also meet institutional needs within a pre-determined time frame. All family members commented on this aspect at length. Thus family members had to rethink what is important and acceptable to them.

I bring in bits from home. ... he seems parched in the hot weather ... the cordial is on the locker but he can't use his hands. The staff haven't got time for any, ah, personalised little things. But it's a great pity anyway (Margaret: Int.1, p.1)

They try and come when the residents need them. Um, on occasion you can tell that they do get busy but they try and come as soon as they can. Uh, but you can't have a ratio of one nurse to one patient. It couldn't be done. But, um ... I'm quite happy Nana is here [laughs] (Sally: Int. 2, p.2)

I thought that's just not right, like some one calling to go to the toilet and being told to wait ... But, most things we're impressed with, um, the

food and the cleanliness, the dining room and the nursing care ... We could never complain. I felt they were understaffed (Chris: Int.1, p.).

...some staff don't want...won't tell you much, even though we're her family. I would like to talk, ask them more but they are always busy. Lots don't seem to even know much about Anne, so that's not much help. They thought that the infection she had would carry her off ... I was able to tell her [charge nurse] that when Anne has antibiotics she needs Nilstatin drops as she gets thrush when on antibiotics. She said she was pleased to get that information about her which made me feel of use. They do seem kind and they certainly work hard... (Barbara: Int.2, p.6)

I think that they [nurses] look after him really well. They're busy but never too busy for a quick, kind word or a pat on the back or something like that, which is so lovely. And that makes me feel a bit better. There's no doubt they do their best. But the staffing levels mean just making sure basically, that basic physical requirements are met... There's not much time to listen and to talk (Gloria: Int.2, p.5)

Fink and Picot (1995) in their study found that family members initially viewed care facilities in a negative way and did not want to place their relatives there. However, like most of the family members in my study, they on the whole had much better experiences with long-term placement than they had anticipated. In both studies, this seemed to be primarily because the majority of them had on most of the visits that they described, relationships of trust and confidence in the care that the nursing staff provided for them and their relatives. Yet at the same time family members were aware of the extensive demands on staff time. Nevertheless, if staff are viewed as doing the best they can with the workloads they have, family members are loathe to voice concerns. Chris illustrates.

Some staff are much more responsive than others to what I think is, works best for Jean ... But most of them make you feel that what you say is of importance ... But they are just so busy. ... Sometimes, especially when they have the same problems with Jean that I had, like quite often it

took a lot of doing to get her to get out of bed for even a short while ... well, then I feel the staff have this problem as well, and it makes me feel less inadequate about when I couldn't cope (Chris: Int.1, p.8-9)

Family members said that nurses often communicate with them in a hurried and mechanical way. Some family members did not complain about staff because, as informal carers in the community, they also experienced being overworked. Yet above all, family members stated that a personal approach is what they valued most and it was very important to them that nurses acknowledged them and their relatives as individuals. For example, being called by their names was important as was nurses telling them what they were going to do to their relatives before it was done.

Some family members who found visiting painful rethought what is of value and adhere to a set pattern to make the visit less stressful. Set patterns meant there was some consistency to an event which could be uncertain and in this way family members thought they exercised some control over the visiting phenomenon. Evan came on the same day at the same time each week (Evan: Int.2). Family members learned to be matter of fact about the value they derived from being visitors. This kind of rethinking protected against distress. Gloria explains:

He always was a rugby fan. ... So we can talk about that kind of thing. That helps to pass the time, sometimes that's hard (Gloria: Int.2, p.2)

Some family members spent time on both visits checking on the staff's care and saw their role as safeguarding their relatives against indifferent care. For example, one family member expressed concern that her husband was kept in a chair for too long a period at a time. Some family members complained of incompetent or insufficient staff. For example, one family member thought that a shortage of staff led to his relative's delayed care and consequent outbursts of temper. The family members all remarked on how the staff had little time to talk, to laugh and to joke, to touch, to be there for residents for extended unhurried periods. For some of the family members their frequent monitoring seemed to lead to a role that was at times competitive with the care staff, that is they seek to establish control over the way in which care is given. However, other family members saw themselves as partners in care and were on the whole

supportive of the staff's efforts even when aware of shortcomings in the care provided. Their interactions with the staff were positive, and they felt valued and supported.

Planning-for-the-future

Planning for the family members concerned thinking about the future and the way they might cope with it. The family members consider that knowledge will help them cope with and plan for future phases of their visiting. Planning-for-the-future is the final subtheme that supports *valuing-commitment-to-visiting*. Family members acquired knowledge informally through sharing the experience of being visitors with others. Discussions with other visitors were seen as valuable. Family members also wanted to plan for the reality of what was happening with their relatives and wanted this information from health providers. This helped them plan-for-the-future and cope with the present. Barbara shares her feelings.

I would appreciate having a little bit of the nurses' time, to sit down and talk about feelings, including her death which must come soon. ... Maybe if they [staff] did understand a little more that, um, death can be a blessing (Barbara: Int.1, p.12)

According to Benner and Wrubel (1988) temporality is specific and formed by what has gone on before and by what is anticipated. A major concern for older family members was the prospect of physical deterioration to the point where they could no longer visit. Gloria and Chris share this dilemma.

I'm 74, so something might happen to me and I might not be able to visit any more. Paul and Karen [children] would go, but ... They wouldn't do all the little things I do for him. I don't know what lies ahead... (Gloria: Int.2, p.6)

We have friends, lots, they're getting older like us, and that's a bit of a worry. I rely on them to visit ... that gives me a break. No children of course, and most of our families, they're overseas (Chris: Int.1, p.10)

All the family members had experienced being the primary informal carer for their relatives in the community and now being visitors in the care facility. Letting past experience go was seminal. In order for the experience of being a visitor to become part of the family members' identities, the experiences which had been associated with visiting needed to be accepted. This most of them seemed able to do. They valued having ordinary lives and so they concentrated not only on visiting but they also anticipated the future without their relatives and tried to do other things with their lives. Some family members told of how hard they found it to convince themselves they were no longer primary carers and how they needed to learn to let go of the past. Letting-the-past-go is a component supporting the subtheme planning-for-the future. However, while family members can and do look forward to the future, they still need to visit, although they don't know for how long. They need to reconcile themselves to lost opportunities in life and adjust to a future with probable restrictions and limitations because of the commitment to visit. Gloria and Chris explain.

To go there [facility], means I've had to give up things I enjoy. My art. And I can't go to [local community hall] for arts and craft sessions
(Gloria: Int. 2, p.1)

I try to leave myself enough time, to do, ah, to do some things for me. I want to continue some life independent of visiting Jean. I'm continuing with the hobbies that I enjoyed before Jean left home but now I'm got more time and energy to enjoy them. Although not that much more, because visiting takes time and energy (Chris: Int.1 p.9-10)

Chris describes the way she has now to rethink the future, as a result of being a visitor.

I did hesitate before I went on holiday not liking to leave her. I felt a bit guilty, me having a good time and her lying in hospital. But I feel that I need to go on with my life. I can't spend all my time visiting, so I've got to keep up the contacts with other people (Chris: Int.2, p.2)

Family members understand that the future health of their relatives is uncertain and most talked about how they would have valued more input from staff as the health of

their relatives declined and as they felt a need to rethink their goals for being visitors. One family member thought, from his experience of being a visitor that an informed, supportive and sympathetic program would have been of assistance. He considers that people who are informal carers need help in understanding the changing nature of their role in order to integrate their experience into their lives as a whole. The family members do not know what lies ahead except that the immediate and near future is filled with a commitment to visit. Family members' ability to prepare for their own future was decreased when the timing of the caregiving endpoint was not known. This leads to the second component of planning-for-the-future, uncertain-duration-of-residency. Gloria and Margaret reflect on how the uncertain-duration-of-residency of their husbands affect them.

I can worry quite a lot about the future... You know, how long will this [visiting] go on for. The staff say they've got no idea. The doctor says the brain and the hands are not working together ... I worry about how I'll cope when he doesn't know me at all. I don't think I could go then. I guess I'll learn to cope as it comes. And as we're able to talk less I could keep myself busy by doing more things for him (Gloria: Int.2, p.5)

I'd like get out more. I've got a friend ... and I do enjoy spending time with him but at the same time I've got my commitment to Harry ... But I feel I've done as much as I could at home and so I now keep visiting him but I would also like something more and not feel guilty about it. ... Ah, when I sat there, I thought how much longer will it [visiting] go on? (Margaret: Int.1, p.3)

It is the formal carers who establish the amount and quality of family participation in a facility according to Maas, Buckwalter, Kelley and Stolley (1991). Their study showed that many long-term care staff believed that family members disturbed and upset the everyday patterns of care. Although not consciously expressed except in a few of the stories, some family members in my study experienced an attitude from some of the facility staff that was barely civil. These family members sensed that staff viewed them as an interruption to their work whom staff had to tolerate and also that staff believed that family members had no or little contribution to make to resident care. Those who

visit often felt staff considered them to be possessive of their relatives and of showing “too much interest”. Conversely, if they visit only sometimes, they believed that staff may consider them to be indifferent to their relatives. Though family members have the final say in decisions that are of interest to their relatives, they have limited control over everyday care. Thus inconsistency affects family members’ caregiving and their situation was thus an uncomfortable and difficult one. Furthermore, though there is less giving of physical care, emotional links usually still keep family members committed to their caring duties and their relationships with their relatives. There is thus tension between these emotional links and the simultaneous need to detach themselves somewhat.

The commitment to visit their relatives imposed a time restraint and was affected by factors such as distance to travel and frequency of contact. Full time work placed a restriction on visiting their relatives as Barbara related earlier in this chapter. Gloria relates here how time affects her.

Sitting there, um, I felt impatient when he started this nonsensical stuff .../. He kept going on and on and worrying that the lawnmower needed petrol. Ah, why I don't know, he hasn't mowed our lawns for what must be about five years now. I knew on one level that he can't help it, it's the dementia, yet at the same time I was thinking of all the things I could have been doing if I hadn't had to go and visit him and I felt, um, impatient and also guilty, I guess, for feeling so impatient when I know he can't help himself (tears) (Gloria: Int.1 p.12)

Visiting can be a positive and constructive event. Family members continue to be involved in the life of their relatives, filling a role that cannot be filled by institutional staff. At the same time being a visitor frees family members from the overwhelming duties they often coped with prior to their relatives’ institutionalisation. Keeping-a-confident-outlook is the last component that supports the subtheme planning-for-the-future. “*Being on my own is giving me the chance for some independence and I'm pleasing myself a bit more*” (Margaret: Int.1, p.7). However, the time left free after release may be family members’ first chance to understand the full degree of their loss

and to acknowledge the likelihood of going back to their previous way of life, that is, having their relatives back home, is virtually non-existent.

Strategies the family members used to live with being visitors such as rethinking what is valuable, preparing for a future and keeping a confident outlook have similarities to coping strategies identified by Carr and Clarke (1997) in their study which describes visiting relatives in two acute care neurology units. For example, the coping strategies used by the families in that study included seeking relevant information and using intellectual resources effectively, utilising hope, preparing for an uncertain future and preserving a sense of control.

According to Heidegger (1962/1927) people are individuals who needs to face the past and the future in such a manner that they can create their lives based on choices within the specific constraints which act as checks and balances for them. They have some freedom to choose how they live their lives within the cultural and historical understandings which structure people's lives. In making such choices people become what they will be seen to have been at the end of their lives. The whole consists of all the daily choices they make. The indeterminedness of their future because of the changes in their lives enable people to have a heightened openness to learning different ways of being (Kitwood & Benson, 1995). For family members to profit from this they needed staff who were supportive and caring of them. All family members longed to have such a relationship with staff.

Summary

In this, the fourth of four chapters in which the study findings are presented, the family members describe their experience of being a visitor. It is important to understand the family's role in a care facility as their role has the potential to exert a powerful influence on the quality of the long-term care facility experience for everyone. The study describes some responses to the experience which may be useful for other visitors as confirming their own experience, explaining the behaviour of others and suggesting strategies or responses that may be useful in the future for people who are visitors. As life expectancy improves, more older people will live longer and so there will also be more people in long-term care facilities and more people who are visitors .

Many family members expressed a need to remain involved in their relatives' care. Visiting their relatives was very important to these family members as a means by which to remain committed to their relatives. For these family members remaining committed was a perceived core value and duty which was modified by prior family relationships. No longer having the primary responsibility for their relatives in the community may free family members from technical tasks and allow them more time to spend on supportive types of tasks while visiting their relatives. For some family members visiting was a time when they planned for a future with reduced or no caregiving. They are able to perceive and come to terms with their past caregiving experience and to let some of it go. They have integrated their past into their present.

Family members' descriptions of their experience of being visitors are meaningful bases for nursing care planning. Family members may need time with a nurse to talk freely about the changes they are experiencing and the ways in which they are learning to adjust to these changes.

The next and final chapter of this study primarily discusses the findings from the data chapters and suggests some implications for nursing practice based on these findings.

CHAPTER EIGHT

DISCUSSION AND CONCLUSIONS

The previous four chapters have provided an insight into the lifeworld of eight people who experienced being a visitor to an older relative in a long-term care facility. Being visitors has significantly affected their lives. I had many interactions with people who visit since starting work as a nurse in a geriatric hospital. My interest in this area evolved as I came to realise some of the effects these visits had on families and how little many of the staff working in this area understood this effect.

This chapter elicits the findings from the data chapters. Comparisons with other relevant research are made and I evaluate what I learnt through undertaking this study. The implications of the study findings for nursing practice, education and research are considered. Limitations of this study are explored. The chapter ends with the contention that this study has added to nursing knowledge through generating understandings and linking this understanding to the implications for nursing practice and in particular for geriatric care.

Findings

The central theme of this thesis came about because a significant finding of this study was the degree of involvement of the participants with their relatives. Most of the family members showed a high degree of commitment to continue the caregiving relationship when they visit their relatives in the long-term care facility. Thus continuing-the-commitment-to-care became the title of this thesis. Family members experience being visitors as a change in caregiving, not the finish of caregiving. While relationships may change due to changing circumstances and while caregiving too may be altered, overall institutionalisation may be thought of as a point on a continuum of family involvement and caregiving. Just one dimension of care is discharged and that is the round-the-clock practical caring. Psycho-social aspects of caregiving continue to be important. For all the family members, being visitors meant sustaining the relatives' welfare: being loving towards, responsible for, solicitous about, observant of and involved with their relatives. When family members felt an overall sense of having

achieved these aims, their own sense of wellbeing was also enhanced. It was further enhanced when the staff at the care facility, especially its senior nursing staff, made an effort to communicate effectively with the family members and showed a genuine interest to sharing the care of the relatives with the family members.

When describing the first visit that I asked them about, approximately two months after their relatives had been institutionalised, all family members described their overwhelming sense of loss. This was the case even when the relatives' placement was seen as an absolute necessity and beyond the control of the family members. By understanding this meaning, family members' responses (crying, anger, depression) became clearer. When describing their experience of being visitors at the second interview, most family members seemed to have made some more adjustment to being visitors and were more reconciled to it. With this change in meaning came the willingness to learn new strategies to continue with visiting. For example, to change the number of times they visited; how long they stayed for the visit; to tolerate better the distractions of noise, smells and activities of other residents; to be more accepting of the visit as it was, which usually meant for them to lower their expectations of it and to rethink what is valuable in order to live with being visitors; and finally to prepare for a future without their relatives.

This study reveals the experience of the family members to be one of both stress and value to which they learnt to adjust themselves. The four essential themes identified in this study are: *perceiving-visiting*; *learning-to-live-with-visiting*; *continuing-with-visiting*; and *valuing-a-commitment-to-visiting*. The themes sheds light on the experience of these family members. The themes revealed that placing relatives in a care facility often alleviates some stress for family members but stress continues especially in relation to new concerns. The family members wish to be treated as clients, and want and expect to be involved to various degrees in the planning and providing of care as they desire. From these themes emerge implications for nursing practice and also for further nursing research to assist family members to make their experience of being visitors as positive as possible.

Not all the family members experienced major needs or problems when visiting their relatives. But some of the major needs or problems experienced by many of the family

members included: the lack of privacy when visiting; communication problems between staff and family members; the loss of some control; and letting go of the primary carer role. Most family members sought from nursing staff emotional and social support for themselves to cope with these needs and problems. Primarily, all family members wanted to be assured that their relatives are well cared for and happy.

Family members experienced *perceiving-visiting* as gaining knowledge of the environment but it also involves experiencing changes in status and understanding the implications of visiting. The experience of family members in a long-term care facility is shaped by their having been their relatives' informal carers in the community. With long-term placement, the primary caregivers tend to go from being central to the care of the relatives to becoming somewhat more peripheral to that care. Not only are the day-to-day physical tasks now taken over by facility staff, the nature of care also changes. When family members cared for their relatives at home, care was carried out in the realm of personal relationships and familial obligation. However, care in long-term facilities is embedded in professional relationships and regulatory obligations.

Most family members expected that staff would recognise that they possessed expertise that could be of use to the care their relatives received. When staff did not do so, family members felt invalidated and also that their relatives were not receiving the best possible care. Stressors perceived by the family members when visiting include loss of privacy, changes in role and feelings of loss of some control of their expertise in caregiving. They depend on staff in the facility for the everyday care of their relatives. Other stressors arise from memory loss of some of the relatives. The effects of these stressors were shown by the emotional distress which troubled many of the family members. Conversely, family members appreciated the presence of pets in the facility and also keeping the continuity with home in other ways, such as all the personal bits and bobs which surrounded the relatives in their bedrooms. Family members felt that such items made the facility more homelike. They welcomed such comforts and the cosiness that the presence of familiar items from home represented both for their relatives and for their own sakes.

Family members wished for information from staff. If their relatives lack the mental capability to inform family members themselves, the range of information which family

members wanted about the relatives and the facility was greater than if their relatives were cognitively alert. Family members with cognitively impaired relatives wished for personal information about their relatives: their relatives' progress; treatment; care needs; changing needs and interests; crises or sudden changes in the relatives' wellbeing; anecdotal incidents of everyday happenings; activities; other visitors; any items required. They also wanted more information about the care facility: daily routines and activities for their relatives; the names of key people working with their relatives; policies and procedures.

Family members' role now was primarily that of providing emotional care to their relatives, for example, giving emotional support, maintaining social interaction or contact and acting as interpreters between staff and residents. Family members perceived that staff expected them to undertake difficult balancing acts. They could show that they cared for and were concerned for their relatives but felt they could not give a sense of being over-protective or over-anxious. They could show an interest in their relatives' care but felt they were expected not to be a bother. They could be at their relatives' side but not be in the way. They could show they wished to participate in their relatives' care and that they were competent in providing care but felt they could not give an impression of taking over from nurses and also felt they were expected to concede that professionals knew best.

Learning-to-live-with-visiting related to the learning that family members underwent in their visits to relatives. Being a learner was a significant statement used by every family member. Family members related learning changes which affected their relationships with others. Although family members described the satisfaction that their visits to their relatives could entail, the relationships with their relatives were changing and required them to make adjustments. Simultaneously, family members were also in the process of establishing relationships with other residents and their visitors and with staff.

Being visitors in the facility rather than primary carers in the community was difficult for all the family members. A few family members talked about sacrificing the relationship with their relatives and in this way they thought they could attempt to move on. Though several family members talked of this possibility, none of them actually seemed to do this. Most family members believed it was important to stay involved with

relatives so they worked hard to maintain relationships with them and also with health care providers. However, some family members experienced tensions between themselves and formal carers about expectations for their role.

Most family members felt that overall they received a passable amount of information about their relatives from staff, although they also felt that ideally, they would have liked more information. However, they felt they had a basic understanding of the care their relatives receive in the facility. These family members recounted positive relationships with the nurses and felt that the nurses were “mostly” supportive, accessible and helpful. Two family members, however, described relationships with nurses that were, at times, less than optimal. Thorne and Robinson (1988) indicate that health care relationships include cognitive shifts and evolve over time. They described three stages in the development of health care relationships: naïve trusting, disenchantment and guarded alliance. Possibly the family members who told of positive relationships with the nurses in my study were in the stage of naïve trusting or else in the stage of guarded alliance. Conversely, the two family members who at times were dissatisfied with and mistrusted the staff might have been in the stage of disenchantment. Nurses can place family members within the process and intervene in a suitable way through their knowledge of the evolution of health care relationships, according to Thorne and Robinson.

The level of information and, as well, the level of participation sought by family members varied considerably. Most family members stay involved in the care of their relatives while negotiating a role of working with the staff. These family members wish to be partners in care and they tend to support the staff’s efforts for their relatives even when they realise that care is sometimes less than ideal. Family members’ perception that competent and caring help is being provided for their relatives seems to contribute to their acceptance of their situation. However, some family members experienced difficulties in negotiating their relationships with health care providers. These family members felt that nurses did not assist them sufficiently in adjusting to the changed relationships they were experiencing with their relatives in the changed environment. Furthermore, negative messages from the staff about family members’ involvement with their relatives decreased their ability to accept their contributions as meaningful. Some family members thought that nurses did not support them to the extent they would

have liked in meeting their needs for information and/or involvement in the care of their relatives. The family members all wanted support from nurses when visiting. They wanted nurses to show understanding of the loss and grief, to provide opportunities for them to interact with staff for consultation and participation in decisionmaking around the issues of care, to talk through their feelings with them and to facilitate the continued cohesion of the family unit. Family members also identified benefits in being able to share their experiences with other residents' family members. Interactions with these people tended to be positive and satisfying.

Visiting their relatives was described as an important activity by the family members. One reason for visiting being considered important was that family members tried to foster some sense of family through preserving family communication. However, some visits were particularly difficult because efforts to communicate, such as talking with their relatives, were foiled if their relatives suffered from dementia and related illnesses. It meant some family members were forgotten about by their relatives and they also faced the need to change role behaviours which they found difficult. The family members had expectations that the nursing staff would assist them in assuming these new roles. Family members wanted and needed help in understanding their relatives' behaviours and the trajectory of chronic illness. They believed that such an understanding would facilitate their relationship changes with their relatives to be constructive ones.

Family members experienced *continuing-with-visiting* as continuing the learning to adjust to the changes that they were subjected to when their relatives entered a care facility and which they then continued to face when visiting the relatives in the facility. They found that stress does not necessarily cease with the institutionalisation of the cared-for persons. Certain aspects meant being visitors was experienced as stressful. Family members' loss of decision-making over the care of their relatives and the difficulty they at times experience in obtaining information means their feelings of control are considerably reduced in comparison to the time when they were their relatives' primary carers in the community. Family members described an emotional upheaval characterised primarily by uncertainty and anxiety. When they do not know about the everyday happenings in the facility, they are made more reliant on the staff for

the care their relatives receive. This can become another stress for them to handle in addition to the grief and other emotional reactions that they experience.

Thus the move into a long-term care facility by relatives was stressful for family members partly because of some loss of control over caregiving. This distress was particularly intense when they described their experience of being visitors at the first interview. Their relatives' health status also affected family members' levels of stress. Visits were more stressful if the relative's health was mentally impaired rather than physically impaired. Most family members were less distressed if they continue to participate in caregiving. The inclusion of these former carers in a partnership with staff (collaborative care) therefore reduced former carers' distress which helped them adapt to the institutionalisation of their relatives and it also improved their wellbeing. Consequently, the transition of relatives into long-term care can be a constructive event for family members. It can free them from overwhelming duties and provide the relatives with constant supervision that would not be possible in their own homes. Family members can continue to be very much involved in the life of the relatives, filling a role that facility staff cannot undertake. All the family members fulfilled an important socio-emotional role in comforting residents, particularly those with cognitive losses, by sitting with them, listening to them and, if possible, talking with them, and trying to reaffirm ties to people and places that had been part of the relatives' lives.

The care activities performed by family members as part of the caregiver role included assisting their relatives with activities of daily living, such as washing or feeding, as well as spending time sitting and talking with them. Such caregiving resulted in lifestyle change and some role strain, but family members also perceived their role in the facility to be a rewarding one, although this was not invariably so. Caregiving has reduced the amount of time the family members have to do other activities such as gardening and taking holidays. Caregiver role strain resulted from care activities and a lack of resources, for example, enough time, enough money, worry about their own and their relatives' future, increased tension and role conflict, that is, family members' decreased ability to fulfil other roles, for example, as spouse, parent. Positive aspects of caregiving included the family members' attributing constructive meaning to the caregiving situation, such as their relatives showing evidence that the family members' care was

appreciated, staff helping the family members to feel good about themselves and appreciating their input in the facility.

Coping was described in this study through accounts of how family members cared for themselves, as well as their relatives, and maintained feelings of hope. Though there were upheavals in family routines and emotional repercussions due to their relatives' illnesses and institutionalisation and the consequent need for family members to make visits, the family members typically described themselves as coping reasonably well. This notwithstanding, the experience of being visitors is also associated with psychological distress such as guilt, anger, resentment, though physical distress was reduced. Family members would like non-judgmental attitudes from staff, open encounters with nurses, and nurses being present for them whenever there are changes concerning their relatives. Family members saw emotional support from nurses as being valuable especially during crises.

For family members visiting is the lifeline they have with their relatives and *valuing-a-commitment-to-visiting* relates how being visitors was a valuable experience, albeit it also a stressful one, to which they learnt to adjust themselves. It was stressful because most family members experienced considerable difficulty in adjusting to being visitors and the impact it had on their lives. However, most family members when describing their experience of being visitors at the second interview, related that they had been able to reshape their lives by minimising the impact of visiting, so that the differences their visiting created had become part of the normal way of being in the world.

Family members recalled the past when they had been informal carers in the community yet trying to let this memory go and to move forward in their lives, now their relatives were in a care facility. Some family members had difficulty in letting go of being the primary carers and thus tended to worry about matters they themselves and certainly the staff, according to the family members, felt did not justify such concerns. Most family members established new routines and modified old ones, and continued to define themselves as informal carers which to them meant more than merely sitting and passing time with relatives. Many of the family members develop and maintain relationships of trust and confidence in health providers, while they are hopeful that the future will bring some positive experiences. Family members would like to reach their

potential of wellbeing and of life satisfaction, given their present situation. They would also like some sense of being in control of their own lives as well as over their relatives' lives and, above all, to feel supported in their caregiving.

Family members stayed involved with their relatives through their commitment to care. However, instead of providing continuous hands-on care, family members maintained their caregiver role by visiting their relatives in a facility, and while there, provided some assistance with activities of daily living, for example, feeding. They also interact with staff to ensure residents' needs are met and they oversee standards of care for their relatives and act as their advocates. They liaised with care staff to provide for their relatives' material needs, advising staff on their relatives' habits, interests, preferences and dislikes. Family members also maintained their relationship with their relatives by reminiscing with them, sharing family information and news. While most of the family members seek active participation/involvement in care, a few others wish to relinquish much of the caring role to health providers, desiring only minimal involvement.

Some family members complained of an insufficient number of staff and of the rapid turnover of some staff. Other family members focused on the slow response of nurses when they or their relatives wanted their assistance. They all remarked on how the staff frequently had little time to be there for their relatives or for them. They also all remarked on the fact that some of the staff, lacked the time and/or inclination to help them work through their losses and the changes in their lives. The charge nurse was a notable exception in the experience of some family members.

Support from similar research

The literature reviewed showed that the nursing literature today encourages the active involvement of clients/patients/residents with nurses in order to negotiate and make decisions about their care. Some of the literature revealed that it was also important for nurses to include the significant others of clients when giving care. Further, that nurses who promote individualised, holistic care need to hold such an ideology as a central belief to their philosophy. However, the literature also revealed that this philosophy is not necessarily very evident in practice. My study shared many similarities with the literature reviewed. My study showed that many family members want and expect to

actively participate in the care of their relatives. Moreover, they want information and support from nurses on how to participate in care and decisionmaking. In turn, they expect nurses to respect their needs and the needs of their relatives and to utilise the knowledge and experience of the family members, and of the relatives themselves if possible, in order to help them cope with the challenges of working together in partnership. Negotiation within a partnership requires an environment of mutual respect and participation, valuing the work of residents and informal carers as much as nurses' work.

My study strongly supported the findings of Bowers (1988). Like the participants in Bowers' study, the family members of my study were, above all, concerned about their relatives' health and wellbeing and emotional care was central. If the care provided to residents by staff met family members' expectations, then positive feelings about the staff was apparent, especially feelings of trust, with a consequent lessening of stress for family members.

My study also showed that good relationships between family members and relatives, between family members and other residents and their visitors and between family members and staff are important to family members' wellbeing as well as to their relatives' wellbeing. In fact, if the relationship between family members and relatives and family members and nurses in the context is not optimal, the family members are less likely to gain the valued visiting experience they seek. Similarly, Bonnel (1996), Bull, Jervis and Maher (1995) and Travis (1996) emphasised the vital role of family members and nurses working together for the benefit of improved client/patient care and my study revealed this was also important for the benefit of the family members themselves.

The findings of my study are consistent with those of Nolan and Grant (1989). Like these authors my study found that only the daily practical caring is usually released for family members, while other social and emotional functions are sustained and remain important. Both studies reveal the disruption that visiting can be to the family members' lives and both also indicate that if the staff do not wish for them to be involved in the facility it could be detrimental to the family members' wellbeing. Both studies further reveal the lack of understanding of the phenomenon of being visitors by some nursing

staff. Finally, both studies show that most family members wanted to share the care with health providers and wanted a relationship where their own knowledge of their relatives was respected by staff.

The findings of this study are also similar to those of Moss, Lawton, Kleban and Duhabel (1993). These authors found like I did that family members spend more time with other family members, with friends and in social pursuits following their relatives' institutionalisation. My study is also consistent with that of Smith and Bengston (1979). Their study showed that family members' relationships with their relatives may be enriched after the placement of their relatives. Family members in my study did not cease caregiving. They continued to watch over the needs of their relatives and to satisfy these needs directly or by working with facility staff. My study, like some other studies, such as Maas, Swanson, Specht and Buckwalter (1994), Pratt, Schmall, Wright and Hare (1987), Schofield (1996), Stewart (1997) and Tilse (1997a) found that this ongoing role did not seem well understood or supported by some staff. It has been thought that family members' emotional responses to long-term care placement promote their continued stress. Nevertheless, a lack of response by staff for the family members' continuing role may also be a significant factor.

The findings of my study indicate that family members tried to preserve some sense of family through maintenance of family communication. Engen (1994), Kammer (1994) and Kaplan and Ade-Ridder (1991) in their studies also found this to be very important to the family members that they studied. However, these authors studied mostly people who were visiting cognitively alert residents. In my study, some visits were especially hard because certain activities, such as talking with and sharing experiences with their relatives, were at times virtually impossible if their relatives suffered from verbal and cognitive impairments.

My study found that with the placement of relatives in a long-term care facility, family members do not abandon the caregiving role, rather they take on different roles in relationship to their relatives. Further, I found that visiting their relatives is very important to family involvement in the care of their relatives. My findings are similar to those of Kelley, Swanson, Meridean, Maas and Tripp-Reimer's study (1999) about family visitation on special care units. These authors emphasised that within the context

of changing relationships with their relatives, family members visited their relatives from a sense of duty and to foster a sense of family through ongoing relationships with their relatives. Again, like the studies mentioned above, and like my study, upholding family rituals were seen to be important in sustaining these relationships.

Thus, overall, the findings of these other studies have many similarities to my study, although differences have also been noted. It can be concluded that nurses have critical roles in promoting physical, emotional and interactive environments which foster family visitation.

The qualitative researcher and what I learnt

This study followed the approach of van Manen (1990) to make “visible” and to “illustrate” the realities of the study participants’ experience of being visitors. The family members described the thoughts, feelings and actions that accompany visiting and talked about their interactions with relatives, other residents and their visitors and nursing staff. Phenomenological methodology allows participants to describe their everyday concerns and practical knowledge and so gives entry to practical worlds. My study revealed the practical worlds that being visitors creates, allowing family members’ perspectives of the experience, including the care they and their relatives receive, to be ascertained. These worlds need to be the focus of health providers, for this study has shown visiting is not just an event that affects the wellbeing of residents. It very much affects the wellbeing of those family members who visit them and it becomes part of a new way of life for them.

Some of the stress and gratification experienced by the family members has received little acknowledgement in the literature, but an understanding of its significance in the total experience is crucial to the provision of appropriate nursing care. As discussed in Chapter Two of this study, although there has been much literature published on the topic of visiting most of it has been concerned with how visiting affects residents while comparatively little has focused on the needs of their family members. The excerpts in the data chapters are only a small part of the family members’ narratives. I consider that if people had the chance to read the interview transcripts they would come to understand how being visitors is the lifeline family members have with their relatives. Being

visitors meant an experience that was both stressful and valuable to which they learnt to adjust themselves. The family members all experienced some emotional and physical distress. However, some family members also recounted humorous incidents, and all expressed hopes for the future such as less stress in their lives. A major impression which I gained was of their continued commitment to caring for their relatives and coping with being visitors despite the distress and difficulties.

The study contains rich descriptions and interpretive propositions which nurses may use as a basis for more understanding of family members. The study has also developed ideas that further nurses' understandings of being a family member and the nature of the nurse-family member relationship. The study offers nurses telling accounts and insights into the experiences of family members and indirectly into the practice of geriatric nursing staff itself. Such accounts and insights can raise nurses' consciousness of the possibilities within their own practices which may be implemented to create more excellent geriatric family care.

It has been a privilege to meet with these eight people and to share some of their experience. I hope that others will find my interpretations of the family members' narratives of value.

Implications for Practice, Education and Research

The findings of this study and my thoughts on the research experience raise issues of interest for the practice of nurses and other health providers. Through learning from the lived experience of others we are able to help those who will experience the event of visiting in the future. The experience of these family members promote a better understanding of what being visitors to relatives in a long-term care facility means to family members. The present health care climate stresses increasing consumer involvement in health care. So in order to provide a responsive, quality service, we need much more understanding of the lived experiences of family members of residents as well as of residents and nurses. This study may promote such a deeper understanding from family members' perspectives.

Practice

Through identifying the experience of these family members, the study revealed that nurses play an important part in family members' experience of being visitors. Through a recognition of the importance of continuing-the-commitment-to-care and the relationship to the four lifeworld existentials, nurses can develop goals for their practice with family members aimed to help them toward a beneficial experience of being visitors.

Most family members wish to continue to be involved in the provision of care. Despite experiencing some feelings of relief that their relatives are receiving the care they need and can no longer receive at home, being a visitor in the early months meant learning to adjust to being in a facility. It provides nurses with opportunities to facilitate the adjustment for families by supporting their need for continued involvement with their relatives through visiting. Such intervention activity could also enhance family members' health and wellbeing.

However, I suggest that the capacity of families to act as their relatives' representatives is limited by the complexity of their relationships with staff and their weak position within the organisation. I argue for a greater understanding by nursing staff of family perspectives on the purpose and meaning of their participation in a long-term care facility; a commitment to providing time, venues and resources to encourage the voicing of family members' concerns and an interest in exploring alternative models of care for promoting and facilitating participation of families in long-term facilities. Family members need help to cope with their relationship changes with their relatives and help to understand their relatives' behaviours and illnesses. An atmosphere of friendliness, understanding and patience could assist families as they learn to adjust to a new and frequently foreign environment. Paying particular attention to families while they visit by sharing with them observations made of their relatives, asking for more information and displaying an interest in their own situations is an important part of nursing. Thus nurses need to focus on the holistic needs of the whole family instead of orienting their care around just the residents and/or procedures and tasks. Greater control and more active involvement in resident care by family members can result in greater wellbeing for the whole family. Nurses need to consider and flexibly balance the needs of family members with those of residents.

The conversations with family members show that their commitment to their relatives continues after their relatives are institutionalised. More understanding of family members' experiences as visitors can help to facilitate family member, as well as, resident, wellbeing. Long-term facilities need to balance their mainly medical perspective with the giving of due regard to other considerations, such as social and psychological, to give more holistic care. They also need to value the family members' role in caring for and supporting their relatives as this role could not be completely filled by others, for example, formal carers. Family members aim to promote their relatives' wellbeing in the facility. Nurses in a long-term care facility can help family members as well as residents. Family members' continuing role as caregivers needs to be recognised and encouraged. Their knowledge of, and caring for, their relatives over a period of possibly some years can be of much help to staff in finding the best approaches to residents' care. They need to be appreciated for their assistance. Trying to establish a trusting relationship between family and staff helps family members in their continuing role. Family members' own different and diverse needs also need consideration.

Consequently, the role of health providers is to enhance the family unit. They need to listen to family members' concerns and to learn from them before they plan services for family members and before they teach them, and before they provide information and emotional support. Only from such a base of such shared understandings can shared and humane care evolve. This change in consumer orientation requires nurses to adjust and move away from the traditional paternalistic approach to care. I suggest that nurses need to learn to communicate and negotiate better with families. They also need more educating about the philosophy and practice of the partnership approach, and then to implement the approach as required for the ultimate goal of excellent care and satisfied residents and families.

Nurses could facilitate a reasonable visiting schedule with family members. Sometimes family members need to be encouraged to share visiting with other family members and friends or to take a break. Nurses could persuade family members that such behaviours are not viewed as neglectful of, or as indifference to, their relatives. They could encourage family members to take care of themselves both physically and emotionally. Moreover, because of frequent contact, nurses in care facilities are the health providers

who are in an advantaged position to work effectively with family members to facilitate their participation in the care of relatives, if family members and relatives wish this. It is opportune to introduce criteria so that the needs of family members are met and that they are able to be involved in their relatives' care in a way which suits both groups of people. Though government policy in New Zealand recommends that older dependent people stay in their own homes, long-term care is an area which is expanding exponentially as the population is growing older.

Education

The stories in the data chapters show the strong impact of being visitors on people's lives. The stories will be of value in nursing education, as they could help students to understand how visiting is experienced which could be useful when they meet family members undergoing similar experiences in clinical practice. Nurse authors who advocate including phenomenological perspectives in nursing education (for example, Diekelmann, 1992; 1993) indicate that when interpretive approaches are given due consideration there is a chance for changing nursing practice. This, in turn, may lead to improved practice for the benefit of nurses' clients.

Visitors require health providers who have some understanding of their individual needs. Continuity of care by health providers who have specialised knowledge and experience for caring for and working with residents and their family members is the ideal. The education and/or training of many of the present nurses and careworkers is not enough for the knowledge that is required to provide holistic individualised care. Most family members ask to be partners or share in the care of their relatives and to have their own knowledge of the relatives acknowledged by health providers. They deserve full recognition of, and support for this, if this is what they, and their relatives, want. Nurse educators need to teach nurses to work empathetically with families. This study suggests significant concerns which could be explored with students, for example, family centred care, nurse-family relationships, and the importance of caring in nursing. The family members' rich descriptions of nurses and nursing practices that they considered to be of benefit and also those which caused them distress could be of use to nurse educators to develop effective nursing care. A collaborative relationship between the education and practice sectors of nursing could also facilitate the obtaining of appropriate and high quality nursing education and client care.

As well, the experience of the family members shows ways in which a caring manner by health providers was both wanted by the family members and would be of use in helping them cope with the difficulties they faced when visiting. The family members often found it stressful to be a visitor. Many health care providers have not been and so cannot share the experiences of people who have been visitors. It thus is very important to listen well to the experiences of visitors and to not disregard what these people say on the premise that nurses are able to understand through a comparable experience. Being visitors for most family members means meeting specific problems and challenges. Nursing expertise could facilitate positive and fulfilling relationships between visitors and other people in the facility which are in keeping with visitors' wishes. If nurses listen well to family members' experiences, chances for learning about these will probably occur, such as the way family members cope with the experience. Nurses can use the knowledge gained when working with families and they can also teach their students to do the same. Consequently, the type of care that is wanted needs nurses with expertise. Mayeroff (1971) suggests that caring is not just good intentions or warm regard. Instead, to care nurses need to understand the needs of the people they care for and then work with them to meet their needs. Such caring relies on understanding those people and then on behaving with integrity towards them.

Research

The findings of this study indicate that family members wish for involvement in the care of their relatives and to share in decisions concerning their relatives in a long-term facility, but more research is needed on how such a participative, collaborative relationship could be achieved. The evidence that the experience of being a visitor to a relative in long-term care is stressful for many families, argues for better understanding of this experience in order to improve long-term care policies and services for family member wellbeing. The existence of a continuing role for family members in monitoring and meeting the needs of residents was supported in this study and needs further examination. How can this role be better negotiated and supported and what would be the impact of this increased role for family members, residents and staff? Further research is needed to tease out ways of identifying practices and supports required to meet family members' diverse needs. More research could further document the multifaceted needs, for example, emotional and financial, and also the resources of

family members, their sources of satisfaction and dissatisfaction and the effectiveness of innovative interventions by health providers. This is of significance partly because previous studies of caregiving have often eliminated the family from study once the older person is placed in a long-term care facility. Yet, though institutionalisation is less widely experienced in later life than home care, the number of families facing this experience is sizable and is growing. Moreover, there is little published New Zealand information relating to the subjective experience of being a visitor. Overseas research cannot be applied directly to New Zealand, however, since social and cultural factors are different. Thus there is a need for further research.

Moreover, a description of family members' experiences after a longer period of time than the first five months post placement that I covered also needs exploration and elaboration to find out how family members' needs change over time if relatives survive long periods in care facilities. There is also a need for intervention studies to investigate whether teaching nurses individualised care improves the quality of care for residents and families and whether the provision of this care decreases their stress. For example, does increased family involvement in care-planning and task performance affect their stress levels?

This study involved participants from only one cultural group and included more women than men. More research is needed to clarify the influence of culture, ethnicity and gender on the experience of being a visitor. The wider society needs to understand these matters if pressure is to be placed on policy makers to provide suitable and culturally sensitive health services.

Trustworthiness

This thesis is my report of my interviews with eight people who are visitors to a relative in a long-term care facility. I have tried to give readers authentic and meaningful stories of people's experience which Sandelowski (1993) considers to be the best check of rigor in qualitative research. I have also tried to reveal the philosophical bases in all parts of the study. The principle of staying true to the phenomena being studied is shown in the way the data has guided the study. It is also shown in the way some of my assumptions about visiting have been called into question and transformed.

In Chapter Three I discussed four procedures suggested by Sandelowski (1986) for assessing the trustworthiness of a study. Firstly, the participants endorsed my interpretations of their stories as faithful, so ensuring credibility. Next, upholding the fittingness or transferability of the study's findings are the strong resemblances to the findings of, for example, Kelley et al. (1999) and Tilse (1997a) as discussed under the section "Support from similar research". Thirdly, I also tried to leave a "decision trail" as Sandelowski recommends, so that readers may audit the work. The audit trail specified in Chapter Three and the data chapters enable readers to understand my point of view. As well, the many excerpts of the family members help validate the data and so help ensure confirmability. People conversant with the hermeneutic phenomenological approach have monitored my study to enhance dependability. Lastly, I have thought deeply about and informed readers of my premises with reference to the intent of my research. Further, I have tried to show the meaning of the phenomenological perspective of the person, examining the implications for me as the researcher.

Limitations of the study

Findings cannot be generalised as the data can only apply to people who participated in this study. Nevertheless, it is probable that similar findings could result with a similar group of family members of older people who are of the same age and gender and who have similar experiences. The usefulness of the findings from this type of study may be gauged when nurses read and consider the findings carefully. Van Manen (1990) referred to the "phenomenological nod" response. It may be used to evaluate phenomenological research as follows "a good phenomenological description is something we can nod to, recognising it as an experience we have had or could have had" (p.27).

A restricted amount of time and resources for this research, some because it was undertaken as a Master of Arts study, have meant participant numbers were small. However, a small number of participants is typical for phenomenological studies, which focus on in-depth analysis of lived experience. Further, the length of the interviews could also be criticised, yet the detailed perspectives of the participants which were gained helps to counteract this criticism. Conversely, the varied circumstances,

occupations, ages and experiences of the participants is greater than I anticipated and I suggest adds to the trustworthiness of the findings.

The participants were volunteers who had come from a much bigger group of possible participants, and in this way the eight family members who participated in the study could, because of their motivation, be regarded an atypical group. It is not possible to evaluate any effects of this difference. Conversely, my association with the long-term care facility may have restricted the willingness of some participants to talk openly about their needs or problems when visiting.

The participants were all given the chance to confirm and clarify with me the transcripts of their interviews. However, I wonder if participants can in fact confirm the mental processes that follow from reflection on the synthesised essential structures of each participant's experiences, without recourse to all the interview transcripts. The participants' stories have been screened through my interpretive framework. I have tried to give a genuine report by checking my work with the family members and with my supervisor in order to decrease the likelihood of misconstructions. I also aimed to show the social reality of people as they experienced it at two different points. Nevertheless, the way the participants described their experiences in their interviews with me may not be the way they would relate them at the present time.

This study involves a series of transformations of experience and is just one of several variants for the same narrative. I have tried to be aware of my part in the research. Intuition is fundamental to phenomenological research. Researchers need to be very aware as to how their beliefs, feelings and values could affect the research process. I accept that my interpretations may be influenced by prejudices and suppositions which I have not recognised as such.

My study concerns the personal response of family members who are visitors to a relative in a care facility. The need to maintain anonymity, as well as the large amount of data collected, meant that the entire narratives of the participants could not be described. These would have added richness and vividness to the description of the lived experience. Instead my study gives a synthesised portrayal of the individual patterns of experiences of the participants. I was helped in the process of deciding what

to leave in and out by repeatedly asking of the data what it is that makes the experience of being a visitor what it is and without which the experience would not be what it is. My considerations are not final.

Nonverbal communication was largely overlooked as I collected data by taped interviews and fieldnotes. However, I noted it in the transcripts if participants seemed particularly emotional, for example, laughed or cried.

I undertook this study while I worked fulltime. Thus my working on the study was done in dribs and drabs. This possibly hindered my understanding. Conversely, I have experienced having a relative in a long-term care facility (although I have not cared for that relative in the community) and so my experience in some ways was similar to that of family members in this study. This probably helped my understanding.

Concluding statement

The literature on visiting has focused primarily on residents. It has acknowledged to a far lesser extent that the lives of their family members are affected by visiting. My study disclosed the phenomenon of being a visitor to phenomenological inquiry to reveal the previously invisible essential structures that embody the experience. A picture arose of most family members showing a high degree of commitment to continuing the caregiving relationship when they visit their relatives in a long-term care facility. This study stemmed from my idea that it was possible to understand better the way people experience being a visitor to a relative in long-term care and that this understanding could facilitate the giving of suitable nursing practice. A phenomenological method was chosen as it provided both a framework and a philosophy appropriate to interpreting and understanding the experience of being a visitor for those family members.

As life expectancy continues to improve, more people will live longer and so more people will be visitors. Nurses need to create systems of care delivery which are based on a meaningful appreciation of family members' experiences. In this way nurses in the geriatric area could assist family members so that they experience being visitors with less stress and are able to move through this period in their lives in a constructive and positive way.

REFERENCES

- Ade-Ridder, L., & Kaplan, L. (1993). Marriage, spousal caregiving and a husband's move to a nursing home: A changing role for the wife? Journal of Gerontological Nursing, 19(10), 13-23.
- Age Concern. (1996). Policy Manifesto. New Zealand.
- Anderson, K. H., Hobson, A., Steiner, P., & Rodell, B. (1992). Patients with dementia: Involving families to maximise nursing care. Journal of Gerontological Nursing, 18(7), 19-25.
- Aneshensel, C., Pearlin, L., Mullin, J., Zarit, S., & Whitlatch, C. (1995). Profiles in caregiving: The unexpected career. San Diego: Academic Press.
- Anells, M. (1996). Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research. Journal of Advanced Nursing, 23, 705-713.
- Astedt-Kurki, P., Paunonen, M., & Lethi, K. (1997). Family members' experiences of their role in a hospital: A pilot study. Journal of Advanced Nursing, 25, 908-914.
- Baum, M., & Page, M. (1991). Caregiving and multigenerational families. The Gerontologist, 31(6), 762-769.
- Beck, C. T. (1994). Phenomenology: Its use in nursing research. International Journal of Nursing Studies, 31(6), 499-510.
- Beck, C., & Chumbler, N. (1997). Planning for the future of long term care: Consumers, providers and purchasers. Journal of Gerontological Nursing, 23(8), 6-13.
- Becker, M., & Maiman, L. (1980). Strategies for enhancing patient compliance. Journal of Community Health, 6, 113-135.

Bedford, D. (1999). A place to rest in twilight years. The Evening Post. May 24, 5.

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

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction and understanding in nursing science. Advances in Nursing Science, 8(1), 1-14.

Benner, P., & Wrubel, R. (1988). Caring is the candle that lights the dark, that permits us to find answers where others see none. American Journal of Nursing, 88, 1073-1075.

Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner, (Ed.), Interpretive phenomenology. (pp. 7-29). Thousand Oaks, CA: Sage.

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

Berando, F. M. (1985). Social networks and life preservation. Death Studies, 9, 37-50.

Bergum, V. (1991). Being a phenomenological researcher. In J. Morse (Ed.), Qualitative nursing research: A contemporary dialogue. (pp. 43-57). Rockville: Aspen.

Bibbings, A. (1994). One year on: The carers' perspective. Primary Health Care, 4(4), 8-10.

Bleeker, H., & Mulderij, K. (1992). The experience of motor disability. Phenomenology and Pedagogy, 10, 1-18.

Bonnel, W. B. (1996). Not gone and not forgotten: A spouse's experience of late-stage Alzheimer's disease. Journal of Psychosocial Nursing, 34(8), 23-27.

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

Bowers, B. J. (1987). Intergenerational caregiving: Adult caregivers and their aging parents. Advances in Nursing Science, 9(2), 20-31.

Bowers, B. J. (1988). Family perceptions of care in a nursing home. The Gerontologist, 28(3), 361-368.

Brody, E. M., Dempsy, N. P., & Pruchno, R. A. (1990). Mental health of sons and daughters of the institutionalised aged. The Gerontologist, 30(2), 212- 219.

Brubaker, E., & Schiefer, A. E. (1987). Groups with families of elderly long term care residents: Building social support networks. Journal of Gerontological Social Work, 10, 167-175.

Buckwalter, K. C., & Hall, G. R. (1987). Families of the institutionalised older adult: A neglected resource. In T. Brubaker. (Ed.), Aging, health and family: Long term care. (pp. 47-56). Sage: Newbury Park.

Bull, M., Jervis, L., & Maher, M. (1995). Hospitalised elders: The difficulties families encounter. Journal of Gerontological Nursing, 21(6), 19-23.

Byrne, H., & MacLean, D. (1997). Quality of life: Perceptions of residential care. International Journal of Nursing Practice, 3, 21-28.

Callery, P., & Smith, I. (1991). A study of role negotiation between nurses and the parents of hospitalised children. Journal of Advanced Nursing, 16, 772-778.

Cameron, K., & Gregor, F. (1987). Chronic illness and compliance. Journal of Advanced Nursing, 12, 671-676.

Campbell, J. M., & Linc, L. G. (1996). Support groups for visitors of nursing home residents. Journal of Gerontological Nursing, 22(2), 30-35.

Caron, W. A. (1997). Family systems and nursing care systems: An ecosystemic perspective for the systems practitioner. In T. Hargrave & S. Hanna. (Eds.), The aging family. (pp. 235-258). New York: Brunnel/Mazel.

Carr, J., & Clarke, P. (1997). Development of the concept of family vigilance. Western Journal of Nursing Research, 19(6), 726-739.

Carter, A. (1991). The needs of patients' relatives. Nursing Times, 87(50), 43.

Chadwick, P. (1984). Social stimulation and the elderly. Nursing Times, 80(10), 41-42.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist, 26, 269-272.

Chesla, C., Martinson, I., & Muwaswes, M. (1994). Continuities and discontinuities in family members' relationships with Alzheimer's patients. Family Relations, 43, 3-9.

Clark, P. G. (1987). Individual autonomy, cooperative empowerment, and planning for long term care decision making. Journal of Aging Studies, 1(1), 65-76.

Cohen, L., & Manion, L. (1985). Research methods in education. Kent: Croom Helm.

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

Corbin, J. M., & Strauss, A. (1988). Unending work and care: Managing the chronic illness at home. San Francisco: Jossey-Bass.

Corson, S. A., & Corson, E. (1983). Pet animals as socialising catalysts in geriatrics: An experiment in nonverbal communication therapy. In L. Levi (Ed.), Society, stress and disease. (pp.28-43). London: Oxford University Press.

Coughlan, P. (1993). Facing Alzheimer's: Family caregivers speak. New York: Ballantyne.

Cox, C. L., & Ephross, P. (1989). Group work with families of nursing home residents: Its socialisation and therapeutic functions. Journal of Gerontological Work, 13, 61-73.

Cox, C. L., Kaesar, L., Montgomery, A. C., & Marion, L. H. (1991). Quality of life nursing care: An experimental trial in long term care. Journal of Gerontological Nursing, 17(4), 6-11.

Cram, F., & Paton, H. (1993). Personal possessions and self-identity: The experiences of elderly women in three residential settings. Australian Journal on Ageing, 12(1), 19-24.

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

Crowley-Robinson, P., Fenwick, D. C., & Blackshaw, J. K. (1996). A long-term study of elderly people in nursing homes with visiting and resident dogs. Applied Animal Behaviour Science, 47(1-2), 137-148.

Cutillo-Schmitter, T., Rovner, B., Shmueli, Y., & Bawduniak, I. (1996). Forming treatment partnerships with patients and their families: A case study. Journal of Gerontological Nursing, 22(6), 23-36.

Daley, O. E. (1993). Women's strategies for living in a nursing home. Journal of Gerontological Nursing, 19(9), 5-9.

Darbyshire, P. (1994). Skilled expert practice: Is it 'all in the mind'? A response to English's critique of Benner's novice to expert model. Journal of Advanced Nursing, 19(5), 755-761.

Darbyshire, P., Diekelmann, J., & Diekelmann, N. (1999). Reading Heidegger and interpretive phenomenology: A response to the work of Michael Crotty. Nursing Inquiry, 6(1), 17-25.

Dekker, D. (1999). The baby-boomer dilemma. The Evening Post, May 22, 13.

Dellasega, C. (1991). Caregiver stress among community caregivers for the elderly: Does institutionalisation make a difference? Journal of Community Health Nursing, 8(4), 197-205.

Dellasega, C., & Mastrian, K. (1995). The process and consequences of institutionalising an elder. Western Journal of Nursing Research, 17(20), 123-140.

Denzin, N. K., & Lincoln, Y. S. (1994). Introduction: Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln. (Eds.), Handbook of qualitative research. (pp.1-18) Sage: London.

Diekelmann, N. (1992). Learning-as-testing: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in nursing. Advances in Nursing Science, 14(30), 72-83.

Diekelmann, N. (1993). Behavioural pedagogy: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in nursing. Journal of Nursing Education, 32, 245-250.

Dreyfus, H. (1991). Being-in-the-world: A commentary on Heidegger's being and time: Division I. Massachusetts: Mit.

Duncan, M., & Morgan, D. (1994). Sharing the caring: Family caregivers' views of their relationships with nursing home staff. The Gerontologist, 34(2), 235-244.

Engen, S. (1994). Effective visiting in the long term care setting. Canadian Nursing Home, 5(1), 18-19.

English, I. (1993). Intuition as a function of the expert nurse: Critique of Benner's novice to expert model. Journal of Advanced Nursing, 18, 387-393.

Erlanger, M. (1997). Changing roles and life-cycle transitions. In T. Hargrave & S. Hanna. (Eds.), The aging family. (pp. 163-177). New York: Brunnel/Mazel.

Field, P. A., & Morse, J. M. (1985). Nursing research: The application of qualitative approaches. London: Kroom Helm.

Fink, S. V., & Picot, S. F. (1995). Nursing home placement decisions and post-placement experiences of African-American caregivers. Journal of Gerontological Nursing, 21(12), 35-42.

Francis, G., & Odell, S. (1979). Long-term residence and loneliness: Myth or reality? Journal of Gerontological Nursing, 5, 9-11.

Friedman, M. M. (1992). Family nursing: Theory and practice. (3rd Ed.). Connecticut: Appleton & Lange.

Friedemann, M., Montgomery, Y., Maiberger, B., & Smith, A. (1997). Family involvement in the nursing home: Family-oriented practices and staff-family relationships. Research in Nursing and Health, 20, 527-537.

Fries, B. E., Scholl, M., Hawes, C., Gilgen, R., Jonsson, P. V., & Park, P. (1997). Approaching cross-national comparisons of nursing home residents. Age & Ageing, 26(Suppl 2): 13-18.

Funk, S. G., Tornquist, E. M., Champagne, M. T., & Wiese, R. A. (1993). Caring for the chronically ill: From research to practice. In S. G. Funk, E. M. Tornquist, M. T. Champagne & R. A. Wiese (Eds.), Key aspects of caring for the chronically ill. Hospital and home. (pp. 3-7). New York: Springer.

George, L. K. (1994). Caregiver burden and wellbeing: An elusive distinction. The Gerontologist, 34(1), 6-7.

George, L. K., & Gwyther, L. (1986). Caregiver wellbeing: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26, 253-259.

Gibb, H. (1990). Representations of old age. Notes towards a critique and revision of ageism in nursing practice. Research monograph series number 2. Deakin University: Australia.

Gibson, M. C., Bol, N., Woodbury, M. G., Beaton, C., & Janke, C. (1999). Comparison of caregivers', residents', and community-dwelling spouses' opinions about expressing sexuality in an institutional setting. Journal of Gerontological Nursing, 25(4), 30-39.

Gonzalez, S., Steinglass, P., & Reiss, D. (1989). Putting the illness in its place: Discussion groups for families with chronic medical illnesses. Journal of Gerontological Social Work, 28, 69-87.

Grant, N. K., Reimer, M., & Bannatyne, J. (1996). Indicators of quality in long-term care facilities. International Journal of Nursing Studies, 33(5), 469-478.

Grau, L., Teresi, J., & Chandler, B. (1993). Demoralisation among sons, daughters, spouses and other relatives of nursing home residents. Research on Aging, 15(3), 324-345.

Greene, V. L., & Monahan, D. J. (1982). The impact of visitation well-being in nursing homes. The Gerontologist, 22(4), 418-423.

Gubrium, J. (1991). The mosaic of care: Frail elderly and their families in the real world. New York: Springer.

Happ, M. B., Williams, C. C., Strump, N. E., & Burger, S. G. (1996). Individualised care for frail elders: Theory and practice. Journal of Gerontological Nursing, 22(4), 6-14.

Hathaway, D., Boswell, B., Stanford, S., Scheider, S., & Moncrief, A. (1987). Health promotion and disease prevention for the hospitalised patient's family. Nursing Administration Quarterly, 11(3), 1-7.

Heidegger, M. (1962). Being and time. John Macquarrie & Edward Robinson, trans.). J. McIntyre and I. Ramsay (Eds.). London: SCM Press. (translated from the German 7th ed. 1927).

High, D., & Rowles, G. (1995). Nursing home residents, families, and decision making: Toward an understanding of progressive surrogacy. Journal of Aging Studies, 9(2), 101-117.

Holloway, I., & Wheeler, S. (1996). Qualitative research for nurses. Oxford: Blackwell.

Holmes, C. A. (1996). The politics of phenomenological concepts in nursing. Journal of Advanced Nursing, 24, 579-587.

Horsnell, T. (1994). April 20. Report to the Wesley Wellington Mission. In P. Swain, (1995). Adding dignity to old folks' last years. The Dominion, p.8-9.

Houston, D. M., McKee, K. J., Carroll, L., & Marsh, H. (1998). Using humour to promote psychological wellbeing in residential homes for older people. Aging & Mental Health, 2(4), 328-332.

Hutchinson, S. A., Wilson, M. E., & Wilson, H. (1994). Benefits of participating in research interviews. IMAGE: Journal of Nursing Scholarship, 26(2), 161-164.

Ikegami, N., Morris, J. N., & Fries, B. E. (1997). Low-care cases in long-term care settings: Variation among nations. Age & ageing, 26(Suppl 2): 67-71.

Jacques, A. (1992). Understanding Alzheimer's disease. (2nd. Ed.). Scotland: Churchill Livingstone.

Jerrett, M. (1994). Parents' experience of coming to know the care of a chronically ill child. Journal of Advanced Nursing, 19, 1050-1056.

Jewell, S. (1994). Patient participation: What does it mean to nurses? Journal of Advanced Nursing, 19, 433-438.

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

Kaasalainen, S., Middleton, J., Knezacek, S., Hartley, T., Stewart, N., Ife, C., & Robinson, L. (1998). Pain and cognitive status in the institutionalised elderly: Perceptions and interventions. Journal of Gerontological Nursing, 24(8), 24-31.

Kammer, C. H. (1994). Stress and coping of family members' responsible for nursing home placement. Research in Nursing and Health, 17, 89-98.

Kane, R. A., Caplan, A. L., Urv-Wong, E. K., Freeman, I. C., Aroskar, M. A., & Finch, M. (1997). Everyday matters in the lives of nursing home residents: Wish for and perception of choice and control. Journal of the American Geriatrics Society, 45(9), 1086-93.

Kaplan, L., & Ade-Ridder, L. (1991). Impact on the marriage when one spouse moves to a nursing home. Journal of Women and Aging, 3(3), 81-101.

Karner, T. X., Montgomery, R. J. V., Dobbs, D., & Wittmaier, C. (1998). Increasing staff satisfaction: The impact of SCUs and family involvement. Journal of Gerontological Nursing, 24(2), 39-44.

Kelley, L. S., Swanson, E., Maas, M. L., & Tripp-Reimer, T. (1999). Visitation on special care units. Journal of Gerontological Nursing, 25(2), 14-21.

Kitwood, T., & Benson, S. (1995). The new culture of dementia care. London: Hawker.

Koch, T. (1995). Interpretive approaches in nursing research: The influence of Husserl and Heidegger. Journal of Advanced Nursing, 21, 827-836.

Koch, T., & Webb, C. (1996). The biomedical construction of ageing: Implications for nursing care of older people. Journal of Advanced Nursing, 23, 954-959.

Kriseman, N. L., & Claes, J. A. (1997). Gender issues and elder care. In T. Hargrave & S. Hanna (Eds.), The aging family: New visions in theory, practice and reality. (pp.199-208). New York: Brunnel/Mazel.

Laitinen, P. (1992). Participation of informal caregivers in the hospital care of elderly patients and their evaluations of the care given: Pilot study in three different hospitals. Journal of Advanced Nursing, 17(2), 1233-1237.

Laitinen, P. (1993). Participation of caregivers in elderly-patient hospital care: Informal caregiver approach. Journal of Advanced Nursing, 18(9), 1480-1487.

Laitinen, P. (1994). Elderly patients' and their informal caregivers' perceptions of care given: The study-control ward design. Journal of Advanced Nursing, 20, 71-76.

Laitinen, P., & Isola, A. (1996). Promoting participation of informal caregivers in the hospital care of the elderly patient: Informal caregivers' perceptions. Journal of Advanced Nursing, 23, 942-947.

Leonard, V. W. (1989). A Heideggerian phenomenologic perspective on the concept of the person. Advances in Nursing Science, 11(4), 40-55.

Leonard, V. W. (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). California: Sage.

Liehr, P. R., & Marcus, M. T. (1994). Qualitative approaches to research. In G. LoBiondo-Wood & J. Haber. (Eds.), Nursing Research: Methods, critical appraisal, and utilisation. (pp. 253-285). St. Louis: Mosby.

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. California: Sage.

Long, J. (1997). Alzheimer's disease and the family: Working with new realities. In T. Hargrave & S. Hanna (Eds.), The aging family. (pp. 209-234). New York: Brunnel/Mazel.

Lyman, K. (1989). Bringing the social back in: A critique of the biomedicalisation of dementia. The Gerontologist, 29(5), 597-605.

Maas, M. L., Buckwalter, K. C., Kelley, L. S., & Stolley, J. M. (1991). Family members' perceptions: How they view care of Alzheimer's patients in a nursing home. The Journal of Longterm Care Administration, 19(1), 21-25.

Maas, M. L., Buckwalter, K. C., Swanson, E., Specht, J., Tripp-Reimer, T., & Hardy, M. A. (1994). November/December. The caring partnership: Staff and families of persons institutionalised with Alzheimer's disease. The American Journal of Alzheimer's Care and Related Disorders & Research. 21-30.

Maas, M., Swanson, E., Specht, J., & Buckwalter, K. C. (1994). Alzheimer's special care units. Nursing Clinics of North America, 29(1), 173-194.

Mace, N., & Rabins, P. (1992). The 36-hour day: A family guide to caring at home for people with Alzheimer's disease and other confusional illnesses. London: Hodder & Stoughton.

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

Maidment, J. (1996). March. Loss and grief: Social work with the elderly. Social Work Review, 10-13, 19.

Matthiesen, V. (1989). Guilt and grief: When daughters place mothers in nursing homes. Journal of Gerontological Nursing, 15(7), 11-15.

Mattiasson, A-C., & Andersson, L. (1997). Quality of nursing home care assessed by competent nursing home patients. Journal of Advanced Nursing, 26, 1117-1124.

May, C. (1990). Research on nurse-patient relationships: Problems of theory, problems of practice. Journal of Advanced Nursing, 15, 307-315.

Mayeroff, M. (1971). On caring. New York: Harper & Row.

McCarty, E. F. (1996). Caring for a parent with Alzheimer's disease: Process of daughter caregiver stress. Journal of Advanced Nursing, 23, 792-803.

McLeod, E., & Schwartz, F. E. (1992). Working together: Collaboration among HCWs and families in long-term care. Journal of Gerontological Nursing, 18(8), 26-30.

McMillan, C. (1998). Perceptions of caring by rest home residents. Geriaction, 16(2), 15-19.

Merleau Ponty, M. (1962). Phenomenology of perception. New York: Humanities Press.

Montgomery, R. (1982). Impact of institutional care policies on family integration. The Gerontologist, 22 (1), 54-58.

Morse, J. (1991). Negotiating commitment and involvement in the nurse-patient relationship. Journal of Advanced Nursing, 16, 455-468.

Moss, M., Lawton, M. P., Kleba, M., & Duhamel, L. (1993). Time use of caregivers of impaired elders before and after institutionalisation. Journal of Gerontology: Social Sciences, 48, S102-S111.

Motenko, A. K. (1989). The frustrations, gratifications, and wellbeing of dementia caregivers. The Gerontologist, 29(2), 166-172.

Muschel, I. J. (1984). October. Pet therapy with terminal cancer patients. Social Casework, 65, 451-458.

Nay, R. (1995). Nursing home residents' perceptions of relocation. Journal of Clinical Nursing, 4, 319-325.

Nay, R. (1997). Relatives' experiences of nursing home life: Characterised by tension. Australian Journal on Ageing, 16(1), 24-29.

Newby, N. M. (1996). Chronic illness and the family life-cycle. Journal of Advanced Nursing, 23, 786-791.

Nolan, M. R., & Grant, G. (1989). Addressing the needs of informal carers: A neglected area of nursing practice. Journal of Advanced Nursing, 14, 950-961.

O' Connor, B. P., & Rigby, H. (1996). Perceptions of baby talk, frequency of receiving baby talk, and self-esteem among community and nursing home residents. Psychology and Aging, 11, 147-154.

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

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

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

Opie, A. (1994). The instability of the caring body: Gender and caregivers of confused older people. Qualitative Health Research, 4(1), 31-50.

Patterson, V. (1997). Who cares?: Making elder carers visible: Eleven women talk about the implications of the caregiving role. Unpublished master's thesis. Massey University, Palmerston North.

Phinney, A. (1998). Living with dementia: From the patient's perspective. Journal of Gerontological Nursing, 24(6), 8-15.

Plager, K. (1994). Hermeneutic phenomenology. A methodology for family health and health promotion study in nursing. In P. Benner. (Ed.), Interpretive phenomenology: Embodiment, caring and ethics in health and illness. (pp. 65-83). California: Sage.

Playle, J. (1995). Humanism and positivism in nursing: Contradictions and conflicts. Journal of Advanced Nursing, 22, 979-984.

Pratt, C. C., Schmall, V. L., Wright, S., & Hare, J. (1987). The forgotten client: Family caregivers to institutionalised dementia patients. In T. Brubaker (Ed.), Aging, health and family: Long term care. (pp. 197-213). Beverly hills, CA: Sage.

Price, B. (1996). Illness careers: The chronic illness experience. Journal of Advanced Nursing, 24, 275-279.

Rather, M. (1992). Nursing as a way of thinking- Heideggerian hermeneutical analysis of the lived experience of the returning RN. Research in Nursing and Health, 15, 47-55.

Ray, M. (1990). Phenomenological method for nursing research. In N. L. Chaska (Ed.), The nursing profession: Turning points. (pp. 173-183). St. Louis: Mosby.

Reed, J., & Bond, S. (1991). Nurses' assessment of elderly patients in hospital. International Journal of Nursing studies, 28,(1) 55-64.

Richmond, D., Baskett, J., Bonita, R., & Melding, P. (1995). Care for older people in New Zealand. A report to the National Advisory Committee on Core Health and Disability Support Services. Wellington.

Reinhartz, S. (1983). Phenomenology as a dynamic process. Phenomenology + Pedagogy, 1(1), 77-79.

Robertson, J. F., & Cummings, C. C. (1996). Attracting nurses to long-term care. Journal of Gerontological Nursing, 22(9), 24-32.

Roenke, L., & Mulligan, S. (1998). The therapeutic value of the human-animal connection. Occupational Therapy in Health Care, 11(2), 27-43.

Rosenthal, C., Marshall, V., & Shulman, J. (1982). Problems experienced by families of long stay patients. Canadian Journal on Aging, 11, 169-183.

Rosenthal, C., & Dawson, P. (1993). Families and the institutionalised elderly. In G. Jones & B. Miesen (Eds.), Caregiving in dementia: Research and applications. (pp. 398-418). London: Routledge.

Rowles, G. D., & High, D. M. (1996). Individualising care: Family roles in nursing home decision-making. Journal of Gerontological Nursing, 22(3), 20-25.

Rubin, A., & Shuttleworth, G. (1983). Engaging families as support resources in nursing home care: Ambiguity in the subdivision of tasks. Gerontologist, 23, 632-636.

Ryan, E. B., MacLean, M., & Orange, J. B. (1994). Inappropriate accommodation in communication to elders: Inferences about nonverbal correlates. International Journal of Aging & Human Development, 39(4), 273-291.

Salvage, J. (1992). The new nursing: Empowering patients or empowering nurses? In J. Robinson, A. Gray & R. Elkan (Eds.), Policy issues in nursing. (pp. 9-23). Philadelphia: Open university.

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

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. Advances in Nursing Science, 16(2), 1-8.

Savishinsky, J. S. (1985). Pets and family relationships among nursing home residents. Marriage and Family Review, 8, 109-134.

Schmidt, M. (1987). The patient's partner: The spouse in residential care. Health and Social Work, 12, 206-212.

Schofield, V. (1996). A fragile sort of balance: Careguardianship as a phase of caregiving for people with dementia. Unpublished doctoral thesis. Victoria University, Wellington.

Schultz, C., Smyrnios, K., Grbich, C., & Pruchno, N. (1993). Caring for family caregivers in Australia: A model of psychoeducational support. Ageing and Society, 13, 1-25.

Schultz, R., & Williamson, G. M. (1993). Psychosocial, behavioural dimensions of physical frailty. Journal of Gerontology, 48, 39-43.

Sharp, T. (1990). Relatives' involvement in caring for the elderly mentally ill following long-term hospitalisation. Journal of Advanced Nursing, 15, 67-73.

Shaw, M. C., & Halliday, P. H. (1992). The family, crisis and chronic illness: An evolutionary model. Journal of Advanced Nursing, 17, 537-543.

Sheeran, G. (1999). Elderly stretched by latest govt turn. Sunday Star Times, October 4, 4.

Shuttleworth, G. E., Rubin, A., & Duffy, M. (1982). Families versus institutions: Incongruent role expectations in the nursing home. The Gerontologist, 22(2), 200-208.

Smallegan, M. (1981). Decision making for nursing home admission: A preliminary study. Journal of Gerontological Nursing, 7(5), 280-285.

Smith, K. F., & Bengston, V. L. (1979). Positive consequences of institutionalisation: Solidarity between elderly parents and their middle-aged children. The Gerontologist, 19, 438-447.

Smith, J. K., & Heshusius, L. (1986). Closing down the conversation: The end of the quantitative-qualitative debate among educational researchers. Educational Researcher, 15, 4-12.

Sorell, T. (1987). Descartes. Oxford: University Press.

Statistics New Zealand. (1998). Sixty-five plus. New Zealand Now Series. Wellington Government Printer.

Stephens, M. P., Kinney, J. M., & Ogrocki, P. K. (1991). Stressors and wellbeing among caregivers to older adults with dementia: The in-home versus nursing home experience. The Gerontologist, 31(2), 217-223.

Stevens Barnum, B. (1998). Nursing theory. Analysis, application, evaluation. (5th Ed.). Philadelphia: Lippincott.

Stewart, A. M. (1997). A study of families' experiences of assisting a member into residential care. Unpublished master's thesis. Massey University, Palmerston North.

Sumaya-Smith, I. (1995). Care giver/resident relationships: Surrogate family bonds and surrogate grieving in a skilled nursing facility. Journal of Advanced Nursing, 21, 447-451.

Swanson-Kauffman, K., & Schonwald, E. (1988). Phenomenology. In B. Sarter, (Ed.), Paths to knowledge: Innovative research methods for nursing. (pp. 153-173). New York: Springer.

Taylor, B. (1994). Being human: Ordinairiness in nursing. Churchill Livingstone: Melbourne.

Tennstedt, S. L. (1992). Response comparability of family and staff proxies for nursing home residents. American Journal of Public Health, 82, 747-749.

Thorne, S. E., & Robinson, C. A. (1988). Health care relationships: The chronic illness perspective. Research in Nursing and Health, 11, 293-300.

Tilse, C. (1994). Long-term care. "We thought we'd be together till we died". Australian Journal on Ageing, 13 (4), 172-174

Tilse, C. (1997,a). She wouldn't dump me: The purpose and meaning of visiting a spouse in residential care. Journal of Family Studies, 3(2), 196-208.

Tilse, C. (1997,b). Family advocacy roles and highly dependent residents in nursing homes. Australian Journal on Ageing, 16(1), 20-23.

Tolley, M. (1997). Power to the patient. Journal of Gerontological Nursing, 23(10), 7-12.

Towsend, A. L. (1990). Nursing home care and family caregivers' stress. In M. Stephens, J. Crowther, S. Hobfall, & D. Tennenbaum (Eds.), Stress and coping in later-life families. (pp.267-285). New York: Hemisphere.

Travis, S. (1996). Formal long term care networks: Forming a partnership with gerontological nurses. Journal of Gerontological Nursing, 22(12), 21-24.

Turkel, M., Tappen, R. M., & Hall, R. (1999). Moments of excellence: Nurses' response to role redesign in long-term care. Journal of Gerontological Nursing, 25(1), 7-12.

Twigg, J., & Atkin, K. (1994). Carers perceived. Policy and practice in informal care. Buckingham: Open University Press.

Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. Ontario: Althouse.

Van Manen, M. (1997). From meaning to method. Qualitative Health Research, 7(3), 345-369.

Van Manen (1998). Modalities of body experience in illness and health. Qualitative Health Research, 8(1), 7-24.

Vinton, L., & Mazza, N. (1994). Aggressive behaviour directed at nursing home personnel by residents' family members. The Gerontologist, 34(4), 528-533.

Vosburgh, D., & Simpson, P. (1993). Linking family theory and practice: A family nursing program. Image: Journal of Nursing Scholarship, 25(3), 231-235.

Vourlekis, B. S., Gelfand, D. E., & Greene, R. R. (1992). Psychosocial needs and care in nursing homes: Comparison and views of social workers and home administrators. The Gerontologist, 32(1), 113-119.

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

Walters, A. (1995). The phenomenological movement: Implications for nursing research. Journal of Advanced Nursing, 22, 791-799.

Waters, K. R. (1994). Getting dressed in the early morning: Styles of staff/patient interaction on rehabilitation hospital wards for elderly people. Journal of Advanced Nursing, 19, 239-248.

Watson, J. (1985). Nursing: Human science and human care. Norwalk, CT: Appleton-Century Croft.

Wenley, S. (1997). Behind rest home doors. GP Weekly, 18 June. 2, 5.

Whall, A. L., & Fawcett, J. (1991). The family as a focal phenomenon in nursing. In A. L. Whall & J. Fawcett (Eds.), Family theory development in nursing: State of the art and science. (pp. 7-29). Philadelphia: Davis.

Whyte, D. A. (1994). Family nursing: The case of cystic fibrosis. Aldershot: Avebury.

Wilkes, L. (1991). Phenomenology: A window to the nursing world. In G. Gray & R. Pratt. (Eds.), Towards a discipline of nursing. (pp. 229-246). Melbourne: Churchill Livingstone.

Wilkin, D., & Hughes, B. (1986). The elderly and health services. In C. Phillipson & A. Walker. (Eds.), Ageing and social policy: A critical assessment. (pp. 29-48). London: Gower.

Willcocks, D. (1986). Residential care. In C. Phillipson & A. Walker. (Eds.), Ageing and social policy: A critical assessment. (pp. 165-183) London: Gower.

- Willoughby, J., & Keating, N. (1991). Being in control: The process of caring for a relative with Alzheimer's disease. Qualitative Health Research, 1(1), 27-50.
- Wilson, S. A. (1997). The transition to nursing home life: A comparison of planned and unplanned admissions. Journal of Advanced Nursing, 26, 864-871.
- Wilson, S. A., & Daley, B. J. (1999). Family perspectives on dying in long-term care settings. Journal of Gerontological Nursing, 25(11), 19-25.
- Wright, L. M. & Leahey, M. (1984). Nurses and families. Philadelphia: Davis.
- Wright, L. M., & Leahey, M. (1989). Nurses and families: A guide to family assessment. Philadelphia: Davis.
- Wright, L. M., & Leahey, M. (1990). Trends in nursing of families. Journal of Advanced Nursing, 15(2), 148-152.
- Wright, L. M., & Leahey, M. (1994). Nurses and families: A guide to family assessment and intervention. (2nd Ed.). Philadelphia: Davis.
- York, J., & Calsyn, R. (1977). Family involvement in nursing homes. The Gerontologist, 17, 500-505.
- Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26(3), 260-266.
- Zarit, S. H., & Whitlatch, C. J. (1992). Institutional placement: Phases of the transition. The Gerontologist, 32(5), 665-672.

APPENDIX A

Recruitment notice

Research Project

Family members wanted to volunteer for research study....

...that aims to present an understanding of the experience of being a visitor to an older relative in a long term care facility.

Lia Holloway invites family members who have an older relative in long term care to take part in this study. The family members must previously have been informal carers of the relative in the community and the relative must not have been in residence at the Sacred Heart Hospital for more than two months. Lia is a daughter of elderly parents, a registered nurse with twenty-seven years experience, five of those working with older adults in long term care and with their families. The study is part of Lia's Masters of Arts Degree through Massey University.

Volunteers in the study would have two interviews about the meaning of their experience of two visits to an older relative in a long term care facility. The interviews would take about 1 hour each. All information would remain confidential. If you are interested in volunteering for this study and are sixteen years of age or older, please contact Lia for more information.

Phone Lia Holloway 4770543 (please leave a message).

APPENDIX B

Information Sheet for Participants

My name is Lia Holloway. I am the researcher in this study and a graduate student of the School of Health Sciences at Massey University. This study is part of the requirements for the Masters of Arts (Nursing) Degree in which I am enrolled. I am a registered nurse and have spent the last five years working with older people in long term care and their families. So far, little research has been undertaken to examine the meaning of the experience of being a visitor to a long term care facility. My supervisor is Charmaine Hamilton who is a senior lecturer at the School of Health Sciences at Massey University. Charmaine is also a nurse and is interested in the area of family nursing.

Outline of Project:

I am interested in studying the meaning of the experience of being a visitor to an older relative in a long term care facility. I would like to talk to families with an older member in long term care about their experience of visiting.

Family members over sixteen years of age who consent to participate in the study will be interviewed individually by me. Appointments to conduct the interviews will be made at times convenient to you. Interviews will be conducted at your home or a place convenient to you, in a quiet, private setting free of everyday distractions. For practical and logistical reasons, interviews will be restricted to people living in Otago.

The Interviews:

In an interview I will ask each participating family member to tell me about actual situations, specific instances and events that describe his or her experience of visits to an older member in long term care. The interview is intended to be a conversation about your experience, not a question and answer session. Any question I ask will come from what you have already told me and will aim to explore your experience to the fullest. If you agree interviews will be audio taped to ensure accurate transcription.

Risks and Benefits:

You may find reflecting on and describing your experience of being in a family with an older relative in long term care distressing. You may also find talking about your experience beneficial. Should the situation arise that you recall an emotionally distressing situation, I can listen and support at the time and refer you on to a professional agency, for example, a counsellor if a need is established. There are, however, known benefits from the sharing of experiences. For example, the process of sharing can make a difference in the life of a participant because it raises the participant's own awareness of what he or she is going through.

Results:

You will be given a summary of the findings from the study when it is finished.

Confidentiality:

The only people who will be able to obtain the tapes and written copies will be my supervisor (Charmaine Hamilton), and me. In order to keep your identity private the written records and any publications from the study will use false names for all people who take part and if you mention other people, false names will also be used. Where the gender of any participant or persons referred to could identify that person it may be changed. If a resident has a particularly rare or unusual disease that might easily identify him or her an alternative diagnosis will be used while trying to retain the essential character of the disorder. Details of the research site will not be published. All taped interviews will be kept safely in my home during the study. If you would like a copy of your tape or the transcript, it will be made available to you.

Statement of Approval:

This study has been approved by the Otago Ethics Committee and the Massey University Human Ethics Committee.

Rights of Participants :

Your participation in this study is entirely voluntary. You have the right to refuse to answer any particular question and you would be free to withdraw at any time without needing to give a reason. The quality of the treatment you or your relative

would receive would not be affected in any way by your participation or non-participation in this study.

If you do agree to participate you are free to ask questions at any time during your participation.

A summary of the findings of this study will be made available to you if you wish.

For more information I can be contacted at:

115C London Street

City Rise

Dunedin

Phone 4770543

Charmaine Hamilton can be contacted at:

School of Health Sciences

Massey University

Palmerston North

Phone 64-6-3504324

Fax 64-6- 3505668

If you would like advice as to your rights as a participant in this study you may approach

The Health and Disability Consumer Advocates,

Dunedin,

Phone 4790265

APPENDIX C

Consent form

A study of the experience of two visits to an older relative in a long term care facility.

INVESTIGATOR:

Lia Holloway, student at Massey University, Palmerston North.

Contact

115C London Street

City Rise

Dunedin

Phone number 03-4770543

SUPERVISOR:

Charmaine Hamilton, Senior Lecturer at the School of Health Sciences, Massey University.

Contact phone number 06 3504324.

STATEMENT BY THE PARTICIPANT:

- I have read and I understand the information sheet dated 1998 for volunteers taking part in this study designed to describe how family members experience being a visitor to an older member in long term care. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my or my family's continuing or future health care.
- I understand that I am free to decline to answer any question in the study.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that the interview will be stopped if it should appear to be distressing me.
- I have had time to consider whether to take part.

- I know whom to contact if I have any questions or concerns about this study.
- I consent to my interview being audio taped. Yes/No
(delete as appropriate)
- I wish to receive a copy of my audio taped interview Yes/No
- I understand that this study has been approved by the Southern Regional Health Authority Ethics Committee (Otago) and the Massey University Human Ethics Committee.

I.....(full name) hereby consent to take part in this study under conditions set out on this information sheet, of which I have a copy.

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

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