THE LIVED EXPERIENCE OF MARRIED WOMEN WHO PLACE THEIR HUSBANDS INTO A NURSING HOME

submitted by

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DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma at any university; and that to the best of my knowledge and belief, it does not contain any material previously published or written by another person where due reference is not made in the text.

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ABSTRACT

The purpose of this study is to deepen understandings of the experience of married women who place their husbands into a nursing home. Interpretive research investigates our lived experience and addresses questions of being. A phenomenological study allows the particular and the unique meanings to be disclosed. Meaning and significance of placing one's husband into a nursing home remains hidden in much of the literature as a consequence of theoretical constructs entrenched within the positivist paradigm. The purpose of this study for nurses is found in bringing to the nursing discourse another perspective on this phenomenon. The insights gained from this study may radicalise thought and inform nursing practice.

Conversation was chosen in anticipation of narrowing the gap between the researcher and the researched. These women's stories were descriptively written using their words. The philosophical thought of Heidegger helped guide the methodology and generate the understandings of the study. Through reflection on the conversations, understandings emerged. Three themes: connectedness; living out the tensions and re-discovery of self formed the thematic statement which describes the everyday experience of these three women.

The lived experience of married women who place their husbands into a nursing home is expressed through a constant working towards maintaining a meaningful connection with their husband, whilst finding a new way of being as they live out the tensions associated with that placement.

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I also wish to thank the three women, who so readily and trustingly shared their journey with me. Their stories, which they so willingly told, will never be forgotten.

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Chapter One

INTRODUCTION

When we cease
to have compassion
for our fellow human beings,
it is the beginning
of the end
of civilisation

(Witcomb 1983).

This introductory chapter sets the background and personal call to the study. It outlines the proposal, provides an overture to the use of phenomenological inquiry, summarises my experience of the research and informs the reader of the beneficiaries of this study. Key terms and styles used in the thesis are outlined and discussed. Finally, an overview of the thesis is presented.

Background to the study

This study emerged from a personal desire to more fully understand the encounter of permanently placing a spouse into an aged care facility. Over the past few years the concept of home care for chronic debilitating illnesses has gained much favour (Schirm 1990, p. 54). Support systems within the community have expanded in number allowing those with chronic illnesses to stay at home for greater periods of time (Hewner 1989, p. 30). In recent years, there has been an increase in the research of chronic illness patterns in the aged (Wischik 1994, p. 10). Many of these studies have focused on dementia; the process of the illness and the support services required to keep the sufferers of this disease comfortable and at home (Henry, 1991; Dunn, 1988). However, despite the improvement in these community services, many spouses deem it necessary to place their loved ones into residential care. The reasons for their decision are many and varied and not the focus of this research. It is the myriad of emotions and understanding of the experience of this placement which although recognised, largely remains uninvestigated in spite of the notion that it can be a situation of severe

psychological stress (Johnson 1988, p.6). Little research has focused on the spouse following placement of a family member and what we do know is based on empirical studies. Whilst much of these studies may provide some insight into the situation, they avoid asking questions of meaning. As a result they fail to develop an understanding of what this experience means for a spouse. In essence, I am asking what is the lived experience of married women who place their husbands into a nursing home.

The personal call to the study

Most of my years as a registered nurse have been spent working in acute care medical and psychiatric settings. However, the interest in this study is derived from my recent experience as a registered nurse working in a nursing home. As a nurse I have a passionate interest in caring, not only for the residents, but also the families who place their family member in institutionalised care. Almost daily I would find myself speaking with relatives about a variety of matters. I would listen to their stories and heed their concerns about the care they perceived their loved ones were receiving. Colleagues too would share their impressions of spouses' understandings regarding responsibilities of care. The notion being that confusion over roles and responsibilities was paramount.

I can vividly recall one wife's experience. When working in an aged care facility I met Pauline; a seventy two year old woman who was visiting her husband, Geoffrey. Geoffrey suffered from dementia. Pauline took great pride in relating to me that she had not missed a day of visiting her husband since his admission. She would arrive and leave at the same time each day. During Pauline's visits, she would sit close to Geoffrey, feeding him drinks and biscuits and attempting to make conversation. On one particular occasion, I accompanied Pauline to the taxi which was waiting to take her home from her usual visit. She was laden with belongings and needed some assistance. Just as we left the front door of the home, Pauline began to cry. I wondered what event had triggered this emotion as she appeared happy during her visit with Geoffrey. I asked her if there was anything I could do for her. Pauline hung her head, continued to cry and said nothing. Feeling rather bewildered, I looked towards the taxi driver who lowered his voice and said "I have picked her up every night for the past three months and she is always crying. I'm used to it". Pauline climbed into the taxi which drove away before I could elicit an answer to my question. I felt perplexed, frustrated and

angry with myself as this woman was obviously distressed and I had no way of knowing her concerns.

The following evening Pauline arrived at her usual visiting time and I noticed she looked withdrawn and exhausted. She spoke of how tired she was feeling. I suggested that she might like to spend an evening at home to recuperate instead of visiting Geoffrey. Her eyes remained focussed on me and she replied "It makes me happy to visit every day. It is like a holiday. I look forward to coming. What else have I got to do!" I felt helpless and lost for words. I had obviously misunderstood the nature of Pauline's experience.

Another example of misunderstanding occurred when Helen admitted her husband to the Nursing Home. She was seventy five years old and had looked after her husband Louis for the past five years. He too, suffered from dementia. Helen appeared confident and in control of the situation as she told me about Louis' daily routine; his likes and dislikes. As I listened to Helen, she began to reveal many concerns and frustrations about her role as a wife with her spouse now domiciled away from the family home. She asked when she could visit. Helen also inquired as to whether she could bring in photographs and pictures to hang on the wall. Her sureness of Louis' habits was being overshadowed by the uncertainty of a new role for herself.

The admission of Helen's husband to a nursing home had interrupted her very way of being. She had to learn new responses to new patterns. I remember her look of disgust as she scanned the room and inquired as to whether there was another available. She suggested there was a lack of space in which to place Jack's belongings. "He isn't used to sharing a space so close, and there's no view". Helen appeared totally overwhelmed as her eyes filled with tears. When I raised this issue with the senior staff members it was met with some distain. They felt Helen should feel lucky and privileged to have found a place for her husband. However, Helen did not feel lucky or privileged; she felt as if she was dumping her husband in jail.

These negative experiences have remained with me and have heralded some important and unanswered questions. How do these women perceive the call to place their husband into a nursing home? Do they view the experience as an invitation or a sentence? What support is given to these women once the decision

is made about the placement? What long term support of spouses is offered, if any? The quality of my communication with the women offered in the above examples was also a matter of concern to me. I was purporting to be as aware of the care necessary for the family as well as the patients in my care, but I had obviously failed to understand the meaning of these women's experiences.

The proposal

In response to the paucity of information about families, or more especially spouses, who admit their relatives in to a nursing home, this study explores the lived world of three married women who admitted their husbands, who were suffering from dementia, to a nursing home. The major aim of this research is to bring into the realm of nursing discourse an understanding of the nature of the lived experience of these women. The questions guiding the study are questions of meaning. These questions are addressed through a conversational process.

Telling stories of the lived experience allows for a time of reflection. Through reflection grows a deeper understanding of the experience and ultimately of ourselves as humans. As these women tell their stories, meaning is given to the ordinariness of the experience, thus the ordinary is seen in an extraordinary way. Through story telling of these women's lived experience, new possibilities for their future way of being may be revealed.

The call to phenomenology

This study takes seriously the call for alternative modes of research in nursing. The positivistic paradigm has dominated nursing research (Omery 1983, p. 49). Within this mode of inquiry explanation and prediction are the foundations for control and human nature tends to be categorised and described rather than understood and meanings generated. Phenomenological research, in its quest for meaning acknowledges the uniqueness of the individual. As the underlying assumptions of what has helped to influence the experience of placing a husband into a nursing home are recognised and questioned, they should be of interest to nurses as a basis for more enlightened understanding of their current practices. This form of understanding may deepen and radicalise thought.

van Manen (1990, p.4) maintains that a certain dialectic between the basic research questions and the research process is required. Conversations with these three women allowed the meaning of the experience to be revealed. Thus, human experience takes precedence over models, tests and outcomes. Conversation as a mode of inquiry allowed these womens' stories to be seen in an embodied, situated way. These assumptions are congruent with the Heideggerian notion of person (Leonard 1989, p. 43).

Phenomenology allows the exploration of humans by humans in ways which acknowledge the value of all evidence and inevitability and worth of subjectivity. In Omery's (1983, p. 50) view, nursing and phenomenology share the beliefs and values that people create their own particular meanings. Omery further states '...both (nursing and phenomenology) consider all that is available in the experience under study, both subjective and objective, and strive to understand meaning that the experience has for the participants' (1983, p.50).

Nursing practice is contextually bound to specific situations, people are viewed in a context. Nurses make decisions on what is appropriate for patients. The positivistic paradigm that values objectified, universal knowledge does a great disservice to the complexity of nursing practice. In nursing, there is a need for a methodology that is tailored to capture the intricacies and peculiarities of life. Hermeneutic phenomenology provides a way of gaining access to human experience and explicating it. Hermeneutic phenomenology overcomes the theory-practice split as knowledge is generated from the everyday world (Wilkes 1991, p. 241).

In the context of my own nursing practice is my recognition of the complexity of these womens' stories as individuals. I strongly identify with hermeneutic phenomenological philosophy and hold the view that there is no ultimate reality or truth. In this study, my involvement with and effects on the lived experience of the women participating in the study is recognised, acknowledged and discussed throughout the thesis.

Experiencing the study

I used a convenience sample of three married women who had recently placed their husbands into a nursing home. The choice was based on these women living in close proximity to my home. These women had looked after their husbands at home for at least six months prior to admission to a nursing home. Directors of Nursing from nursing homes within the district were contacted for a list of potential participants. Many Directors of Nursing responded in a protective way, advocating that it was a very sensitive subject and that people would not be willing to talk. On the contrary, my experience was that these women were more than willing to talk about their experience. I am not denying that sensitive issues arose within the research process. However, when these sensitive topics emanated, I made room for them by remaining silent, thus allowing sufficient space for their stories to unfold.

There were four encounters, which I refer to as conversations, with each woman. In order to safeguard the identity of each person the participants will be known as Bernice, Frances and Alice. On the first visit to their homes I talked with each woman about the research in general terms and the need to see them several times before completion of the study. Without exception all three women were eager to relate their experiences. Bernice consulted her calender and suggested that *'any day would be convenient'*. Frances told me that she did nothing on Fridays and would look forward to seeing me and Alice hastily consulted her diary to see what days she had free. Each invitation to conversation was greeted with enthusiasm and a willingness to be part of the study.

In addition to consent from each participant (see Appendix), permission to conduct the study was obtained from the University of Tasmania Ethics Committee. All conversations were tape recorded and transcribed. The tapes and transcriptions were kept in a locked cupboard in agreement with the University's policy for data storage.

Following each transcription, a copy was shared with each woman before the next conversation. Two participants read the script themselves but one had poor eyesight requiring me to read the script to her. A joint reflection on these transcripts provided new thoughts for future conversations.

The aim of this research was not to solve problems but rather an attempt to provide understanding. The purpose of this study is not to translate or reduce the experience into clearly defined concepts, but to seek to bring the mystery of the experience of married women who admit their husbands to a nursing home, more fully into our presence. Ultimately, the project of phenomenological reflection and explication is to effect a more direct contact with the experience as it is lived (van Manen 1990, p. 78).

Generating meaning

In a phenomenological study analysis cannot be restricted by an uncompromising approach. The lived experience must be explored in all its aspects and not restrained to just what is said but by what is meant by what is said. The concept of how something is said and the accompanying emotion is also of great relevance. The interpretive aspect of this research approach therefore portrays appearance and essence, '...between the things of our experience and that which grounds the things of our experience' (van Manen 1990, p.32).

Each time I returned to the conversations I gained a greater understanding of the experience. Together with my journal entries (field notes), the taped conversations became alive. These field notes included the non verbal aspects of the conversations - mannerisms such as hand movements; facial expressions; eye contact and other bodily gestures. These descriptions became invaluable as they provided additional meaning to the conversations.

My journal too acted as my own vehicle of reflection. I was very much part of this research. This study had its origins in my life as a nurse and I cannot negate my previous nursing background and life experience as an influence on the meaning generated by the study (Leonard 1989; van Manen 1990). I heard these womens' stories in the way I did as they coalesced with my experiences. In retelling their stories an openness emerged, permitting basic and 'up front' descriptions using the participant's language to describe the experience. The method of writing of these stories is detailed in Chapter Four.

Beneficiaries of the study

This research may be of potential benefit to nurses, families and government agencies in considering the formulation of policy programs to support families who place their loved ones into nursing home care. The interpretive approach of this study seeks to make a contribution to our fundamental understanding of the nature of the lived experience of married women who place their husbands in a nursing home. The willingness of the women to participate in this project demonstrated their interest, concern and call to the question. An opportunity to reflect upon and discuss any experience has the potential to be liberating and powerful. Sharing of another's experience of a similar phenomena can foster empathy and provide significance to the listener's own situation.

This study will be of interest to nurses as the meaning of these women is explored and unveiled. Through the sharing of these women's feelings and thoughts about the experience, nurses will have a broader understanding from which to conduct and reflect on their own practice thus, adding to the quality of their experience.

Explanation of key terms and styles used in the thesis

Lived experience - refers to the world as it is immediately experienced without conceptualisation, reflection or categorisation of that experience. The meaning of the experience lies in the reflective grasp of the event (van Manen 1990).

Phenomenology - refers to the study of lived experience. The study of the lifeworld as we immediately experience it, rather than as we conceptualise or theorise about it. Phenomenology is that kind of thinking which guides us back from theoretical abstractions to the reality of the lived experience, to the essences (van Manen 1990).

Hermeneutics - originally viewed as interpretation with respect to biblical studies, hermeneutics sought to uncover hidden meanings in these texts. In the twentieth century, hermeneutics became allied to philosophy in an attempt to understand human existence and the living tradition (van Manen 1990, p. 180). Hermeneutics is not directed at devising a 'method' for understanding, rather it focuses on what actually happens in any genuine understanding (Hultgren 1986,

p. 4). Our understanding of being is so pervasive in everything we think and do, we can never arrive at a clear presentation of it. The hermeneutic circle acknowledges that people bring prior understanding to interpretation.

Hermeneutic phenomenology - aims to be both descriptive and interpretive. It is descriptive as it is attentive to how things appear. It is interpretive because it claims there are no such things as uninterpreted phenomena (van Manen 1990, p. 180). The implied contradiction may be resolved if one acknowledges that the phenomenological 'facts' of lived experience are always already meaningful experiences (van Manen 1990, p. 180). Moreover, even the 'facts' of the lived experience need to be captured in language and this is inevitably an interpretive process (van Manen 1990, p. 180). For Heidegger, phenomenological description means interpretation (van Manen 1990, p. 180).

Ontology - is the study of the modes of Being-in-the-world of human being. Heidegger calls ontology the phenomenology of being (Gelvin 1989, p. 45). Being is an ontological dynamic asking about the nature of being. Being is not an object of knowledge but simply the way we are.

Being-in-the-world - is a Heideggerian phrase that refers to the way human beings are involved in the world through their concerns (van Manen 1990, p. 175). The term is hyphenated to avoid the misunderstanding that beings are isolated objects for example, chairs. The term refers to our self interpreting way of being.

The term conversation describes the repeated encounters between the researcher and the participants. Pseudonyms are used throughout the thesis.

Prior to each chapter of this thesis, a selection from Nan Witcomb's poetry captures the illusive dimension of my experience of this study.

Italics type denotes those parts of the conversation that are transcribed verbatim.

The use of 'I' recognises myself as part of the human community. The use of the first person also recognises my connections with these women in that we share a common world. Our shared knowledge is constructed rather than being 'out there'

to be discovered.

Overview of the thesis

Chapter One provides a background to the study and the call to an interpretive research method. Key terms and styles used in the thesis are explained.

Chapter Two details an overview of the philosophical underpinnings and the rationale for the choice of methodology used in the research.

Chapter Three places the study in the current discourse about families experience. Through exploring the literature a number of concerns are identified. Assumptions and understandings from the literature about the experience of placing a relative in a nursing home are discussed.

Chapter Four outlines the phenomenological research method used in this study. The use of conversation is elaborated and applied to this research.

Chapter Five re-tells the journey of these women using a narrative style. Similar to the preceding and subsequent chapters, a poem introduces each woman's story. Poems are a way of setting the context of the conversation and permits the reader to live the journey with these three women.

Chapter Six presents the integrative wisdom of the study and explores the understanding of these women's stories. Woven through this chapter are the possibilities for these understanding to give insights into nursing practice when dealing with married women who place their husbands into a nursing home.

Chapter Seven reflects upon my own journey of discovery through the research process. It captures my experience of the research and Being-in-the-world of these women.

Chapter Two

METHODOLOGY

You can have
money,
security
and love
taken from you—
but never
experience—

(Witcomb 1979).

This chapter examines the philosophical assumptions of hermeneutic phenomenology. The philosophical underpinnings used in this study were based upon the work of Heidegger (1962) and Gadamer (1975) and described by van Manen (1990). The questions this study investigated are questions of meaning. Questions of meaning require understanding. This chapter will briefly outline the writings of Heidegger (1962) and Gadamer (1975) as they inform this study. Heideggerian phenomenology is discussed in relation to Husserlian phenomenology. In particular, the Heideggerian notion of authenticity is examined and described. Additionally, van Manen's (1990) work is used to provide further clarification for understanding phenomenological research. Furthermore, Gadamer's (1975) notion of conversation is outlined. A section on storytelling highlights the relevance of narratives to this and other interpretive research. Finally, this chapter will briefly consider the use of phenomenology in contemporary nursing research.

Heideggerian phenomenology

Heidegger (1962) believes that traditional philosophies misinterpreted human beings. Dreyfus (cited in Magee 1987, p. 267) suggests that this misinterpretation begins with Plato's fascination with theory. Plato believed that one can have a theory of everything, even of human beings and their world (Dreyfus cited in Magee 1987, p. 256). On the other hand, Heidegger maintains one cannot have a

theory of what makes theory possible as it is humans that make theories possible. Thus Heidegger challenges the basic assumptions of philosophers such as Plato, Descartes, Kant and Husserl (Gelvin 1989, p. 6). Traditional philosophers treated Being as an object or entity. Being, for Heidegger, is not a noun but an infinitive (Gelvin 1989, p. 8). Instead of treating the concept of the world cosmologically as an objective entity or epistemologically as an object of knowledges, Heidegger examines what it means for a human being to be in the world.

At university, Heidegger was a student of Husserl. Husserl was considered to be the 'father' of phenomenology (Stumpf 1994, p. 490). Heidegger's hermeneutic phenomenology developed in opposition to Husserl's transcendental phenomenology. For Husserl, the purpose behind phenomenology was to achieve a vision of consciousness totally untainted by interpretations. The motto of such phenomenology is 'To the facts [or things] themselves!' (Gelvin 1989, p. 38). Husserlian phenomenology 'must describe what is given to us in immediate experience...' (van Manen 1990, p. 184). Husserl believed that this description could be achieved through the performance of bracketing or phenomenological reduction. Thus, a phenomenology that Husserl called self-responsible demanded that presuppositions must be abandoned (Gelvin 1989, p. 38). However, Heidegger maintains Husserl's method of complete freedom from prejudice cannot be used when trying to understand a phenomenon as our background forms the very basis from which all understanding takes place (Benner & Wrubel 1989, p. 46). Gelvin (1989, p. 71) further states 'Husserl's bracketing cannot be possible if the total given is a self already involved with the world'. Heidegger reverses Husserl's idea of phenomenology by showing how phenomenology is an interpretive enterprise (van Manen 1990, p. 128).

Everyday experience as it is lived is the focus of attention in phenomenological study (Stumpf 1994, p. 505). Because our lived experience is taken for granted in its everydayness, much of its meaning remains hidden (Rather 1992, p. 48). Heidegger believes phenomenology is concerned with rendering the lived experience intelligible as it is the place where meaning resides (Leonard 1989, p. 52). Heidegger further regards that Being-in-the-world is disclosed to itself in two ways; through the affects and through understanding (Heidegger cited in Macquarrie 1968, p. 20). In his concept of understanding Heidegger shows how we are thrown into the world (Gelvin 1989, p. 30). Hultgren (1986, p. 10) presents a view of Heideggerian understanding:

> ...understanding is not the way we know the world, but it is the way we are. Understanding, then is ontological; it is not something to be possessed but a mode of Being-in-the-world.

Heidegger starts the analysis of Being by investigating our own Being. Dasein is a term used by Heidegger to refer to the entity which is capable of inquiring into its own Being. Human beings are not a Cartesian transcendental subject. Human beings have a self-interpretive way of Being, that is we find significance and meaning everywhere in the world (Gelvin 1989, p. 98). In contrast with the Cartesian tradition, Heidegger claims that to be a conscious subject or self is neither necessary nor sufficient for existence (Dreyfus cited in Magee 1987, p. 257). Being human is a laying open of what is hidden as we approach the question of what does it mean to be (Hultgren 1986, p. 9). Only a person can reflect on what it means to be and Being can be realised or analysed only through the self-reflective consciousness of human existence (Gelvin 1989, p. 19). Heidegger (1962, p. 27) states,

> To work out the question of Being adequately we must make a being the inquirer conspicuous in his [sic] own being. This Being which each of us is himself and which includes inquiry as one of the possibilities of his being we shall denote by the term Dasein.

The reason why Being cannot be defined or explained but only interpreted according to Heidegger is because we dwell in our Being. Through background practices persons embody a sense of being that no one has in mind. Thus we have an ontology without knowing it (Benner & Wrubel 1989, p. 46). Shared ways of behaving are not mere facts to be studied objectively, as in the way of sociology. Dasein contains an understanding of being that must be studied by interpretation. In this way Heidegger's phenomenology became hermeneutic (Benner & Wrubel 1989, p. 40).

Heidegger's phenomenology allows for this disclosure of our background (Benner 1985, p. 7). Our understanding of being is so pervasive in everything we think and do, that we can never arrive at clear presentation of it. It is not a belief system, but is embodied in our skills (Allen, Benner & Diekelmann 1986, p. 28). It is within this context that understanding takes place. Phenomenology provides for Heidegger the approach and entry into the lived world of Being. As our personal experiences of Being-in-the-world are called forth, we find, through

language and speaking, 'memories' of experiences we actually may never have deeply thought or felt before (van Manen 1984, p 38). This notion of understanding requires more than an epistemological view of knowledge.

Ricoeur (1981, p. 128) explains the affinity between hermeneutics and phenomenology. Phenomenology uses a method of interpretation as it explicates lived experience to reveal meaning. Explication relies on interpretation hence phenomenology presupposes hermeneutics. All phenomenology is an explication of evidence and an evidence of explication. All evidence is explicated; an explication which unfolds evidence, such is the phenomenological experience. It is in this sense that phenomenology can be realised only as hermeneutics (Ricoeur 1981, p. 128).

Instead of context-free theory, Heidegger proposes different ways of studying human beings. According to Packer (1985, p. 1086), the discipline that studies human beings in a context is called hermeneutics. Originally, hermeneutics was a set of techniques for interpreting written texts, initially biblical texts. The first philosopher who addressed the question of understanding biblical texts was the nineteenth century German philosopher, Schleiermacher (1768-1834). Schleiermacher's aim was to gain an understanding of the person better than the person understood themself. Heidegger (1962) extends the way of understanding texts to a way of studying human activities. However, Heidegger's hermeneutics aims at understanding another's experience as revealed by the text (van Manen 1990, p. 180).

Authenticity

Heidegger's analysis of everyday existence has revealed an understanding of two modes; the authentic and the inauthentic (Gelvin 1989, p. 74). According to Gelvin (1989), Heidegger is not making any claims about how to achieve authenticity or how to avoid inauthenticity. Heidegger is merely making use of the rich supply of insights into the human condition.

Our basic mood, says Heidegger (1962) is the mood of anxiety. However, Gelvin (1989) translates anxiety or *'angst'* as 'dread'. Dread is our response to the fundamentally unsettling character of being-there, our 'throwness' into the world.

Dread is not a psychological state but a mode of being. Dread puts us before ourselves, naked as it were; aware of our possibilities; either to be genuinely ourselves, or to lose ourselves in the comforting chatter of the 'they' (Gelvin 1989, p. 118).

Stumpf (1994, p. 507) posits that 'a person's drift into an inauthentic existence is subtle but in every case it involves a tendency to escape from one's self by finding refuge in a public self'. We can respond in an inauthentic way by conforming and abiding by societal norms. We behave as we 'ought to' or are 'expected to' rather than as we feel is right for us (Stumpf 1994, p. 507). In this existence we are dominated by the society and a drab kind of uniformity is imposed upon us. We lose ourselves in the routine tasks and conventional ways. The 'they' of society is neither authentic itself nor conducive to an authentic existence. It is just another way in which 'they' stifle and dominate the individual and take away possibilities and self awareness from the person (Heidegger cited in Macquarrie 1968, p. 23).

To choose possibilities is what distinctively belongs to existing, but when inauthentic the possibilities of choice are taken away. Possibilities may have been relinquished or suppressed. There is a security in a public self, in an impersonal identity. Much of our everyday living is shaped by society and there is little or no opportunity for Dasein to reflect upon involvement (Gelvin 1989, p. 118). The whole persuasion of the 'they-self' is not even to consider such questions. Therefore, our everyday being is not authentic in the sense of being our own, something we have definitely chosen (Heidegger cited in Macquarrie 1968, p. 19). It is in this tranquillity and everydayness that one can avoid the confrontation of the self. Gelvin (1989, p. 118) explains how the whole persuasion of inauthenticity is to make one feel comfortable in the unexamined and uncritical life of the 'they'; '...through such moods as anxiety the they-self may not seem so "natural"'. Dasein then seems forced to stand back and reflect upon existence. The feeling of comfort in the 'they' is lost, Dasein turns to itself. This awareness does not force one to exist authentically. However, it does present Dasein with a choice (Gelvin 1989, p. 121).

Presumably, each individual Dasein exists for much of its time in an inauthentic way and certainly authenticity is not something that can be gained once and for all, but must be decided in each new situation as it comes along (Heidegger cited

in Macquarrie 1968, p. 14). Heidegger shows that the mode in which one loses the view of the self is a mode of the self and not of others. Thus, we can blame only ourselves for our own inauthenticity. The 'they' is a characteristic of the self that determines a mode of existence (Gelvin 1989, p. 73).

Authentic existence is being aware of the meaning of existence by owning up to what it is to be Dasein. For Heidegger, to own up means to hold on to anxiety (Dreyfus cited in Magee 1987, p. 269). Authentic existence requires that human beings recognise their unique selves with their responsibility for their every action (Stumpf 1994, p. 507). To be authentic is to listen and to be guided by our conscience. Conscience is the disclosure to someone of what they want to be, of the authentic self (Heidegger cited in Macquarrie 1968, p. 32). However, authentic existence does not require abandoning major life projects rather, may involve changing how we carry them out. For example, in an authentic existence one does not embrace a project anticipating it will provide the ultimate meaning of life (Dreyfus cited in Magee 1987, p. 267); rather, authentic existence involves being open to the possibilities the situation brings.

In authentic activity, Heidegger (cited in Macquarrie 1968) maintains the person no longer responds to what he terms the 'general situation'. Rather, the person responds to the unique situation without concern for conformity and respectability. Langan (1984, p. 109) presents an appropriate definition of authenticity as 'the self's assumption of full responsibility for itself through its ability to respond to the deepest needs and possibilities of the situation'. Heidegger (cited in Macquarrie 1968, p. 17) further suggests that in an authentic existence, the person is open to dimensions of the world beyond the merely instrumental understanding of it.

It could be argued that Heidegger is subscribing to a doctrine of individualism. However, Heidegger believes that our basic existential is 'being with' so that community is an indispensable dimension of any authentic existence and the conscience could not call to an authenticity that rejected community (cited in Macquarrie 1968, p. 32).

Gadamer and conversation

Gadamer (1975) expanded the meaning of the nature of conversation and showed the way in which conversation leads to understanding. Gadamer (1975) has described conversation as having a dialogic structure of questioning and answering. The conversation has a hermeneutic thrust as it is oriented to interpreting and making sense of the phenomena that stimulate the conversation. Gadamer (1975) uses the analogy of play to illustrate conversation (Bernstein 1983, p. 121). In play, the individual player is absorbed into the back and forth movement of the game. Like play, the conversation moves back and forth between the researcher and the participant. In a game, participants are not leaders but it is the game that carries them along (Bernstein 1983, p. 121). In conversation, it is the topic that carries us along. A conversation, like a game keeps us captive and enthralled, it invites us to join in. Barthes (1979 cited in Carson 1987, p. 81) maintains that the conversation never really specifies what it is about. Rather, it is carried forward by the participants' effort to discover what it is. Bernstein (1983, p. 121) maintains play is an experience which transforms those who participate in it; it is an edifying experience. Conversation too, has the possibility to change us as it deepens our understanding and broadens our horizons.

Gadamer's (1975) contribution to our understanding of the lived world rests in his concept of experience. 'It is the experience of reflection. Experience in this sense is always seen as contributing to our own understanding of something' (van Manen 1990, p. 37). Bernstein (1983, p. 137) cites Gadamer (1975) who states that while there is a need to return to the things themselves this openness is not achieved by bracketing or forgetting prejudices and maintains this activity is 'neither possible, necessary, nor desirable'. Rather in Gadamer's (1975) view, prejudices enable us to understand. Prejudices define the ground the interpreter occupies when understanding. We each bring our past experiences to each new situation. Our present attitude is situated within our past understanding of our tradition. In hermeneutic inquiry the assumptions and prejudices found in our tradition are revealed (Bernstein 1983, p. 138).

Gadamer (1975, p. 238) describes the attitude that is adopted when undertaking a phenomenological study:

> A person trying to understand a text is prepared for it to tell him [sic] something. That is why a hermeneutically trained mind must be, from the start, sensitive to the quality of newness. But this kind of sensitivity involves neither neutrality in the manner of object nor the extinction of oneself, but the conscious assimilation of one's own foremeanings and prejudices. The important thing is to be aware of one's own bias, so that the text may present itself in all its newness and thus be able to assert its own truth against one's own foremeanings.

According to Gadamer (1975, p. 239) 'prejudices are biases of our openness to the world'. He makes the distinction between blind prejudices and enabling prejudices. Blind prejudices are false prejudices, ones by which we can misunderstand. Enabling prejudices are true prejudices by which we can deeper our understanding. For Gadamer, the critical question of hermeneutics is how to discriminate which prejudices are blind and which are enabling (Bernstein 1983, p. 125).

Narrative

> Human meaning rests in stories. Life making calls for accounts, for story, for sharing. To be human is to be entangled in stories...When we want to share our practice with each other, the best way we can do that is to tell each other stories...Each story contains many stories interwoven in it. The task of expression is to open up the story more fully - rather than to tie it down...A story is any event re-told from life which appears to have meaning (Reason 1988, p. 82).

When we want to share our practice, we tell stories. Leggo (1973, p. 223) suggests why story is the best way to share our practice. He advocates it is because narrative is epistemological, ontological and communal. Narrative is epistemological in the sense of knowing life as an episodic narrative. In story we seek totality in an attempt to make sense. In story making we search for truth, but the truth is never total, it is always ongoing (Leggo 1973, p. 224). Narrative is ontological, we are participants in creating a social world; we create meaning and self at the same time. There is no fixed centre subject, autonomous subject that psychology and other disciplines hold. Meaning resides not wholly with the individual or situation but in the transaction between, we are a listener and

transformer of meaning (Benner 1985, p. 7). Narrative is communal; often in communities there is marginalising of those that do not conform (Leggo 1973, p 225). We need to build a community that recognises and allows differences. The denial to relate to others by indifference or domination is the refusal to respect another's existence; it is the refusal to communicate (van Manen 1990, p. 108).

Nouwen (1977, p. 56) suggests, one of the remarkable qualities of the story is that it creates space. We dwell in a story, walk around, find our own place. The story confronts but does not oppress; the story inspires but does not manipulate. The story invites us to an encounter, a dialogue, a mutual sharing. Furthermore, Nouwen (1977, p. 66) purports a story that guides is a story that opens a door and offers us space in which to search and boundaries to help us find what we seek, but it does not tell us what to do or how to do it.

Stories 'carry the values of our culture by providing positive role models to emulate and negative role models to avoid' (Polkinghorne 1988, p. 14). These stories can provide a starting point for reflecting on our own attitudes and actions. In this research it can be asked; in what ways did these stories speak of us and of the married women who place their husbands into a nursing home we know and what do the stories say about the nursing homes we provide for their husbands?

The contribution of phenomenology to nursing research

Traditional nursing research has followed the scientific paradigm which quantifies and in doing so fragments into entities that can be measured and observed. Science, in its quest to objectify and define, labels the person's experience. The focus then is on categorisation or classification, not on description and understanding; the lifeworld is dismissed. The aim of logico-positivist research is to seek causal explanations of social phenomena. There is a belief that if cause and effect can be determined then the problem can be solved (Burch 1986, p. 7). Nursing research is restrained whilst remaining exclusively within the empirical social world. By adhering to this paradigm it fails to account for our Being-in-the-world. However, phenomenological research provides for discoveries and new understandings.

As stated previously, phenomenological research discloses the lived experience and reveals the meaning of that experience. In nursing, the quality of life and the quality of the nurse-patient relationship are of great importance. There is a focus on interpersonal approaches to nursing care such as empathy and on concepts such as stress and perception (Oiler 1981, p. 178). Furthermore, Oiler (1981, p. 178) suggests that in phenomenology, priority is given to the person' experiences that is, a person is valued and seen as definer of their own reality. It can be argued that nursing is moving towards a holistic approach to care, viewing the person within a social and historical context. Phenomenology retains the integrity and context of experience and in this way is a valuable approach to utilise in nursing research. For the past thirty years nurses have sought to increase their understanding through more humanistic research methods such as phenomenology. This awareness has been utilised in a range of clinical and educational studies, directly and indirectly related to nursing practice (Vohland 1994, p. 25).

Thibodeau (1993) an American nurse researcher conducted a study on the lived experience of an adult child who assumes live-in care for a parent. Hermeneutics was used to interpret the transcriptions. The impetus for the study was the Government's need for older adults to remain in the community easing the financial burden on nursing homes. The study revealed that families who experience few demands on time, space and energy perceive the phenomenon of caring for a parent as a positive experience (Thibodeau 1993, p. 17). These three aspects provide a useful framework for analysis and nursing intervention. As nurses, we should not underestimate the value of services such as 'adult day care' and similar services that help reduce demands on time and space.

Kondora (1993) utilised a Heideggerian hermeneutical analysis to reveal the lived experience of women who had experienced incest. The constitutive patterns which emerged from the data were 'Remembering as a coming of what has been' and 'Care-reconstituting a sense of me' (Kondora 1993, p. 14). The findings show how memory shapes and is shaped by our experience. Caring acts were seen to create the possibility of these women to care for themselves. As nurses we must be aware of the pervasiveness of remembering and consider the potential influence that remembering can have on the life of an incest survivor. By listening to stories, healing and transformation may occur.

Other phenomenological nursing studies include Neal (1989 cited in Conway 1990) with her inquiry 'A room with a view: uncovering the essence of the student experience in a clinical nursing setting'. This study focused upon the nurses' experiences in a mental health setting. The themes which emerged from the experience of giving nursing care were encountering hopelessness; apathy and one's own silence. These themes were related throughout the study to the notions of bonding and bounding. Bonding is defined as 'the processes that produce lasting relational connections and ties between and among persons who share lived experiences', and bounding is the 'fundamental structures or contexts of meaning that enclose, limit, anchor or give shape to the ontological space of lived experience (Neal 1989 cited in Conway 1990, p. 326). These themes are linked to caring as foundational for effective human relationships, nursing practice and models for teaching in nursing (Watson 1989 and Noddings 1984 cited in Conway 1990). Overall, this study brings to light what many nurse educators know occurs in clinical learning. The use of storytelling, reflective thinking and writing and sharing within a group context are shown as effective teaching strategies for enhancing learning in the clinical setting (Neal 1989 cited in Conway 1990, p. 326).

Yonge (1985) utilised phenomenology to reveal the experience of giving constant care to a psychiatric patient. The themes that emerged from the study were the experience of trustful and mistrustful space (Yonge 1985, p. 127). The study showed how trust is the basis of a therapeutic relationship and what it means to trust or mistrust. The study further described the meaning of healing and how nurses can heal and show care through bodily gestures and presence. Also, how unpredictability and untrustworthiness of the patient can make the nurse feel isolated and fearful. As a psychiatric nurse caring for suicidal patients I can identify with these descriptions.

A Heideggerian, hermeneutic phenomenological study conducted by Gullickson (1993) considered the experience of twelve persons living with chronic illness. The pattern 'my death nearing its future' emerged from this research (Gullickson 1993, p. 1388). The understandings gained from these individual narratives provide important insights for all people interacting with persons living with a chronic illness. Nurse educators, in teaching aspects of caring for the chronically ill may re-examine the meanings of chronicity as well as the context and situatedness each person presents. The study found that chronic illness can be

viewed as more than just a disease; chronic illness becomes part of the background meaning for each of the twelve participants in the study (Gullickson 1993, p. 1391).

Finally, King (1993 cited in Streubert & Carpenter 1995) conducted a phenomenological study into the experiences of midlife daughters who were caring for their ageing mothers. Using Giorgi's (1985 cited in Streubert & Carpenter 1995, p. 39) method of analysing the transcripted data, King found a continuum of care framework was described by the seven participants in the study. In addition, six themes were integrated into this framework namely: 'knowing mother and her needs; responding to mother's needs; deferring to mother's needs; recognising; grieving and identifying own fantasies' (King 1993 cited in Streubert & Carpenter 1995, p. 57).

Phenomenological nursing research is increasing and in doing so identifies subjective phenomena unique to the field of nursing and thus contributes to the ever expanding body of nursing knowledge.

Chapter Three

LITERATURE REVIEW AND CRITIQUE

In this world today—
so many people
searching for love
and truth
in the wrong places

(Witcomb 1979).

Investigating the question 'what it means to place a spouse in a nursing home' suggests an inquiry into what is previously known about the experience of families who have experienced a similar situation. The role of the family has been investigated in terms of caring for the family member at home or in an institution. However, the experience of 'placement' has received comparatively little attention in the literature. Looking into the prevailing nursing discourse surrounding the experience a number of concerns dominate the literature. The areas of concern are focused on the following issues: changing relationships; burden and linking the family to the nursing home where placement has occurred. This literature review and critique is organised around these concerns. Through an examination of the contemporary literature, understandings and assumptions about the experience of these families are discussed. The purpose of highlighting these assumptions is to show how they have helped define and shape the experience.

Changing relationships

Rubin and Shuttlesworth (1983) refer to the family as a 'support resource' focusing on the work that families do in providing patient care within the nursing home. A survey was conducted with one hundred families and sixty four staff members from two nursing homes. The survey findings indicated that ambiguity in the subdivision of tasks hinders family involvement (Rubin & Shuttlesworth 1983, p. 632). Additionally, the following broad categories of tasks were identified as the most problematic: personalised care; monitoring and ensuring

provision of care; clothing needs and providing grooming and reading materials (Rubin & Shuttlesworth 1983, p. 633). Recommendations from this study include the needs for orientation sessions in which the nursing home administrators and others concerned about engaging families in the care process, can assess clarity of the subdivision of tasks within their respective programs. It was concluded that meaningful family involvement depends upon agreement in task assignment and must be systematically reviewed by both staff and family members (Rubin & Shuttlesworth 1983, p. 636).

Other writers have also focused on the work that families do in providing care for their relatives who are placed in a nursing home (Bowers 1988; Hall 1989; Schwartz & Vogel 1990). Rosenthal and Dawson (1991) also suggest the ambiguity of a family's role after placement may exacerbate the stressors involved in on-going care. Many family members continue to engage in 'invisible care-giving' by managing their relatives legal and financial matters. They must also cope with a range of social and psychological problems related to visiting their relatives in an institution (Wilson 1990).

York and Calsyn (1977) found that visiting increasingly demented elderly family members in a nursing home is not generally viewed as a positive experience. York and Calsyn (1977) interviewed seventy six patients and their families at three nursing homes. This research focuses on the quantity and quality of resident-family interactions before and after placement. It was found that whilst the number of visits is a mean of twelve per month, the quality of those visits remains problematic for many families (York & Calsyn 1977, p. 503). Enjoyment of visits is not related to what is done on visits but to the amount of mental deterioration of the patient as perceived by these relatives. The problem relates to the families lack of knowledge concerning their relatives situation and lack of skills in the act of visiting (York & Calsyn 1977, p. 504). The researchers suggest programs should be developed to help family members to better cope with their older relatives illness. These program interventions should include information about organic brain syndrome and suggestions for how to improve visiting. The family of the nursing home patient is said to be a powerful 'treatment resource' when productive involvement is maximised (York & Calsyn 1977, p. 503). Their findings also support the need for active institutional encouragement.

A contrasting study by Smith and Bengston (1979) found that family relationships are enhanced following a nursing home placement because of the decrease in stress on family care-givers. The act of placement alleviates the strain of 'technical care' and allows families to refocus their efforts on the emotional aspects of the relationship. Smith and Bengston (1979) used open-ended interviews with one hundred institutionalised elderly parents and their middle-aged children. The majority of the respondents from both generations express either an improvement of, or continuation of, close family ties following institutionalisation (Smith & Bengston 1979, p. 440). It is interesting to note that the facility used for this research already ran extensive educational programs for the families of those in their care.

These studies are significant in comprehending certain aspects of the families experience; yet it could be argued that reducing the experience of family involvement to variables such as tasks carried out and how many times these tasks are performed does not bring one any closer to the experience as it is lived. Viewing family involvement in terms of statistics is one way of showing that the family remain involved. However, the reduction of experience to mere statistical order may obscure the needs of human beings and being human. This line of inquiry dismisses issues of meaning and significance.

In order to explain relationships and concerns between people, human behaviour is defined in terms of roles. Benner and Wrubel (1989) contend this categorisation does not allow for an understanding of the person in the situation and discards the way people constitute and are constituted by their situation and relationships. It can be argued that to talk about changing relationships in terms of role change and role ambiguity does not allow for meanings and personal concerns to be disclosed. The emphasis of these studies appear to be concerned with the 'why' rather than the 'what is' of the experience. This objective mode of understanding is a deficient mode of seeing human beings. The language of roles is about 'doing' and does not account for meaning (van Manen 1990, p. 42). To talk about family members in terms of 'productive involvement' and 'support resources' requires treating the family instrumentally. In our technological understanding of ourselves we infer that families are a commodity that can be used to help the residents well-being; the word resources implies employment rather than engagement. The study presented in this thesis has the possibility of portraying these women as having a much deeper relational connection with their husbands.

Burden

Much of the literature characterises the admission of a family member to a nursing home as burdensome. Wiancko, Crinklaw and Mora (1986), in their descriptive study of ten women, maintain that when a spouse places a cognitively impaired loved one in a long term care institution, the responsibility and burden remain with the family, although the family dynamics change. The activity these women find burdensome is being a patient advocate. The women see themselves as having a moral responsibility to be a patient advocate; they worry about how nurses will know or anticipate their spouse's needs as they feel they alone know what is or isn't best for their spouse (Wiancko, Crinklaw & Mora 1986, p. 31). Similarly, the finding of a study by Barnes, Raskind, Scott and Murphy (1981) support this position, stating that making decisions on behalf of the elderly person is a troubling responsibility which continues for many care-givers after the institutionalised person's health deteriorates. The action of visiting was another concern (Wiancko, Crinklaw & Mora 1986, p. 30). Whilst the women agree that visiting gives a sense of satisfaction, they report experiencing sadness as they depart from the nursing home. In addition, not having support from other relatives is stressful and they feel isolated (Wiancko, Crinklaw & Mora 1986, p. 30). Another problem for these women is communication. They are apprehensive in their communication with staff, especially when they perceive that the staff do not listen to their needs (Wiancko, Crinklaw & Mora 1986, p. 31). Furthermore, these women feel burdened when they view the care given by staff is not consistent with the care they would expect to give to their loved one (Wiancko, Crinklaw & Mora 1986, p. 31).

Richie and Ledesert' s (1992) study maintains that institutionalisation may also incur new obligations for the care-givers such as, travelling to visit the person, or the need to participate in nursing home based activities and meetings with medical staff. They found that many care-givers resent being deprived of a care-giving role and manifest feelings of frustration and exclusion in relation to the staff. The participants in this study report still being unhappy one year after the placement (Richie & Ledesert 1992, p. 7). However, it has been suggested by George and Gwyther (1984 cited in King, Collins, Given & Vredevoogd 1991, p. 323) that the immediate well-being of care-givers may decline because they have not yet begun the process of gradually relinquishing the care-giver role. Burden is thus said to be experienced when the family is both excluded and included in the

institutionalised caring of the family member.

The research discussed has attempted to locate the source of the burden. This approach to burden reflects a mechanistic assumption where burden can be understood in terms of cause and effect. According to Aoki (1985, p. 13), this orientation is based on the taken for granted view that 'human and social life can be explained away with degrees of certainty, probability and predicability'. As explanatory knowledge is sought, questions such as "what works" are asked. Knowledge in this orientation is nomological and law-like, giving an explanatory view (Aoki 1985, p. 13). In maintaining this stance there is a struggle to open up new horizons of significance and to see the possibilities for human dwelling-thinking that are beyond control.

Matthiessen (1987) provides an examination of the emotional impact on six adult daughters who became responsible for continued supervision of their mothers who were placed in a nursing home. Matthiessen (1987) suggests guilt and grief are two psychological themes describing their experience. Grief not only occurs at the time of placement but at every medical crisis. In addition, grief is perceived by the daughters to be the result of a loss of the relationship with their mothers (Matthiessen 1987, p. 13). On the other hand, guilt is experienced by the daughters when the mothers express a desire to return home. The daughters regret their decision to place their mothers into institutionalised care. It is in the discussion of guilt that the daughters attempt to balance the two main issues involved in placement, that is, their duty towards their mothers and the real costs to themselves in terms of health. Matthiessen (1987, p. 14) states the message for nurses is clear,

> Nurses should include daughters in caring by collaborating with the daughter in providing continuity of care for the mother. They should be informed about what goes on and what to expect in the nursing home. Nurses should offer counselling and support services for the daughters.

This study focused on grief and guilt as psychological entities. Guilt and grief are seen as problems to be solved.

In 1991, Rosenthal and Dawson conducted a longitudinal study with sixty nine women whose husbands had entered a nursing home; their experience being

described in terms of 'quasi widowhood' (Rosenthal & Dawson 1991, p. 317). In contrast, Buckwalter and Hall (1987) assert that women in a similar situation are considered by society to be neither married nor widowed and remain living in the community with many social limitations. In Rosenthal and Dawson's study, the experience is conceptualised as a life course transition comprising of four stages (1991, p. 320). Stage one is characterised by feelings of ambivalence; uncertainty of the future; depression and loneliness. Stage two is distinguished by an improvement in physical and mental health and there is increased activity in visiting their husbands. Stage three is identified by some negotiation of roles - some are relinquished and additional roles are taken on by the women. Stage four is marked by resolution and adaptation. Rosenthal and Dawson (1991, p. 321) contend this final stage will be reached within a period of eighteen months following admission of their husbands to the nursing home. Whilst this study acknowledges the subjective experience of these women, the assumption of fixed developmental stages negates the possibility of disclosure of the particular and the unique of each experience. The stage theory demolishes the experience as a whole and is largely directed towards prediction, control and mastery. This perspective dismisses the view that as humans we are always in the process of becoming (Heidegger 1962) and as such cannot be categorised into discrete stages.

Linking the family to the patient and the nursing home

The literature alludes to a number of programs which attempt to increase and strengthen the relationship between the nursing home, family and patient. Hirst and Metcalf (1986) suggest that meeting information needs of the family through education enables the family to continue support. Needs of the family are viewed in terms of cognitive and affective domains. In the cognitive area Hirst and Metcalf (1986, p. 25) assert that information relating to the type and extent of impairment, expected prognosis and course of treatment is expected. Whereas in the affective domain, learning needs focus on the realisation that emotions of anger, depression and guilt are part of the normal response when placing a relative into a nursing home (Hirst & Metcalf 1986, p. 26).

Hayter (1982) also maintains that the desire to know this information is important. He acknowledges that the family also need to know information about the health personnel who are engaged in the care of their relative. Northouse (1980) confirms this desire to know and maintains that when families know how

to get their questions answered they have a sense of control over the situation. It can be argued that families also need to know what is expected and required of them within the nursing home setting. They may want assistance in knowing how to visit, including a selection of discussion topics and activities in which to engage (Northouse 1980, p. 14). The need for this support is reinforced by Safford (1980) who has developed a booklet to assist families to cope with the institutionalisation of a relative. She suggests that relatives can bring favourite foods, photographs, or games they can play with their relative.

To view family as a set of needs is a deficit view of the person. The deficits are seen to be correctable through the process of education. The assumption here is that through education, behaviour will change. In attempting to predict certain behaviours there is an element of sacrifice in understanding the transactional process occurring between the person and their world. To speak about family needs in generalities, without reference to particular contexts or situations, implies these needs are universal. The experience of a married woman admitting her husband to a nursing home is talked about in 'the general' yet, it always happens in 'the particular'. What is needed is an understanding of Being-in-the-world of the wife from within the situation to reveal the meaning of the particular.

In attempting to objectify these needs there is a tendency dichotomise the cognitive and affective domains. The approach to needs as comprising of cognitive and affective fields reflects reductionist thinking. Needs are treated in the abstract overlooking the role of the situation. These identified areas serve as a check list by which to assess families needs. There is an assumption that what is important to the family is known prior to engaging in conversation. To talk about our being as cognitive defines the self as a thinker, a knowing subject. This assumption is committed formally to logical individualism (Schmidt 1983, p. 168). Whereas within the phenomenological perspective, persons are being-in-their-world in a sociocultural community with a history.

Buckwalter and Hall (1987) maintain nursing homes must be receptive to family involvement. Cohen (1983) suggests that families may find it therapeutic to serve as 'adjunct staff'. In order for this notion to materialise, families are trained to approach their relative in a similar manner to nursing staff. Buckwalter and Hall (1987) believe families can serve as a resource in the long term setting through involvement in rehabilitative strategies. Rehabilitative strategies are manifold

however, they aim to compensate the negative effects of the nursing home setting (Buckwalter & Hall 1987, p. 178). These strategies include psychosocial stimulation, social interaction, positive reinforcement, remotivation therapy, music and movement regimens. These strategies are designed to promote more positive interactions between the nursing home staff and families (Buckwalter & Hall 1987, p. 178).

The paradigmatic stance adopted in these studies reduces visiting to a technique which must be learned and mastered. The accomplishment of techniques and skills may not necessarily invite the family to be and become part of the lived-world of the other. Cohen (1983) can be critiqued as viewing the family as working in the capacity of another staff member. Adoption of this assumption brings an instrumental attitude to the word 'family'. Individual members of families may be construed as 'another pair of hands', with a concrete purpose in mind. There is little room for an expressive attitude where meaning and reflection are viewed as crucial to the nature of the experience. This mechanistic stance tends to separate the act of caring from the person who is caring.

Hansen, Patterson and Wilson (1988) recruited seven families to be involved in 'Resident Enrichment and Activity Programs'. These programs consisted of being involved in such activities as unit photography; weekend snack and social hour; religious and holiday observances; resident birthday parties. Matching family skills with patients' needs is an essential part of the program. Hansen, Patterson and Wilson (1988, p. 509) maintain the benefits of the project are multi-dimensional, producing a sense of shared care-giving responsibilities which may have been relinquished when their relative was admitted to the nursing home. Although the program looks at matching certain activities with family member's capabilities, the interest remains technical. This approach treats the development of skills as being of paramount importance in terms of being involved with their relative.

Other interventions such as workshops have helped family members become involved with the nursing home. A series of workshops that stress increased understanding of the ageing process and communication was studied by Schulman and Mandel (1988), who observed that families desperately sought the opportunity for information and coping skills. Schulman and Mandel (1988, p. 796) highlighted sixty practical ways of improving communication which were

offered to family members and whilst it was emphasised that not all techniques work in every situation, family members were asked to attempt a variety of new approaches. Participants in these workshops reported increased satisfaction with nursing home visits and more positive relationships with their institutionalised relative. There is no shortage of experienced professionals who attest to the need to work with families, not around them (Kramer 1972; Schmidt 1970: Silverstone 1978). Once again, a rather mechanical view of visiting is posited in these studies. By simply trying out activities until one is appropriate closes the chance for the interaction to make a difference to both the family member and the resident. Coping is seen as the result of a problem solving process and control and mastery is highly valued. Those who do not cope are seen to be weak and having failed. The problem solving approach; the pervasive human desire for absolutes; encourages objectification of the individual and discourages personal involvement (Gulino 1982, p. 353). Problem solving is intrinsically abstractive, calculative and extracting. If the attack is successful, the problem is defeated once and for all. The goal of problem solving is closure (Burch 1986, p. 7). There is no conversational space in which to disclose the feeling of vulnerability; there is no genuine sharing.

Too often the family is relegated to the status of visitor. Clifford (1985 cited in Buckwalter and Hall 1987) maintains the new patient may be seen by the staff as 'theirs'. Thus the family feels compelled to adhere to rules and norms set down by the nursing home. Adaptation to a nursing home requires the family to adopt unfamiliar and unnegotiated roles. All too often family and staff develop a competitive or even adversarial relationship trying to care for the new patient (Buckwalter & Hall 1987, p. 179). It can be argued that the family member is seen as no more than an appendage of the new patient. The family's behaviour can be said to be guided by role expectations. To know how to behave and what is expected, for the visiting relative, is seen to be critical to adjusting to the nursing home environment. Rather than assuming responsibility for their own existence, the families are alienated from the world of the nursing home and any possibilities for being part of it.

Buckwalter and Hall (1987) purport the appointment of a family liaison nurse is the best way to increase family involvement. The responsibilities of this nurse are to train the family members in rehabilitative strategies, refer family members to support groups and evaluate family involvement. The notion of the nurse to be in the best position to evaluate the efficiency of such programs places the nurse in

the position of an expert. The family are seen as passive recipients of the learning process; a somewhat paternalistic attitude. Efficiency is seen as something that can be measured and defined. It can be argued that family involvement is ineffable, it cannot be reduced and measured.

A contrasting group of studies view families of nursing home residents as clients, maintaining that families have needs of their own to which nurses and nursing home policies should attend (Montgomery 1982; Green 1982). Montgomery (1982) conducted a study of three nursing homes with one hundred and four residents and staff to measure the quality of family relationships through interviews and surveys. In this study, family needs are not seen in terms of increasing the well-being of the resident, rather in terms of meeting the families own desires. Nursing homes that adopt care policies that reflect families needs are said to have the greatest impact on relationships. These nursing homes have care policies that have regulations and practices that portray a welcome message for the family. Inclusion of open visiting hours, refreshments for visitors and arrangements for family dining are features of these nursing homes (Montgomery 1982, p. 55).

To summarise, most research is grounded in an empirical, analytical methodology. The literature on families tends to neglect the lived reality of the family. Favour is given to explanatory causes in terms of variables. This methodology arguably provides a particular form of knowledge or understanding which is not exhaustive. Research oriented in the positivist paradigm, with its demand for objectivity, causal modes and quantification provides only one lens among several with which to view human experience.

Little consideration has been given to the day-to-day lived experience of married women who admit their husbands to a nursing home. The purpose of this study is to bring into the realm of nursing discourse an understanding of the nature of the lived experience of the married women who place their husbands in a nursing home. The dilemma is that our pre-understanding and assumptions predispose us to interpret the nature of the phenomenon before we have come to terms with the phenomenological question (van Manen 1990, p. 46). This phenomenological study attempts to disclose the real life experience of admitting one's husband to a nursing home. It is anticipated that these following stories will reveal the inherent, multi-faceted nature of the experience. These are the stories so easily forgotten by

nurses and others who seek causal explanations in hope of a solution to problems. Admitting one's husband to a nursing home is not a problem in need of a solution but a phenomena that needs to be understood.

Chapter Four

METHODS USED IN THIS STUDY

Sometimes I wish I could be
Right inside the minds
of the ones I love—
What would I do?
probably nothing—
just dwell there
and watch them...

(Witcomb 1979).

This study seeks to bring into the domain of nursing discourse and understanding of the nature of the lived experience of married women who admit their husbands into a nursing home. A number of different frameworks are available to researchers using phenomenology as a guiding philosophy. This chapter describes the method used in this study to obtain descriptions of the participants' experiences. This method is a compellation of two procedural steps first described by van Manen (1990) and Colaizzi (1978 cited in Streubert & Carpenter 1995, p. 39).

van Manen's methods are highlighted throughout this chapter, indeed they form a guide for the reader, and Colaizzi's (1978) method is well described by Streubert and Carpenter (1995, p. 39) as:

> Description of the phenomena of interest by the researcher. Collection of subject's description of the phenomena. Reading all subject's descriptions of the phenomenon. Returning the original transcripts and extracting significant statements. Trying to spell out the meaning of each significant statement. Organising the aggregate formalized meanings into clusters of themes. Writing an exhaustive description. Returning to the subjects for validation of the description. If new data are revealed during the validations incorporating them into an exhaustive description.

In this research, I have brought the attention of the reader to my interest in the study. I conversed with the participants and transcribed their stories about their experience. I read and re-read these transcriptions, re-wrote their stories in a narrative style, using their statements to identify the significant experiences and through clustering their experiences into life-world descriptions, uncovered meanings and returned these re-written stories to the participants for validation and further elaboration, if necessary.

In presenting these methods, the researcher has utilised a arrangement described by van Manen (1990) and further formulated to suit this particular research. In 'doing' phenomenology van Manen (1990, p. 30) suggests there is a dynamic interplay between the following four steps:

> Turning to a phenomenon which seriously interests us and commits us to the world. Investigating experience as we live it rather than as we conceptualise it. Reflecting on the essential themes which characterise the phenomenon. Describing the phenomenon through the art of writing and re-writing.

Within the explanation of the research method, this chapter will consider the advantages of conversation, storytelling and re-telling stories as a suitable approach and application for this particular study.

Turning to a phenomenon

Phenomenological studies reveal the experiences that people have in everyday life (van Manen 1990). In researching human experience, the researcher is permitted to enter into a shared relationship in order to uncover the essential meaning of that experience.

As discussed in a previous chapter, the phenomenon of married women placing their husbands into a nursing home was initially explored through reflections on my own nursing practice. The ambivalence and uncertainty of my past experiences gave rise to my questioning. It is because of my background and prior knowledge that I rejected the notion of using the Husserlian approach to the research. Reading research literature on families within institutionalised settings provided background to this experience. However, within the literature, accessed by me, there was little or no mention of the specific experience of married women

who place their husbands into a nursing home. The resultant understandings brought about by my conversations with these women challenged my own previously perceived inadequacies as a nurse. The phenomenological question namely, what is it like for married women to place their husbands into a nursing home, unfolded through an attempt to offer more insightful descriptions of their way the world is experienced (van Manen 1990, p. 9).

Investigating the lived experience

I have chosen conversation as a way of entering into the lived world of these three women. Conversation offers a direction for an activity of reflection and conversation encourages the participants to question the taken-for-grantedness in their lives.

Each woman was asked to engage in four conversations. Each conversation lasted for approximately half an hour to one hour. All three women invited me to converse with them in their homes. This home environment allowed for a relaxed atmosphere and the place of familiarity for the participants facilitated an easy recall of their experiences. One participant chose to meet with me immediately after visiting her husband in the nursing home. The other two participants met with me on regular occasions but not related to their visits with their respective husbands.

Each conversation was taped and transcriptions were performed by a professional typist. Initially, one participant felt uneasy about the use of the tape recorder. However, after placing it in an unobtrusive position in the room she relaxed and entered into conversation quite readily. Acknowledging the vulnerability of the participants, I approached the conversations with sensitivity. I reassured each participant of the confidential nature of the research and explained to them that should they wish to, they could discontinue the conversation at any time.

In this research I have used the term conversation rather than interview. The art of conversation is described by Gadamer (1975, p. 330):

> To conduct a conversation means to allow oneself to be conducted by the object to which the partners in the conversation are directed. It requires that one does not try to out-argue the other person, but that one really considers the weight of the other person's opinion. Hence, it is an art of testing. But the art of testing is the art of questioning. For we have seen that to question means to lay open, to place in the open.

The nature of questioning in conversation is different to the interviewer's interrogation of the interviewee. An interview is 'a face-to-face verbal exchange in which one person, the interviewer, attempts to elicit information or expression of opinion, or belief from another person' (Minchiello, Aroni, Timewell & Alexander 1990, p. 88). In contrast, a conversation is an intersubjective enterprise of persons with '...the revealing of something held in common' (Carson 1987, p. 81).

There is a danger, in an interview, of the interviewer being perceived as an 'expert'; one who asks all the questions and is in control of the interview situation. This hierarchical notion disrupts the atmosphere conducive to an easy exchange of ideas. Similar to an interview, a conversation has a focus, but is not one-sided. Weber (1986, p. 68) describes how the conversation is very much a shared experience affecting both the participants and the researcher; 'a genuine dialogue occurs when we talk to each other rather than past each other'. In an interview, interviewers may deny what they feel in the name of being 'objective'. Rather, in conversation, having thoughts and feelings about a person is not an abandoning of what it means to be a researcher. Weber (1986, p. 69) further states '...it is only in relating to the other as one human being to another that conversation is really possible'.

Weber (1986, p. 67) also alerts the researcher to the possible risk when the private conversation goes public in the form of the text in a thesis. It is important that the experience is not distorted. In this study, transcripts of the conversations with each woman were shared with each respective woman as I reflected with each of them on their particular experience. The final draft of each transcript was approved by each woman.

Through conversation there is a seeking of shared understanding. There is an

openness and willingness to learn. The openness of questioning however, is never absolute because a question always has a certain direction. As Heidegger (cited in Weber 1986, p. 68) asserts,

> ...the very act of posing a question is disclosure, for to question is to sketch in advance the context of meaning in which a particular inquiry will move.

In turn, answering invites more questioning. Thus, the direction of the conversation guides the conversation. The conversation is shaped by both people engaged in it (Weber 1986, p. 68). Reason (1988, p.172) comments that as a researcher he found that having input into the questioning initiated different areas for exploration and allowed him to transcend the situated passive role and enter into a two-way interaction. Reason (1988) further contends that should the participant reject the direction of exploration that he accepted that situation and 'backed off'. In this research, the participants always guided the direction of the conversation yet like Reason (1988) suggests, I had input into the dialogue. 'It is through the seeing of that which is neither only *you* nor only *I* but it rather *our* between that we learn about each other' (Weber 1986, p. 68).

There exists a certain harmony between conducting a conversation and the aim of a phenomenological approach to research. van Manen (1990, p. 13) purports,

> Phenomenological research is not a problem solving research; it does not offer solutions and general conclusions. Phenomenology addresses not problems but the questions that make problems intelligible as problems.

This research has become an ongoing inquiry. There is no conclusion to the research rather, the topic is never closed as meaning questions are never complete. The aim was not to solve, but to open new possibilities through dialogue, thus striving for deeper understanding is an ongoing project.

Reflection on and in the conversations

The point of phenomenological research is to 'borrow' other people's experiences and their reflections on those experiences in order to be able to come to a better understanding of the deeper meaning or significance of an aspect of human experience in the context of the whole human experience (van Manen 1990, p.

16). Through reflections we can come to a better understanding of the lived experience of these women in the context of the whole human experience. Consequently, we may be able to see those experiences as an aspect of possibilities of our being human (van Manen 1990, p. 58). It is in this sense that phenomenological descriptions have a universal character.

During the conversations, remaining focused on the experience was of great importance. The transcripts were shown to the women as a guide to focus on subsequent conversations. The women were eager to talk about their experiences and some began relating these experiences as soon as they met with me. Bernice related that I was the first person with whom she had really discussed her feelings about her husband's admission to the nursing home. Most of the conversations began with the women relating what is was like to look after their husbands at home and how they came to the decision about a nursing home admission. Coming to an understanding of the meaning of this event for each of these women allowed the stories to unfold. It was as if their story had to be told. Their respective pasts had coloured the present and future possibilities of their experience. This often traumatic past was never a closed chapter of each story.

The hermeneutic reflections moved fluid-like, to and fro, as we attempted to make sense of each of the women's experience. As we travelled together to a place of openness, the experience unfolded beyond definition. The conversations drew us in like a magnet as we searched deeper into our existence, wrestling constantly with questions of meaning.

Throughout the conversation I made room for 'the other' by carefully listening to each woman's story. I resisted the temptation to interrupt which may have lead to premature foreclosure. As I listened to their stories, I became aware I would never really know what the full experience was like for each of these women. All of the women had their own personal history from which they interpreted the experience. A background of differences, yet so similar in relating their experience of placing a husband into a nursing home.

Attempting to follow the line of thought through each conversation was very exhausting. When further clarification was needed I sought van Manen's (1990) advice and asked "can you give me an example?" or "How did that make you feel?" or "In what way?". In addition, Polkinghorne (1988, p. 164) believes that

researcher behaviour influences the way in which the story can unfold.

> The interviewee is the teller of the story, the interviewer the hearer. In this context, the story selected to be told can function to present a particular image of the teller; and the kind of interview the hearer undertakes can affect the kind of story told.

During our conversations, the women created a space and time that was truly ours. One woman invited me into her 'special room' where we sat in the comfort of an open fire. On some of the conversational occasions I noticed that the telephone had been disconnected so as not to interrupt the flow of our dialogue together. On another occasion when the telephone did ring, the woman quickly ended her telephone conversation saying she had something important to do.

After the transcripts were completed I re-listened to the stories and felt there was something deep and somewhat mysterious to be understood. As I dwelled within the stories, it appeared that the stories also dwelled within me. I began to understand how these women transformed and transcended their loss and suffering into hope.

Each transcript was read and re-read many times and together with my field notes and reflective journal I began to get a sense of the whole. I read one story at a time which allowed me to become fully emersed in that story. At the end of the four conversations with each participant, their stories and subsequent meanings were reflected upon by both the woman and myself. This opportunity afforded each participant time for clarification if needed.

Writing and re-writing the stories

The aim of phenomenological description and interpretation is to allow the significance of the lived experience of the particular phenomenon under investigation to be exposed. There are many ways to organise the texts of conversations. van Manen (1990) identifies at least five possible ways this exposé can be achieved; thematically; analytically; exemplificately; exegetically and existentially. These suggestions are neither exhaustive nor mutually exclusive. In this research the text of the conversations has been written in a narrative form.

I have used storytelling to capture the lived experience. The logic of story is that there is the retrieval of what is unique and particular (van Manen 1990, p. 152). Polkinghorne (1988, p. 36) states 'narratives show the interconnectedness and significance of seemingly random activities.' Narrative is concerned with creating a hermeneutic unity. Storytelling reveals the unique and the particular, evoking a quality of vividness. These stories have the possibility to be an experience that could be a part of any married woman's life. Through story, we live through an experience that provides us with the opportunity of gaining insights into certain aspects of the experience.

Polkinghorne (1988, p.163) suggests that in rewriting stories obtained from research participants,

> The researcher needs to move from the specific stories a person uses to account for particular episodes to more general life stories that provide self-identity and give unity to the person's whole existence.

In re-telling the stories I had a choice in what was told and how it was told. Tesch (1987, p. 237) describes the importance of intuition in presenting the research. The researcher learns to trust and have confidence in their intuition. This trust grows out of prereflective familiarity with the experience.

One of the difficulties of writing stories is to write in a way that captures the experience which is 'true' for the women and for myself. My Being-in-the-world as a wife, mother, female, nurse and daughter influences how I re-tell their stories. van Manen (1990, p. 31) reminds the phenomenological writer 'a phenomenological description is always one interpretation and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even richer description'.

Meaning making and coming to the understandings

Burch (1991, p. 41) warns that phenomenology risks subjectivism when it considers its task to be the 'reproduction' of the conscious projects and purposes of others. I cannot know directly the intentions of others but can only conjecture or speculate as to what these are from what others say and do. These conjectures

reproduce meanings not in themselves but ever only from my own perspective. Gadamer (1975, p. 264) states 'it is enough to say that we understand in a different way, if we understand at all'. My Being-in-the-world influenced how the stories were told and hence were meaningful to me as a nurse. My personal experience and history were the very condition of my understanding, its locus and medium.

According to Reason (1988, p. 82) human meaning resides in the story. In phenomenology, the researcher has to be mindful of imposing themes on the data. This type of analysis has the possibility to reduce and fragment the experience. Through categorisation, the phenomenon can be oversimplified as it is considered to be one thing or another. van Manen (1990, p. 33) posits,

> Unless the researcher remains strong in his or her orientation to the fundamental question or notion, there will be many temptations to get side-tracked or to wander aimlessly and indulge in wishy-washy speculations, to settle for preconceived opinions and conceptions, to become enchanted with narcissistic reflections or self-indulgent preconceptions, or fall back onto taxonomic concepts or abstracting theories.

Rather, the intention of phenomenological interpretation is to capture the very essence of the participants' experience and relate it to the reader in a manner which is genuine. In narrative, this authenticity is preserved, there is a sense of the whole. The lived experience remains in a context revealing the tensions, ambiguities and complexities of the experience.

Narrative expression is the mode of allowing the meaning of experience to become manifest (Reason 1988, p. 80). It requires the inquirer to partake deeply of the experience rather than standing back in order to analyse it. Meaning is 'part and parcel' of all experience although it may be so interwoven with that experience that it is hidden. It needs to be discovered, created, or made manifest and communicated. To make meaning manifest through expression requires the creation of an 'empty space', a clearing which becomes the vessel in which meaning can take shape (Reason 1988, p. 81). van Manen (1990, p. 33) explains,

> In other words, one can get so involved in chasing the *ti estin* (what is it?) that one sets stuck in the underbrush and fails to arrive at the clearings that give the text its revealing power.

These stories have their own meanings, they derive from the participants' '...strive to organise their temporal experience into meaningful wholes...' (Polkinghorne 1988, p. 163).

In the action of re-telling the stories, it became clear to the researcher that there were significant similarities expressed by each of the participants. These similarities can be described as key events or 'happenings' which occurred for each of the three women.

Thematic analysis commenced with dwelling in the data as a whole. It was a process of reading and re-reading the whole conversational text in order to get a sense of the total picture. In working with the text, I used the highlighting approach described by van Manen (1990, p. 93). I looked for statements in the text which were particularly revealing about these women's experience. Tesch (1987, p. 233) refers to this looking for precious elements as 'panning'. These elements take the form of descriptive expressions in the text that 'are at the centre' of the experience. That is, parts of the text which address its 'nature', or directly pertain to the experience.

van Manen (1990, p. 90) does not think in terms of categories, but uses a metaphor of discovering the 'knots in the web of experience'. Bateson (1979 cited in Tesch 1987, p. 233) likens these emerging themes as 'patterns' in the sense of 'patterns that connect'. The themes identified in this research were not exhaustive nor do they fully capture the experience as lived. However, this analysis provided a systematic way of presenting my understandings.

Chapter Five

RE-TELLING THE STORIES

What fools we are
to miss
the importance
of laughter—
the warmth
of understanding
and the gift
of friendship
that wait for us
between the extremes
of love and loneliness—

(Witcomb 1979).

The following stories are my interpretations of three conversations with each woman. All of the encounters were undertaken in the comfort of their individual family homes. A brief autobiographical sketch introduces each woman. This history furnishes the background of the evolving relationship between the women and their respective husbands.

There was a genuine commitment to the study. These conversations were our time together and each woman, in their own way, made room for me in their life. Sincere interest and enthusiasm was shown both for me and the study. I was asked personal questions on our continued meetings; there was a real sense of wanting to know me as a person rather than a researcher gathering data.

Although the written word tends to present the participants language in a one dimensional domain, I have attempted to re-tell their stories in a manner which captures the appropriate moods and emotions these women shared with me during our conversations. I have extensively used the participant's words and these statements appear in *italic* print. I have transcribed the quotations verbatim making no changes to the grammar or expression. The stories told reveal the

unique, ambiguous landscape of these women's lives. An additional poem introduces each story, inviting the reader to enter the world of each participant. Each conversation would continue long after the tape recorded session had finished, the women being eager to show me around the family home. During this time together, personal belongings of their husbands would release intense emotions and I remained with these women until they appeared composed and peaceful.

Alice

When we lose
those we love,
you must understand
that it takes time
to learn to feel again—
for nothing
can touch
the heart
which is frozen
with grief—

(Witcomb 1989).

Alice was a seventy-five year old woman who married late in life. She described herself as a rather independent lady. She had three children, two of whom lived interstate but she kept in regular contact with them all. She replenished herself intellectually and physically when her youngest child was ten years old by attending summer schools at an interstate university. She cared for her partially blind father until his death at age eighty-three. Alice also cared for her mother until her death in their family home. She raised her family in the home in which she had spend her childhood. Having cared for her own husband at home, she was hesitant to place her husband into a nursing home as they seemed noisy and overcrowded. Alice had played the piano in the nursing home as part of her work for charity organisations, so she felt she knew what to expect from such an institution. A determined lady, she looked after her husband until she could no longer cope. She utilised respite care but it proved unsuccessful for her. Initially, she viewed caring for her husband as challenging, but in the later stages of his illness, she felt defeated.

Alice's story

She hesitated. She did not want to be the one to have to tell Jack that he would be going to the nursing home. Alice was offered temporary placement for her husband at the nursing home. The doctor was aware of her circumstances and asked her to make an appointment to see him and requested her to bring her son

along. At the meeting with the doctor Alice learned that the Director of Nursing at the nursing home requested to have Jack for three days to assess him. She left the meeting relieved, thinking,

> *well that is marvellous, three days, you know we will have three days in which we can recuperate because I'd been through it.*

After three days Alice received a telephone call asking her to bring more clothes; they were going to keep Jack for another week. At the end of seven days she received another telephone call and was given an appointment to see the staff of the nursing home, she was offered a permanent place for her husband. The decision weighed heavily on her. Her feelings were mixed, she barely knew what to make of any of it. Alice described her feelings as,

> *relief in one way but then against that there was a terrible feeling of having...it's like letting someone down ...you know?*

The doctor placed the onus of the implications of the decision on Alice. She found it very hard to tell Jack that he had to move from the family home. She wanted the doctor to tell him but he adamantly rejected her request. The nurse, sensing Alice's anxiety, handed her a cup of tea and invited her to sit down. The ultimate decision to place Jack in a nursing home still played on her mind. She sat there, tears trickling down her face; it was the first time she could remember crying. The thought of making such a decision was more than she could bear and she went to pieces. She was alone, yet in the midst of others. It all seemed so clinical, so procedural and unfeeling; she felt detached and very, very alone.

Unlike many women of her era, Alice had always made the big decisions in their marriage and taken much responsibility; but somehow making this decision was different as she wondered whether she had done the right thing. Thoughts of guilt overwhelmed her as Jack's words echoed like thunder in her mind. He had once said "I will never go into a home". She felt content and satisfied that the nurses knew how to look after him. She felt she had done the right thing as long as he was happy; but Jack's words lingered on in her mind.

Alice hastily handed over the care of her husband to the staff of the nursing home. She rationalised this action in her own mind by acknowledging,

> *I thought well, they are the experts, that's up to them, they have probably seen it all before. That part didn't worry me at all, I just thought he was in good hands and that was a great relief to me. So it has never worried me, anything about his bowels and all that is their affair. The only thing that worried me was if he was happy and you know I didn't want him to be there feeling neglected and sad.*

Alice reminisced about her first visit. With apprehension she walked towards the nursing home. She was nervous, trembling and worried - had she made a mistake? She was afraid of what she was about to face. She wondered if he would remember her. Her eyes combed the dormitory, she saw him, he looked well cared for and clean. On seeing him in the home she believed she had made the right decision. On leaving the nursing home she experienced a feeling of warmth, peace and contentment. For a moment, Jack was happy and Alice was relieved.

On her next visit, Alice described finding Jack squashed into a four bed dormitory. She felt that his personal space had been invaded and she was displeased. She felt that they did not have any private space to chat or to be together. She felt somewhat reluctant to bring photographs into the home because she was uncertain of the staff and Jack's reaction.

Alice's experience of the staff was to find some of them patronising. On one occasion when she visited Jack she witnessed a nurse saying "Come on!" to him. It was not what had been said with which she took issue, but the way in which it was said. Her spine tingled, she could not bear him being addressed and spoken to in such a degrading manner. She knew that he hated being spoken to in such a manner, after all *'who would like it?'* She wondered whether the staff would like to be spoken to like that. To Alice, it was not an appropriate way in which to communicate with another human being. She felt that Jack had been robbed of his 'personhood'. She felt there was a clear lack of compassion, *'after all these people were somebodies'*.

Alice recalled one particular visit. She approached the home alone and unannounced. She was horrified; nothing could have prepared her for what she was to see. Jack was unrecognisable, dressed in someone else's clothing, looking withdrawn. In desperation and anger, she left. Not knowing who to talk to, she telephoned the assessment nurse. The nurse accompanied Alice to the nursing

home and agreed with her that things were not right. The smell of urine hung heavily in the air, 'what *a stench!*' It was sights such as these, combined with pressure, tension, despondency and loneliness that often convinced Alice that she had done the wrong thing by placing Jack into the nursing home. Alice reflected on her unannounced visit, *'it was silly of me, I really should not have done it'*. Now, Alice telephones the nursing home ahead of time and informs them that she will be visiting as she thinks, *'they might like to get him sort of prepared'*. Alice further stated,

> *The next time I decided to go I rang them (the staff) up and said "I'm coming around this afternoon, will that be alright?", and again it was a male nurse and his answer to that was "Yes, well he is not going anywhere is he?".*

Alice clenched her fist and concluded *'they (the nurses) are very insensitive'*. She recalled a time when she visited and found him neglected. She does not want to find him in such a state again.

Alice wished there was some way she could monitor and predict when Jack would be in a rationale state of mind when she visited. If only she knew when he was going to be rationale, then she could bring him home for the day. She wondered how she would cope with him at home and whether a day at home would be of any benefit to him. Would he enjoy a home visit? How would she cope with such a visit? She sought advice from the doctor about bringing him home for the day.

> *So I asked, would it be possible to have him out for the day, for a drive and following the drive I could take him home for afternoon tea or something like that. And the doctor said, oh, oh of course, if you want to. I wouldn't, you will never get him back . And I said, no, that is what I am afraid of and that is what I am trying to find out. And he said, well you can try. Of course I can't stop you.*

Alice felt that perhaps she had been talking to the wrong staff member, but she didn't know who else to talk to about bringing Jack home for the day.

Appearing to be unclear of her role when visiting, Alice resorted to playing 'Scrabble' with Jack as it helped to occupy him. The idea dawned on her as she sat with Jack at the table in the nursing home not knowing what they could do.

Alice found a room where they could be away from the others and described how they played the game for an hour, *'several times he did things better than I did, it was astounding'.*

Recollecting her visits with Jack, Alice described his appearance.

> *He looks fairly normal; he looks like he was about six months ago; so clean and nice and dapper. And I mean, I just felt I could say, put your hat and coat on and we will go out.*

However, when Jack started to talk incoherently, Alice remembered that he wasn't really okay. She lamented on what it was like at home caring for him and she reminded herself sternly, *'...she must not forget this'.* The ambivalence which was evoked in seeing Jack and remembering Jack as he used to be, still made her wonder as to whether she had done the right thing. She was never sure of her decision to place Jack into the nursing home. Jack's lucid moments were the times that Alice said had pleased her.

> *He is not really that bad and how mean I am for leaving him there and this is what happens every time I visit.*

Jack requested to go home and the distress associated with these requests was overwhelming and Alice was unable to cope with this situation. She discussed Jack's constant requests with the Doctor and how she should react. Before her next visit with Jack, Alice purchased some tapes and books. She decided to use them as a distraction,

> *I sort of go straight into him and start showing him these and how it works and talking to him so he doesn't have to start on me about when he is coming home.*

She was concerned that her visits unsettled Jack and made him aware of where he was — in a nursing home. Alice debated as to whether to visit or not. She felt she was in a dilemma. When Jack expressed a wish to come home, Alice consoled herself by saying, *'it's not me he really wants, it's his independence'.* On the occasions when he wanted to come home, she left the nursing home feeling very despondent. Each time Jack made this request Alice said,

> *it's like a pin prick and that adds up so visits really consist of this matter. What should I say? A terrible lot of swallowing goes on with the lump in my throat.*

Feeling overwhelmed and confused, Alice again contacted the Doctor.

> *Do you think perhaps that I don't visit? And he said, "No, that would be cruel, you can't do that." To use the word cruel makes me feel unkind. I already have enough on my head. I think wives do need a whole lot more sympathy and loving attention from somewhere, somehow or...it does help me so much when people are understanding you know.*

Alice felt misunderstood. She had a desire to take Jack home to be a part of her life. Many thoughts raced through her mind. She remembered the times they once had. Then she thought of how he would keep running away and how she couldn't cope any longer.

> *I still get the funny little feeling coming through from some people that, oh aren't you going to have him back? What did you do it for? You know, this sort of feeling and I think, they don't know, they haven't been with me, how do they know.*

Feeling alienated and judged by others she said she felt pressure to conform to other people's wishes. There was a real tension about what she felt was expected and what she was capable of doing. Alice watched the nurses attentively and how they dealt with her husband's obsessive behaviour. She noticed how he listened to the nurses and reflected on what his response might be if he was at home with her.

> *If that had been me there would have been a different attitude. He would have said, oh, you don't know anything. He just would not listen to me.*

As Alice started to feel more at ease with the situation of Jack being in a nursing home, she was pleased to find that she had a useful role within the home. When she learned that some residents were not visited she made time to speak with them finding that, *'they are busting to talk, they are, and I feel there is something I can do'.*

On another occasion Alice went looking for Jack and when she reached the dining area of the nursing home, she saw patients dressed in their pyjamas, walking around aimlessly. The television in the room was loud, it had a piercing sound.

> *There seemed to be so many people in one little area. Nobody seemed to be talking much, they were all sort of sitting around, looking a bit like a funeral.*

She wondered where her husband could be. As she walked around the home, she found him curled up on a bed and he was cold. The other patients distressed her. They seemed to her to be in a much worse state than her husband and she was surprised at her feelings. She wondered if Jack would ever deteriorate to such an extent. She felt that depression and tension permeated the nursing home.

Alice thought back to her outlook on life before Jack was admitted to the nursing home. She would *'let life flow on and you take it as it comes, what is going to happen next?'* Whilst nursing Jack at home her life was all consuming and there was no time to think of the future. There was no future which offered any hope and she felt she had no control over her own future. Shortly after Jack was admitted to the nursing home for assessment, Alice fractured her arm. She said this incident helped her as she could truthfully say that she could not care for her husband. She felt relieved that she did not have to tell a lie about the situation. When Alice returned home from the nursing home she was faced with a dark old empty house.

> *Not even a husband to come home to, and then I had nothing to do with myself. There was no-one to look after. That's what I really needed, someone to do something for. I only had myself and I was wandering about from room to room thinking, giving myself a shake and saying, this is ridiculous.*

Alice felt a lot of her life's purpose had suddenly been taken away. Trying to combat the loneliness, she would go out into the garden. However, the garden would bring back a flood of memories. She reflected on the times she had spent the day in the garden as she kept an eye on her husband. The hedge in the garden took on a new meaning for her.

> *He wanted to get rid of the hedge so that he could look down the back of the garden and I wouldn't do it. Now, I think I could have done it.*

As we talked together Alice lamented that the house seemed empty. She looked out of the window from where we were sitting and said,

> *We always had cars. This place has always had cars and bikes and wheels and this (the emptiness) most unusual now. Can you imagine what has happened to me?*

The house was now a vivid reminder of what had been and was filled with a fear of an unknown future. For Alice, life could not be the same, it had to change. She felt robbed of a future as she lamented over her many unfulfilled dreams. However, most of the time Alice thought about her husband and questioned her own freedom. Nevertheless, now Jack was in a nursing home, Alice felt she could make plans. She anticipated that now she could have time to care for herself.

> *Now I am looking forward to getting my health back on an even keel and I thought well, with him out of the way now I can turn to me. There are a whole lot of things that I want straightened out.*

Being a person who, in many respects, led an independent life, Alice felt she would have no difficulty in finding things to do; finding a project.

> *I am very lucky in that I have a lot of interesting things at my fingertips, particularly the music. And if I want people I can have...the phone is there.*

Living was no longer mechanistic for Alice. At first, when Jack was placed in the home she felt that she did not have any input into Jack's care. She described that time as a blur, everything was dull and grey, like living in a fog. Overwhelmed by concern and exhausted from lack of sleep, she had no time for herself. Now, she has time to reconstitute a sense of herself and enjoys shopping and seeing friends she has not seen for sometime. Alice did not experience the freedom she first thought that she would enjoy and explained this phenomenon using the words of her daughter.

> *She said to me, I quite resent my father doing this to us. he can't help it I know, but we haven't had a chance to grieve. The grieving process is good, you have got to grieve, everybody has to. But we haven't got anything to grieve over you see. Now if he were dead, I don't want him to die, but if he were dead, then we would be grieving, the process would be over and we would start again, but this way we can't.*

Alice anticipated resuming a normal way of life after Jack was placed into a nursing home. She looked forward to going out with friends and doing her garden. However, she found things were not the same and she couldn't *'just start again'*. Everything she did or tried to do took on a new meaning without Jack.

Bernice

When you stop
making the past
your scapegoat
for the present—
you can begin
taking charge
of your own future—

(Witcomb 1983).

Bernice was an eighty year old, warm and friendly woman who described her marriage as being a close partnership. She assisted her husband, Allan, in his professional life; typing his manuscripts; entertaining his colleagues; planning his career; she supported him one hundred percent with his ambition. Bernice followed Allan around the world as his occupation meant they had to travel. They shared three children, one of whom was in the medical profession. Bernice felt that her son had been of great assistance to her. She kept in touch with her children through letter writing and the telephone. Bernice's first contact with nursing homes was when her father was diagnosed with Alzheimer's Disease. The experience with her father helped her to know what to expect when her husband was similarly diagnosed. Bernice cared for Allan for four years in their family home. When she found she could no longer cope, she admitted Allan into a nursing home and moved into a smaller home unit. Bernice was of the opinion that Allan would receive more care in the nursing home.

Bernice's story

The combination of relief and guilt led to numbness which rippled through her body. Although Bernice had been in touch with her son, who was overseas, and discussed Allan's admission, she knew this decision was not going to be easy. She could no longer care for Allan, she could no longer cope with his illness. She wished someone would have reassured her that she was making the right decision, it was so hard to make the decision alone. She willed the staff to offer some reassurance, but they didn't. *'I wanted them to say it was the only sensible thing and then I had just to agree'*. Bernice wanted to be distanced from the decision.

The decision weighed heavily on her conscience. She described the burden of the decision as,

> *having to take over and because he was no longer able to, and I don't think he liked it. You think, did I boss him around too much and yet I had to say do this or that or stop him when he wanted to do impossible things.*

She understood that ultimately it had to be her decision but she wished someone else had been by her side. She imagined what it would be like if her son had been with her, anybody as a back-up; she felt alone.

The day of admission was a blur for Bernice.

> *The nurses asked me questions about his care, was he allergic to anything? How he slept. I really can't remember it all. I was just worried, overcome by it all. I wondered whether he would be happy there and hoped he knew I could no longer care for him.*

Thoughts echoed through her mind of what others had said. *'You should try to keep him in this lovely environment (own home) for as long as possible, at home with all his books'*. Thoughts raced through her mind, questioning whether she could have kept going a little longer. She felt inadequate as a wife as she doubted herself, *'why can't I cope? I must be weak'*. However, Bernice knew she had done all that she could. Nevertheless, knowing that did not prevent her from feeling that she had failed in a fundamental way. *'To be a wife means that you have to look after your husband'*. The tension between what she wanted to do and what she ought to do tormented and tortured her. Had she made the right decision?

Bernice reflected about how she cared for Allan *'as long as possible'* as if to have convinced herself that there was no alternative to placing him in a nursing home. She was comforted with the knowledge that even if her decision had been a little hasty, she knew there would come a time when she could have no longer coped. It was all a matter of timing and when the time came she was overwhelmed with the feelings she experienced.

Bernice's initial visit to the nursing home was delayed as she had taken advice from the staff at the nursing home to allow Allan to settle in; she visited Allan alone.

> *The nurse said, go home and have a rest, leave visiting for a while; just a few days until he settles in. I couldn't have gone, I don't think, I didn't have the strength, emotionally.*

It was only after she had admitted Allan to the nursing home that she realised how exhausted she was and how desperately she needed to sleep.

Initially, Bernice would visit everyday. She described how she became enveloped in a narrowed existence as visiting took up most of her time. Initially, she felt that she should visit Allan when she had something of interest to convey to him, as her news brought pleasure to him. *'I get invited to things, functions, and I feel I should really go so I have something to talk about when I visit'*. Bernice felt that it was not a good idea to visit just out of habit, her visits had to have a purpose.

> *I took a letter along and he read through it. I had it read to me so I knew roughly what was in it. For quite, oh about four pages he read, not all the words right but he was taking it in. He knew who it was from and then he got tired of doing that and wanted to have a little wander around the room. I try to keep his interest in things, keep him a person. It seems to keep him in touch. I can visit and feel like I have helped. Well, that is what matters.*

Bernice talked about the visits being relaxing and pleasing. She felt unthreatened by his apparent strange ways, and accepted when he wandered off.

> *I think he quite likes to feel I am there, you know just sitting there and sometimes he will just get up and go and then comes back and says hello and off again.*

During her visits, Bernice would sit and watch Allan wander around the lounge room of the nursing home. He would stop and talk with others using a foreign language and then start walking again. He would return to Bernice, looking perfectly happy. The nursing home was now his home. He had always been used to having people around him and seemed comfortable in a place with people and where nothing was expected from him. *'He is with his kind; he has not got the pressure there'*. Bernice felt a sense of peace and calm and felt truly convinced she had done the right thing by placing him in the nursing home; the right thing for him.

> *He is not going to be judged by others there. Other people he knew might get impatient with him but there they all communicate with one another. It is a friendly place.*

Bernice was pleased that he had his own little room. She brought in some pictures, a chair and books and tried to make it as cosy as possible so he would feel at home, not in an institution. Creating this space for him was very important for her.

> *I put pictures all up on the walls because he was lucky enough to have a room to himself to begin with, until recently. It was good for him to have his own little area where he had his own space. But curiously enough he never liked going into it much when I visited. He wanted to be with the others.*

Bernice would constantly try to find the person she knew in Allan. She talked about the paradox, *'He is, but isn't himself; he isn't exactly the person I knew'*. Although she had tried to revive his lost personality at home, she now felt she had more energy and time to be with him. Also, she could choose the time she wanted to spend with him. In this sense, Bernice experienced freedom, *'I visit when I feel I have something to give'*.

Bernice described how she would make use of Allan's lucid times as she realised there would come a day when he would not even recognise her. *'He isn't going to get better. He is going to fade more and more away and perhaps get to the stage where he won't know me'*. She would show him photographs of the family and talk with him about what she had done for the day. Bernice cherished every lucid moment, making everyday count — she treated everyday as if it were his last. These times were very precious to her and it gave her great comfort to know,

> *that he is still there. You cling on to it because you realise that something is there. You may get this absolutely lucid sensible thing said and then he will go off into not being able to arrange his speech. So it makes you realise that somewhere behind the mind he is still there. The emotions particularly are there and it is nice that he knows family and that really makes you feel good.*

Bernice delighted in recalling a friendly encounter with Allan.

> *The person I know is still there. I can't always see it and the emotions I am sure are there because he will...he said, "goodbye darling", as I went away yesterday and his face lights up; usually when I come he will come towards me and kiss me.*

Bernice interpreted this display of love as Allan being pleased to see her. She felt his own sense of individuality and person was still alive.

Bernice visited one day to find Allan had been moved to another room. She wondered why he had been moved and hoped that the staff had not moved him arbitrarily; that there was a reason for doing so. Feeling upset and concerned, Bernice asked one of the nurses. The nurse answered in a reassuring manner saying that Allan had been wandering and that the staff wanted to keep a closer eye on him. Bernice seemed to be satisfied with the reason given.

Bernice recounted that she saw her husband's name abbreviated and referred to as 'Bed Number One'. She felt this nomenclature said nothing about the person he was, or his personality. She felt as though the staff were diminishing his personality. She described and emphasised how she struggled to keep him the person he was. On visiting one day, Bernice was horrified to find Allan in someone else's clothes. His clothes had been lost in the nursing home's laundry. What appeared to be a routine occurrence to the staff was very upsetting for her. Bernice talked about how well dressed Allan had always been, right up until he was admitted to the nursing home. Later, once she was over the shock, she resigned herself to the situation. *'I have come to realise what is important and what is not, and it doesn't seem to worry him at all what he wears'.* Bernice was comforted by the idea that Allan did not care about what he wore. He seemed happy and his happiness was what was important.

Bernice found it important to discuss Allan's background with the staff. It was important that the nurses knew he was a clever and successful man. She hoped he would have his needs met and knowing about his past may have helped the nurses see him for who he was as well as who he has become. She felt if they knew him, they would be more accepting of his ways.

> *The staff must realise that he has been a rather intellectual sort of person, involved in education. When he trails off into French, as he did for a while and does sometimes still, they realise that it is a part of his background.*

Bernice experienced an enormous sense of relief, knowing he was in a nursing home. She emphasised the gravity of the responsibility associated with dispensing his medication whilst he was at home. Although the Doctor had explained everything to her, Bernice had found this task very difficult. She worried that she was not doing enough for Allan. She asked herself, how could one person have attended to all his needs twenty-four hours a day? She was concerned that when he went to the Day Centre that he did not always receive his medication when he needed it. She felt totally helpless; she did not enjoy peace of mind; his safety plagued her.

> *When I went to the Day Centre I told them about the times he needed his medication and how he had to be given it. And the nurse said he had the right amount but not at the right time. And I knew that it was only in a sort of hospital situation that they could get it right, which I am sure it is better and that weighed on my mind quite a lot. I feel that, although the Doctor told me, you know, when I could give an extra one or you know whatever, it was still a big responsibility and I knew I wasn't really helping him enough.*

Although Bernice felt as though no-one knew Allan as she did. She felt that as he was in a nursing home, he could be monitored and she was comforted. She no longer had to make the day-to-day decisions and she was no longer solely responsible for him. Now, she could spend quality time with Allan, *'I just come to him and try to give him, well, just love after all'.*

Bernice wondered how the staff knew when Allan was in pain. As she became more anxious about Allan's well-being she questioned the nurses about how they knew when he was in pain. The nurses replied that they could tell, they were trained for this type of thing. Bernice was reassured by their reply but admitted, *'it is not easy, letting others look after him, you really have to get to know them (the staff)'.* She acknowledged the care Allan was receiving was good.

> *I know the care there is the best that he can possibly get because there are trained people there, although the environment isn't sort of, you know, to an outsider it is a bit grim.*

Bernice would often telephone to find out how Allan was going and felt he was treated as important; the staff were attentive to his needs.

> *They look up the records and say exactly what has happened on the last shift. He has been continent or not continent; eating well; slept well, or not well or whatever. They keep records the whole time. You see them sitting there, making notes, which I find very reassuring.*

Bernice described the nursing home atmosphere as one big friendly family, she felt at home there.

> *I sort of feel that I am part of that family in a kind of way. I go through the doors and see the others and I say "Hello" and they recognise me because I have been visiting there and some of them pat me on the hand. I know some of their (the other residents) names. Part of me does belong there with him.*

On visiting, Bernice found the nursing home to be a place to meet other wives whom she would have never met. As she talked with them she tried to offer some support.

> *There is one lady there whose husband has just come in. He has got the one and only single room, Allan had to start with. And I wondered why they had moved him (Allan) but this poor man has got cancer as well as dementia and she (his wife) knows he has not got long to go. And so I have sat with her a bit and talked to her. I think she is completely confused. She hasn't been in a hospital situation very much and she doesn't understand. I try to help her and tell her the nurses are doing their best. I felt that is something I can do to try and help her understand.*

It was natural for Bernice to help others and she reflected on the support she had received from other visiting partners, knowing that the offer of support was reciprocal. These experiences were shared experiences and had been helpful in learning how each person coped with the same dilemmas. Bernice drew strength from their experiences, it helped her understand what to expect in the future.

Bernice said the staff at the nursing home were friendly and made her feel comfortable. If she visited just before lunch they would invite her to stay.

> *We had lunch together (with Allan) in a little private room. Another time when it was nice weather, we had lunch out in the courtyard and you know, if he is seen to be a bit restless they (the staff) will say don't worry.*

In addition, she felt that the staff were very understanding about the patients, *'they treat each one as an individual and try to accommodate things to their particular needs'*. She continued to say that she felt Jack belonged in the nursing home as the place met his needs.

> *His world is amongst people. I know they are very...and some of them are sort of much more advanced in their dementia than he is. But they are sort of gentle, most of them, reasonably quiet, and he hasn't got the stress he would have in the normal world.*

Bernice felt included in the activities in the nursing home and felt she assisted the staff in developing new policies.

> *I heard they were going to have these packaged meals, like they have been having at XXX Hospital and there was rather a lot of bad publicity about those. Something went wrong at the beginning, but anyway I was assured by the head of nursing that they were going very carefully about this and they were going to invite friends and relations to have a meal with them to see what they were like. And we were rather anxious that they were going to give the same thing to everybody and they might not be suitable for older people. But they are going to monitor it, I understand, carefully before they take it up.*

Bernice felt that the facilities at the nursing home were good. She was especially impressed with the concept of a visiting room as it gave a *'homely touch'*. When Bernice visited she tried to sit next to her husband if she could find a chair. *'There is such a human touch there, even among the patients themselves. They lead each other around and say Hello'*.

At times Allan said he wanted to come home and Bernice became distressed. She hesitated as she wrestled with notions of what was best for him.

> *I feel bad sometimes because I feel I am deceiving him all the time. When I say it is much too cold we won't go out today and I make some sort of excuse and temporarily it makes me feel that I am just not telling the truth and it's not fair. But that is the kind of emotional part of me. Rationally, I know it is the only thing because he accepts it. This way, there is no struggle on his part.*

Bernice considered whether she visited too often and if it was too unsettling for Allan. Finding a way to leave which does not unsettle Allan was important for her. Her ideal was to find a way which was painless for them both.

> *They all say when I am gone he settles down and carries on. I come away when he is having a meal, that's the time to come away, and it is good if you can arrange that.*

During one visit, Allan fiddled with the knobs on the door, as if he was trying to get out. Bernice found this incident disturbing. As she left the visit, the rattle of the door handles echoed in her mind. It was a reminder to her that he was perhaps not where he wanted to be; perhaps he wanted to come home. She felt miserable.

Bernice showed no hesitation in bringing Allan home for a day. She wanted to bring him home for his birthday and realised that she might not be able to manage him at home so she recruited the help of a friend. As Allan glanced around Bernice's home she sensed he recognised familiar objects and she was satisfied with her decision to place him in the nursing home and move herself into a unit. The decision had been in his best interest and she felt contented.

Contemplating the future, Bernice sat at home and imagined what life might have been and then snapped into the cold, harsh reality of what life was really like. She talked about a different way of being. She felt she was unable to go away on trips whilst Allan was in the nursing home. She recalled the feeling of his presence in their former home as she packed up his belongings; to her he was always partly present. Bernice was mindful of Allan's responses to questions she posed about her life, had he been living with her. She anticipated what he might have said, feeling that she still brought him into her present life.

The telephone rang and Bernice answered. It was a staff member from the nursing home requesting her consent for something. Allan was alright but they wanted to

restrain him. Confused and anxious she consented to the restraints. However, after the telephone call she began to doubt her approval, wondering why Allan needed to be restrained. She pondered over the decision she had just made and found some comfort in the thought that the nursing staff would have known what was best for him. After contacting her son, the medical practitioner, she felt relief from his reasoning and explanation about such a measure. Later, Bernice spoke about what it was like for her seeing her husband restrained for the first time.

> *The first time I went in after they had started having to restrain him , he called out, "Come quick". He was very much alive and I came and he said "where are some scissors" and then the nurse came along and untied him because I was there and I could walk him if he wanted to get up.*

Her anxieties were alleviated when the nurse untied the restraint and allowed Bernice to be with her husband. When she realised the restraints were being used as a protective measure, she felt reassured. *'I thought he must be sort of terribly agitated but it is not that, it is just when he is unsteady that he is restrained'*. She commented that the nurses were receptive to how she felt and would always ask how she was, *'they are so caring I think, for the partners'*.

Frances

I would rather leave now—
taking my memories
of the good times—
than stay to watch
our love shrivel
into contempt—

(Witcomb 1983).

Frances was a sixty-eight year old woman who had been married to Harold for forty-four years; they shared three children. Following Harold overseas for most of her life, Frances undertook studies as an artist and supplemented the family income by selling some of her work. The family was close and kept in touch. Two of the children lived in Tasmania and the third child in New South Wales. They were a supportive family, telephoning frequently and visiting when finances and time away from work allowed. Dating back to a period of seven years, all the family noticed the subtle changes in Harold's behaviour. Harold undertook two physical and psychological assessments during this time and finally in 1993, he was diagnosed as suffering from dementia. Keeping the diagnosis a secret from Harold and his friends, Frances did her best to care for him until 1994. As there was little support at home she felt she had no alternative other than to place Harold into a nursing home.

Frances' story

On the day Harold was to be admitted Frances gathered his personal belongings, photographs, *'trunks and the like'*; she wanted to make his room appear 'lived-in'. Her daughter from New South Wales had arrived especially to help her mother; to ease the transition. She was by her mother's side, helping to gather her father's possessions. Harold did not know what was about to happen as the decision to place him into a nursing home had not been discussed with him. They left the house as normal to go to the Day Centre. From there, Frances had made arrangements for Harold to be transported to the nursing home. The nurse at the Day Centre had suggested this strategy and Frances was happy to incorporate the suggestion into her plan. For her, the decision was difficult and anything was

welcomed which made the transition easier. She had broken one of her promises to him.

> *I really realised that he needed full-time care but I didn't want to let him go, you know. Having looked after him for so long, I just felt sorry for him. I just understand what was going on and I knew he would resent it terribly as he once said to me "you will never put me away, will you". And I said, don't put it that way, it's a horrible thing to say, of course I wouldn't.*

Apart from being concerned about the physical aspect of the transition, Frances was worried about how she would cope alone. She and her children had made plans which ensured she would not be left alone in what was to become an empty house. After forty-four years of living with someone, she did not think she would be able to face being alone.

Frances had mixed feelings about the admission, feeling both relieved and grieved by the decision to place Harold into a nursing home. She knew her limitations and realised that she could not physically look after him in their home for any longer, yet the inevitable plagued her, like a nightmare. She wrestled with the relief and the guilt, circumstances dictated which feeling was uppermost at any given time. At times the grief weighed heavily on her shoulders as she contemplated life without Harold. This feeling was partially relieved by her son who moved in when her daughter left to return home to New South Wales. Thinking of Harold in the nursing home was a comfort for her, as she knew he was being well cared for and he had his own bedroom.

> *I have confidence in the nursing home. I mean it was a sense of, you know, when I actually left him. I had a great sense of relief really, combined with the sort of grief you have, grief you feel with the loss. Because I wasn't on my own at home. My daughter was with me, then it wasn't so bad. Then my son came. It would have been much worse if I had come home to an empty house, for that week. I was wondering how I was going to cope. But the fact that he was there (in the nursing home) I think it was an overwhelming sense of relief because I knew he was well cared for . And they (the staff) were so understanding and I could talk to them all. Harold has his own room with everything he needs and he seemed comfortable. I just could not manage any longer at home.*

On the day of admission when Frances arrived at the home with her daughter, they found Harold covered in faeces. She watched not one, but three nurses clean him, quickly and easily, without making any fuss. He was made comfortable; he was in good hands. She had been warmly welcomed into the nursing home and in spite of the unpleasant circumstances that greeted her, she felt at ease; she felt at home. It was not just the environment—for the first time Frances felt comfortable with the decision she had made to place him into the nursing home.

> *They (the nursing staff) took it all in their stride and said "Don't worry about it". A male nurse helped Harold and got him comfortable and unpacked his cases and he was comfortable in no time. Once Harold got into his tracksuit and had a cup of tea, he was comfortable and happy. I think he will be okay. He did not seem to mind.*

Once the unpleasant circumstances of Harold's soiling episode had passed, Frances was able to look around the room. He had his own bedroom and she was happy. The room was freshly painted and had plenty of room for his clothes and his belongings. *'We took a few pictures and photos, anything that made it look like his bedroom, side tables and things like that'.* Although Frances felt at ease with the surroundings of the nursing home and the support of her daughter, she was uncomfortable with the advice espoused by the nurse in charge. He had suggested that she and her daughter leave for a holiday immediately and Frances wondered how anybody could go away.

> *How could I go on a holiday? I would be thinking of him all the time. I needed time to get myself together. What if they (nursing staff) needed me or something? Oh no, I just couldn't go. I just would not feel right. I had to wait and see. We thought we would see how he settles and each day he seemed a little better.*

Although Frances was unhappy with the advice offered by the charge nurse on this occasion, she felt that he was approachable and always willing to listen to her concerns and ready to answer her questions without making her feel uncomfortable. *'I could talk to the charge nurse, he never hurried me. If I wanted to talk he was very understanding'.*

Although Frances continually thought of Harold, it took her sometime to realise that he was not by her side. She would wake from a restless sleep, haunted by the

thought that he needed something in the dark of the night, only to find that she was alone. As she went about her daily chores she thought it was a shame that Harold could no longer share these times with her and she questioned why she had to do everything on her own. She sat quietly at home and remembered how he followed her around the house and Frances was somewhat relieved that the constant stress of being followed had gone and she had a chance to do things normally. It was now a different type of stress which with she had to deal.

> *It is not like a death where you grieve very much and it takes a long time to get over. But this is different, it is sort of a lingering death. It's just awful because you see his personality just disappearing. They are not the same person you knew and it's horrible.*

Frances noticed Harold's physical deterioration. Saliva dribbled down his face; drooling like a helpless child. She wondered whether she noticed more as she did not visit everyday. When he was at home with her, she did not notice all those subtle changes. Frances kept telling herself *'that he could not be in better hands, he's left with the professionals who cope so well'.*

'Is he on some kind of medication?' Frances wondered. She had seen him only once since his admission. She asked herself if it was really him; was it the same man she had fallen in love with all those years ago? Had he really changed so much in what seemed like only a few weeks. His mannerisms were disturbing and unsightly. He was no longer the tall, slender, confident and self assured man with whom she had shared her life. She knew things would never be the same; her life was different. It was as if she had been struck by lightening, the realisation of a new life for herself.

> *The change in Harold upset me terribly because the first day I saw him they had tried him on the new drug, which one of the side effects made him put his head down. His head fell right on to his chest and he was sort of dribbling and I was really upset over it and I went home utterly miserable and then they found that it was no good so they took him off it. It really is hard to imagine coming home to an empty home after all the years together and all the time we had, and for this to happen.*

One day Frances visited to find her husband dressed in odd socks and in someone else's shirt. She was unaffected by Harold being dressed in other's clothes as she

remembered how difficult it was to dress him at home. She appreciated that he was dressed and accepted that the staff were doing their best.

Frances often felt miserable on leaving the nursing home, especially when she was greeted by Harold saying,

> *"You don't love me any more. You have put me in here; you have rejected me" and that made me feel absolutely terrible. I said, well you are here for a time, a certain time just to give me a rest. Respite Harold and to give you a rest. He won't accept that. he doesn't believe me. He said "you are planning". As if I am doing things in an underhand fashion. "You are planning to leave me here" he said, "I am not happy". Now this has been going on for weeks and I go home in tears. I don't let anyone see me like this, but I go home in tears. Drive all the way home, floods of tears and I think what have I done?*

Frances also felt miserable when she would visit and find him pacing around the home.

> *You know he paces. He's like a caged lion, he never stops walking. He grabs me by the hand and we walk. If it's a good day I don't mind walking around because that is good for him but he won't sit down. He won't rest; he's been agitated.*

Frances spoke to the charge nurse about how agitated her husband was. She felt reassured after speaking with the nurse. She found comfort knowing that Harold was not always agitated; that he would mix with the others; enjoy their company and be much happier. Accepting this reassurance Frances took the advice of the charge nurse and did not visit everyday. She began to visit every second day and timed her visits shorter. She felt it upset Harold when she stayed for too long. When the family visited, Harold became very agitated and the charge nurse asked Frances not to visit for three days.

> *The three days when I was told not to come in I felt very miserable. I wondered how he was. I would ring every day. But you know it's better to see them isn't it, than ring really. They will tell you that he is going well, that he is good. I suppose they won't upset you on the phone.*

Frances drew an analogy between a child and a mother and described how she

viewed the situation.

> *He probably does settle down when I am not there. It is much like a child and its mother. As soon as the mother appears if she has been away, the child has been fine while they have been away and as soon as she comes, they are at you, aren't they? Pulling at you, grumbling and telling you all their troubles.*

Frances recalled how on some occasions Harold had greeted her.

> *As soon as he sees me he recognises me and runs towards me and hugs me and kisses me and then he takes me by the hand and we go off walking.*

On these occasions, Frances was relieved that Harold was in the nursing home and drew strength from her decision to place him there. She was comforted when Harold had called his bedroom 'his domain'; she was pleased he thought of the place as his home; Frances too felt comfortable.

> *they let me do whatever I want. I am free to wander wherever I want and they (the staff) are never too busy to talk to you or to put your mind at rest if there is anything worrying you.*

Frances spoke of the central position for the kitchen and how she could smell what was for dinner as it was being cooked. She wondered whether the place could have been any more homely than it was. She liked the way each resident had their own room and that only eight people lived in one unit. Having nearly the same staff all the time impressed Frances as she felt it gave her the opportunity to get to know the staff a bit better and that made such a difference. The nursing home was now the place she wanted Harold to call home.

> *I am gradually getting to know the staff. I seem to see the regulars all the time, well nearly, which is good. The other day Harold said to me "you really should not be in this room.". I was sitting on his bed rubbing his back. I thought this is good, he thinks this is his area. He said "this is my domain". I was pleased to think he felt this was his home.*

When Frances spent most of the visit going for walks, they sometimes sat together on the garden bench. She found visiting difficult and sad as she experienced trying to make conversation with Harold. He failed to make eye contact with her and she questioned his non-responsive approach by asking him

"are you looking at me?". He merely replied "yes" and continued to look in the distance, *'There's not an awful lot to talk about'*. Even the use of family photographs failed to restore enthusiasm into his dull, expressionless eyes. Harold appeared to remain disinterested, yet the photographs systematically reflected the story of their life together. Frances wondered if Harold no longer cared about their relationship. She found it difficult to know what to do for him as he no longer conversed with her. She did not know when he was bored; she hardly knew what interested him. She had brought in the wireless and the exercise bike, but she knew that neither would be effective. Harold no longer knew how to turn on the wireless.

> *I try to jog his memory about things. I often do that or I will get out...I have got an album there full of photographs which my daughter and I got together just before we left. The same week that he went in and we got it all together and we thought now, this will be good for him to go through even if we are not there. But whether he does, I don't know, somehow I doubt it. We have got photographs right from when he was a baby with his parents in Belgium and things that he always used to look at and love. You know, all early pictures and then his university photographs and the things he did at university and they are all very interesting. And if I get them out and I look through them, there is no sort of real enthusiasm. He will say, "Yes yes" and I will say, "who is that?" and sometimes he will say "Oh yes, that is so and so" But there is no real interest. It doesn't sort of jog his memory to that extent. Music, I've got a little wireless in there for him and I don't think he knows how to turn it on. That is the trouble but I noticed the other day it was on. So I said "Are you listening to the music Harold?" and he said "Yes". But there is no real follow-up and interest.*

Once again, Frances asked the charge nurse for reassurance and assistance. She asked the nurse what she could do for him. The charge nurse told Frances that often the residents were bored so the staff gave them small jobs to do. Frances appeared comforted by this news. Frances was also told that Harold participated in a musical morning but she wished there were more activities for the residents. Frances recalled how one day Harold escaped. He had climbed over a fence and no-one had seen him disappear.

> *He must have sensed he wasn't at home and obviously wanted to get out. He didn't tell anyone he was going, he just went. There is very little I can do, very little relief really, unless sometimes if I stay and have a meal with him...but there is very little other than for me to walk around with him.*

There are times when Frances felt she might have been able to manage Harold at home. She spoke with the charge nurse.

> *I feel I could take him home and he said "don't think of that, you might take him home and then tomorrow he will be different again. He might be completely different and you will regret it" When he's out there I feel as if I could have him at home again, but when he's agitated I realise that I can't. That he is a full-time job and my home is not geared to have locked doors and a high fence all around.*

Frances felt worried about taking Harold home for a day. She was concerned about his rebellious nature or or the possibility of him adamantly rejecting being returned to the nursing home. She felt she would be unable to enjoy taking him out for the day. However she did take him home.

> *'We risked bringing him home for lunch. I have to admit I couldn't have risked bringing him home on my own because I was nervous of his reaction, but he was fine.*

Frances fears were unfounded and she was glad of the family support. She understood that it was times like this when the family could make or break an option.

> *He came in and he didn't say, well, this is my house, I am pleased to be home. Nothing like that. It was Just...you could see he was happy to be here and comfortable, it was giving him pleasure.*

However, Frances found it difficult to return Harold to the nursing home. The charge nurse suggested she should not visit for the next few days, saying Harold was suffering from over-stimulation. Frances left the nursing home questioning herself as to whether she had wronged Harold in bringing him home in the first place. She felt punished for her actions; being told not to visit. Her daughter visited from Sydney and had difficulty accepting that Frances did not take Harold out of the nursing home. Frances sought some comfort from the staff that she was

doing the right thing by Harold. She needed reassurance that she was acting in his best interests. Frances still felt that she could not cope alone with her husband visiting her home. One of her friends remarked that she was brave to bring him home. Frances commented,

> *well, it wasn't a question of being brave. I mean I had my daughter with me, we did it together. I wouldn't have managed on my own, I will always have someone with me. My family have got to trust me. They have got to trust that I am going to take him out as often as I can. They sort of feel that I am not going to do that, that I am holding back and he is unhappy. I mean we all agreed that we should try and take him out (when their daughter visited from Sydney) yet he went back to square one and he has been terribly agitated and it has upset me.*

Frances recalled Harold's visit. She described how he knew where everything was, as he went down to the bedroom, he opened the wardrobe, got another hat and put it on. He sat in a chair and said "this is marvellous". The entire family thought they had done the right thing. It was only on Harold's return to the nursing home that he became agitated and Frances felt he had regressed.

Visiting every second day, Frances had time to pursue her own activities.

> *I used to swim every morning but then I had to stop it all together because I couldn't leave him. I used to swim very early but now I am getting up at 6.30 am to go. I have so much painting to do but I haven't been ready for it, until now. The mood just hasn't been there. These are the things that we hold on to and I must start to do again.*

Frances could not find the words which adequately described how she felt when her husband did not recognise her or mistook her for his mother. After forty-four years of marriage she said,

> *I have mixed feelings really. I was sort of happy for him in a way. But I thought, well you know, he is getting this satisfaction because he loved her (his mother) so much, you know he is getting comfort really. So I suppose you know, I had that feeling that it was comforting him and it did not upset me. It makes it easier for me to leave.*

'I have difficulty leaving him when I visit, he won't let me go'. Frances walked with him until he settled. Finding leaving after visiting increasingly difficult, she sometimes asked a nurse to distract Harold in some way while she made a hasty departure. However, after a while this strategy proved to be unsuccessful.

> *He knows now, he suspects, because he knows me so well and he knows when I am going to leave. I tell him I have to go out and do some shopping now.*

Leaving was a dilemma, a constant battle.

> *One day last week a very nice male nurse found the only way we could distract him (Harold) was to suggest that he had a rest after lunch. So he actually gave in, in the end. He removed his shoes and got on the bed and the nurse said "in half an hour I will come back and wake you. Do you promise to rest?" And he said "Yes". I was able to go, it surprised me. It is such a relief when that happens and I go away feeling so much better and thinking well, he's more at peace.*

Frances yearned to talk with the other patients and visitors in the nursing home but found it very difficult as her husband would not let her talk with anyone, yet she wanted to share her experiences. She found it helpful to exchange views and very often she felt the rest of the visitors were experiencing similar things to her.

> *He is quite possessive when I am there, because he won't let me talk to anyone and you know, I want to talk to others too. One lady who visits her husband, well he seems so much more settled than mine. But she said he said, 'you are not going to leave me in here?' He knew where he was. So she is going though a similar thing to me.*

Frances felt the other patients annoyed her husband. *'Some of them hardly smile and they sort of bang each other and I think he gets tired of it'.* The aberrant behaviour of the other residents was distressing for Frances. She constantly compared Harold's progress to the other people and wondered if he had regressed as much as they appeared to have done. Again, she felt uncomfortable and questioned whether Harold was in the correct environment.

Chapter Six

UNDERSTANDINGS AND POSSIBILITIES

My fragile dreams
were built upon
the understandings
in your eyes

(Witcomb 1983).

This chapter explores the researcher's understandings of the lived experience of married women who place their husbands into a nursing home. Understandings and possibilities for nursing practice were revealed through analysis, interpretation and shared insights into, the three women's experiences. According to Barritt, Beekman, Bleeker and Mulderij (1985, p. 70) 'research is alienated from practice'. However, the intent of this phenomenological research is to narrow the gap between the researcher and the researched; to live a research that 'isn't separate from life, but is a special way of regarding life' (Barritt et al. 1985, p. 69). In this research, the life-world of these women is the ground of the phenomenological inquiry.

Carson (1987, p. 78) maintains there is a moral content immanent to the questioning itself and not just 'added on' in the application to practice. Thus, it is a practical type of inquiry; it is not a quest for knowledge for the sake of knowledge. To paraphrase Heidegger, the more important question is not, can we do something with phenomenology? Rather, we should wonder can phenomenology, if we concern ourself with it, do something with us? (van Manen 1990, p. 45). Carson (1987, p. 82) emphasises that in a hermeneutic sense, understanding is not complete unless we see what is understood as applying to us in some concrete way. To understand means that what is understood has a claim on us; we appropriate the meaning to our thoughts and actions in some way.

In this research, three emerging themes: connectedness, living with the tensions and re-discovery of self, have been coalesced to form a thematic statement that embraces the essential meaning of this lived experience for these three women.

The lived experience of married women who place their husbands into a nursing home is expressed through a constant working towards maintaining a meaningful connection with their husband, whilst finding a new way of being as they live out the tensions associated with that placement. Using the three emerging themes as a guide, this chapter attempts to unravel the mysteries of this experience.

Connectedness

Connectedness is revealed in different forms with these women: through their relationship with their husband; their relationships with the staff; their interaction with the nursing home environment, and the need to fashion a 'homely' space for their husband.

These women showed a strong desire to maintain a relationship with their husbands. The essential connectedness of their lives was revealed as they struggled to find new ways of being with their husbands. Bernice spoke of her visits as *'just to be there'*. She was present in the full sense of the word and did not want visiting to be subsumed by 'doing'. Presencing was found in her silence as she sat with Allan, watching his every move. 'Being there' for Allan was about making lucid moments count. Her story told of how, in a mood of anticipation and anxiety, she attempted to communicate with Allan. Bernice attempted to give pleasure to Allan, and realised there would be a time when this interaction would not be possible.

On the other hand, Alice engaged in 'doing' activities when she visited Jack. Alice thought of activities that she and Jack once shared and she brought a game of 'Scrabble' with her when she visited the nursing home. She expressed the paradoxical feelings evoked when Jack was able to communicate with her through the game.

> *It half pleases me, it does and it doesn't. I think, he really is not that bad and how mean I am for leaving him there and this is what happens every time I visit.*

Frances spoke of the difficulties she experienced when attempting to maintain a relationship with her husband. Taking Harold out for drives was unrewarding because of his confusion associated with the dementia. There was no depth of response from him; no sense of sharing the experience. On the occasions when

Harold did respond, Frances spoke of the happiness she felt.

> *The other day I said to him, "I've got a stiff neck Harold". He got up and stood behind me and started massaging my neck and I thought, it is quite amazing really that he's actually thinking of me. Because he used to do that, he used to massage my neck. He could actually think of me. I felt good, pleased about that.*

Each woman, in light of the fluctuations with their husbands' conditions, attempted to remain meaningfully connected to their respective husband. Each woman found unique and creative ways of being with their husband. In the literature, visiting was described in terms of 'things to do'. This recipe approach dismissed the meaning and personal concerns of these women whilst visiting. These stories showed how each woman felt at home with herself through seeing her own possibilities.

The stories revealed how these women struggled as they attempted to maintain their husband's individuality. The importance of clothes surfaced in their experiences as an illustration of this struggle. For these women, clothes gave their husband an embodied sense of identity.

> *Allan had always been very well dressed with jacket and tie and so on. He was tying his tie until the time he went in. He was always dressed well for work. Now, as long as he is warm they (the nurses) just put anything on him. It really does bother me* (Bernice).

> *I found Jack with an old pair of pyjamas on. So I said, "where are your clothes?" and I went hunting around and there weren't any clothes in any of the drawers at all. He was dressed very scruffy. He would never have worn these pyjamas before. It's just not him* (Alice).

These women felt that their husbands were depersonalised when they were dressed in someone else's clothes, or dressed in a different way. Bernice related how she felt Allan's personality was being diminished when he was referred to by an abbreviated name. Bernice interpreted the event as a *'violation of his being'*. In the struggle to keep their husband's identity alive, these women felt it was important for the nurses to know about their husbands' backgrounds.

As these women gradually came to terms with handing over the care to the nursing home staff, their priorities changed. Bernice highlighted this change in attitude, *'I have come to realise what is important and what is not and it doesn't seem to worry him at all what he wears'*. Bernice let go of the compulsion to see Allan cared for in her way.

> *They (the nurses) are doing their best to take care of him and I realise this. As long as he is happy and content, that is the main thing. He had a hair cut the other day and I thought it was too short, but the other visitors seemed to think he looked good.*

For Frances, seeing her husband dressed differently was not distressing, as she reflected on how difficult it was for her to care for Harold at home. She understood what it was like for the nurses to care for Harold.

> *I can remember when he would fall asleep and I would try to get him undressed for bed. It was very hard. He would become agitated, it was nearly impossible. It does not worry me when I see him dressed in someone else's shirt. I know (the nurses) have not got time for everything.*

The women's self-identity began to unfold. They began to show acceptance and not feel so guilty by not indulging in self blame or blaming of others. They began to see new possibilities revealed in each new situation. It was a letting go of their own insecurities as they became attuned to their husbands' needs. It was this sensitivity which allowed the placing aside of preconceived ideas about what they deemed was good for their husband.

> *I thought, how lovely for him to have his own little room, but you know he never wanted to be there, he never stayed in it long enough. Now he is in a four bed dormitory but it doesn't bother him. I think it bothered me more. I sort of sometimes wonder would he have gone down so quick, I mean if I kept him at home I know he would have been happy. But he is safe at the home, I realise that. He is with his own kind. They (the nurses) understand him.* (Bernice).

Feeling 'at home' within the confines of the nursing home was important for these women. The idea of comfort was seen in their attempts to form a home-like space in the nursing home for their husbands. A 'home away from home' was created by furnishing their bedrooms with personal belongings. The husbands'

own possessions helped to make the bedroom at the nursing home feel as 'their own'.

> *We had a day or just a few hours to pack his things and we wanted to take a few things to make his room look lived-in, you know, and we took a few of his pictures and photos and trunks, anything that made it look like his bedroom, side table and things like that. I did not want it to look like an institution* (Frances).

The creation of this area allowed the women to make their husbands' presence known. *'I wanted to have pictures and photographs and put them all up in his room'* (Bernice).

In describing space, Heidegger (1964, p. 334) shows that space is something that stays among the personal things, 'even when we relate ourselves to those things that are not in our immediate reach, we are staying with the things themselves' The possessions from home and the space of the family home are united and hence help to create a sense of home. In the things themselves, there is the space of home. Heidegger (1962) refers to home as a place where one can be oneself. The visitors room provided this space.

> *...it is a pretty room and restful and I did enjoy that, and we both sat on the sofa together and she (the nurse) brought us a cup of tea and cake* (Alice).

In order to feel a sense of belonging in the nursing home space, these women searched for how they could dwell intentionally. Until they began to dwell as a wife, the nursing home continued to feel foreign. Alice remembered how she felt about the *'wasted space'* in the nursing home and how different that was from their family home. When she was approached by one of the staff to play the piano in the nursing home, she felt she was bringing part of her home and herself to the place, thus a new sense of belonging materialised. It took time for the nursing home to be called home and as they became familiar with the nursing home environment, they felt comfortable dwelling as a woman still married to their husbands who were placed in the nursing home.

Being involved in decision making within the nursing home gave these women some sense of belonging. Decisions that may appear routine to nurses, such as relocating their husband to another room and the use of restraints were significant

to Bernice.

> *He had a room on his own. There was a room, one single room. When he went in I thought that was lovely for him to be on his own, to be in there. Then my friend rang up to find out what was happening. They (the nurses) said he would get up in the night and walk around. He used to get out of bed and move into the four bed one. So where he is now they can keep an eye on him. Obviously it was more difficult where he was before.*

The invitation to stay and have a meal with their husband signified that these women had become part of the social fabric of the nursing home. The simple fact of the nurses asking Bernice how she was feeling, made her feel cared for and a part of the nursing home environment. This inclusion created a sense of belonging and developed a sense of community spirit.

> *They (the nurses) ask me how I am. I think they really do care for the partners. Ant time I want to chat or ask something, if something is bothering me, they told me to just ring up.*

These women sought the advice of the nurses about when to visit, how frequently to visit and the possibility of taking their husbands home for the day. The women relied on the advice of the nursing and medical staff as to what was the most appropriate thing to do. In the story about Alice, she was told it would not be a good idea to take Jack home; her concerns were dismissed.

> *He has been taken away from everything that he knew; where he fostered his own little area and now he has to tow the line a bit. It isn't nice you know. It's a bad way to end up.*

The possibility of taking Jack home was not considered, thus alienation and disillusionment were two possibilities Alice faced when the nurses intruded.

When nurses fail to listen to the needs of married women who place their husbands into a nursing home, nurses deny these women the opportunity to move forward towards their authentic being. These women expressed a need to be enabled to cope. To become and to fulfil their unique way of being in the world required the nurse to be present for them. When nurses were present for these women, they were interpreted as truly caring.

> *I felt Harold had gone back to square one after visiting and taking him home. I felt very bad when my daughter went back to Sydney because Harold became terribly agitated and it upset me again. I spoke to ...(the charge nurse)... about all this. You know he (the charge nurse) is only too pleased to talk about things and he doesn't rush you and he understands. He said it might have happened anyway.*

In the literature, communication was referred to as a skill. However, these stories showed how listening and remaining silent truly made room for the other. Heidegger (1962) says that the silence 'rings'.

Inviting the woman to participate in decision making allowed her to recognise hope and possibilities in the experience. *'Allan is not shut in for life. I can bring him home'* (Bernice). Thus, nurses encouraged the women to respond to the situation in their own unique way. Often nurses helping relationships can be characterised by domination as they impose their views. Nurses may unintentionally deny these women authenticity by acting in a domineering manner, denying freedom and a sense of responsibility. This patriarchal stance happened when the nurse acted in a routine way and treated these women as an appendage.

> *The three days I was told not to come in I felt miserable. I wondered how he was. I would ring everyday, but you know it's better to see them isn't it than ringing really? They will tell you that he is going well, that he is good. I suppose they won't upset you on the phone* (Frances).

A sense of community could be developed where there was a sense of belonging. The possibility was created for the nursing home and the women to work together in a way that did not deny the authenticity of the other.

> *One of the nurses said how they give Harold jobs to do and he really enjoys this. I thought may be Harold is bored, so I rang up and asked (the charge nurse) could I bring his exercise bike, he said that would be a good idea. So I think that is something I can do. I think it will help.*

When our relationships with others are one of dominance, we deprive the other of freedom. There is no sense of authentic community or authentic 'selfhood' when

possibilities are taken away. This phenomenological study has provided a way of disclosing the authenticity of the experience of married women who admit their husbands to a nursing home. Authenticity of being a wife was revealed as they responded to the possibilities that the nursing home situation created.

Living out the tensions

Living out the tensions associated with placing their husbands into a nursing home was revealed by the womens' descriptions of the admission day; questioning their decision of placement, and coming to terms with changes in their husbands' condition.

These women spoke about their feelings of ambivalence and self doubt on the day their husbands were admitted to the nursing home. The ambivalence was expressed in terms of wanting to care for their husbands but realising they could no longer care for them at home. Alice's experience of the day her husband was admitted to the nursing home was a reflection of her self doubt and uncertainty as to whether she had made the right decision.

> *I felt, have I been too quick off the mark? Have I kicked him out, sort of thing? Have I done all that I could have done? I think that is what all the guilt is about. I just sat in the office and cried. The nurse said I want you to be absolutely sure before you pay your first visit to him. He (the nurse) said don't hurry, just leave it and I said, well how long, three or four days? And he said, no a week, a fortnight, don't come, just let it slide, so I did.*

The nurse advised her to come back when she was sure. In our technological understanding of humanity, being in control and being certain are seen as essential attributes. To be unsure is a sign of weakness. The notion of having to be certain places unrealistic expectations on people. It demonstrates the prevalence of the domination of science inherent in nursing practice today.

Although each of these women anticipated placement of their respective husbands into a nursing home, the actual day was experienced with an overwhelming sense of uncertainty and ambivalence.

> *I had that feeling that I should have been able to look after him more, knowing perfectly well that I couldn't. The other part of me knew that he would respond to the home* (Bernice).

> *I had these mixed feelings. My heart went thump, like that. I didn't know what I thought, it was a bit hard to say. Relief in one way but then against that there was a terrible feeling of having...it's like letting someone down* (Alice).

All three women spoke of the importance of having someone with them on the day of admission. Bernice articulated the burden of the decision, *'I wanted them to say it was the only sensible thing and then I had just to agree'.*

What are the lived concerns of married women as they seek to place their husbands into a nursing home? They hoped their husbands were happy in their new found home and hoped they realised that their wives had done all they could in caring for them prior to admission. Living out these tensions revealed itself in the women's self questioning of right or wrong. When Alice witnessed a nurse speak to her husband in a rather derogative manner, she felt he should not be in a nursing home and reconsidered her decision resulting in feelings of guilt. Similarly, when Alice found Jack in a state of disarray, looking uncared for, she was convinced that she had made a mistake placing him in a nursing home.

> *I found him curled up on his bed. He had someone else's trousers on. He just lay there and seemed quite out of sorts. It was a very traumatic thing to see him in that state which I haven't seen before. It upset me so badly and I kept thinking, gee I have done the wrong thing here.*

When Bernice talked about the 'humanness' of the patients and the staff at the nursing home, she felt happy and content. It was not only what nurses did but how they attended to the husband which was important for these women. Frances described how friendly the staff were and how they attended to Harold on the day of his admission to the nursing home. *'They took it all in their stride'.* This comforting recollection was based on the nurses presence, directed towards Harold. Frances then felt as if she was doing the right thing. Bernice recapitulated how she was comforted by the nurses constant observation of Allan. She felt the nurses were taking notice of Allan; he was being cared for.

> *They look up the records and say exactly what has happened on the last shift...they keep records the whole time, you see them sitting there making notes, which I find very reassuring.*

When these women witnessed some deterioration in their husbands condition, they wondered if this worsening of their husband's condition would have happened if they were still being cared for at home. Again, the tensions resurfaced and whilst they knew they did all they possibly could for their husband at home, some self doubt remained. Many aspects of their husband's care were recognised as having either a positive or negative emotional impact on these women. When Alice found Jack looking withdrawn and dressed in someone else's clothes, she wondered whether she had made the right decision placing him in a nursing home. On the other hand, the day Alice visited and found Jack well cared for she commented, *'he was so clean and nice and dapper'*. Alice described this visit as a *'good visit'*.

These women left the nursing home community to return to the family home alone. The family home was full of reminders of their respective lives together. When the women were happy with the care their husband was receiving and pleased with the substance of the visit, they left the nursing home with comforting recollections of the visit. If they perceived their husbands to be uncared for in the nursing home, they re-visited their decision to place their respective husband into the nursing home. When these women thought their husbands were uncared for or were unhappy, there was a feeling of helplessness and that they had breached the trust of the relationship, or their marriage. This was the 'price' of Being-for-the-other. Alice talked about how Allan would constantly tell her he did not want to go into a nursing home. Alice contended, *'I wasn't going to be beaten, I wasn't going to walk away from that responsibility. No way, I kept going'*. Frances talked about never considering the idea of placing Harold into a nursing home until the very end.

> *I knew that he would resent it terribly. Once he said to me, "you will never put me away, will you?" and I said don't put it like that, it's a horrible thing to say, of course I wouldn't.*

A part of living out the tensions associated with placement was highlighted when Alice said, *'he (Jack) is, but he isn't himself'*. This apparent paradox was met with ambivalence as she stated, *'it pleases me, then it doesn't'*. The perceived

normality of Jack's behaviour brought about intense emotions of guilt in Alice. For Bernice, there was some comfort in finding Allan like she knew him. However, this comfort was coupled with feelings of sorrow. *'I just think it must be frustrating for him'.*

Every day, these women saw and touched their own uncertainties. These women expressed concern as to whether their visiting was beneficial for their husbands. They feared the visits may have reminded their respective husbands of home. At the same time, the women expressed a desire to be present for their husband.

> *I want to go more than I have been, It is very hard. I haven't been going a lot, partly because I think it upsets him. I reasoned it out that when he sees me he immediately thinks of home, so it is really better if I don't go* (Alice).

> *I wonder whether I upset him coming too often. I asked the nurse and she said, it makes no difference really. He settles when you go. I want to see him, he knows I'm there. It is up to me when I go and visit. I get a little annoyed when people tell me I am going too often. I go when I want to* (Bernice).

The desire not to upset their husband was voiced by all the participants. This desire was illustrated by how each woman found a way of leaving the nursing home after each visit.

In the handing over of the care of their husbands to the staff of the nursing home, uncertainties in the lived experience of these married women was discussed. Questions such as will he like it here? or, how do the staff know he is in pain? were overtly expressed. As the care was handed over, these women were somewhat comforted by the perception that *'they (the staff) are experts, they know what is best'.* These women looked to the nurses for guidance and support. When the women were asked to make decisions on behalf of their husbands, they needed the necessary support and information to make these decisions. Bernice vividly recalled the confusion she experienced when requested to give consent to the use of restraints for Allan.

> *I had to go in and sign some forms. It sounds dreadful I thought, what has happened, as if he was sort of terribly agitated and struggling, but it is not that. I quickly rang my son and asked him what it meant. He told me it was just a formality and they (the nurses) had to get permission.*

These women lived the tension of wanting to do what was right for themselves and what was expected from their families. Frances expressed the pressure that she felt from the family to visit more regularly and take her husband home, *'they have to realise I am doing all I can'.*

These women witnessed the gradual deterioration of their husbands' condition. This realisation was accompanied by intense emotional distress. Frances felt it would be only on the event of Harold's death that she could live life fully by depreciating the past.

> *It is not like a death where you grieve don't you...very much., and it takes a long time to get over. But this is different, it is a sort of lingering death. It is awful because you see his personality just disappearing. You know they are not the same person you knew and it's horrible. The first day when I saw him, they had tried him on the new drug, which one of the side effects made him put his head down. His head fell right on to his chest and he was sort of dribbling and I was really upset over it and I went home utterly miserable.*

The women made visible, in daily events, the fact that behind the tensions and insecurities were challenges and rewards, hope and possibilities. Alice found the possibility of spending time with other patients, *'I saw others that were busting to talk'.* Frances found that taking the risk and bringing Jack home revealed many rewards, *'it was just...you see...he was happy to be here (at home) and comfortable, it was giving him pleasure'.* As Bernice disclosed her lived realities, she disclosed her own insecurities, *'perhaps I could have gone on (caring for her husband at home) for a bit longer'.* She attempted to return to some former harmony with herself and her situation by realising her potential, *'I will just do what I can'.*

The literature offered solutions to the problems faced by families, the emphasis being on how to cope. In the main, the literature concurs that one either copes or

does not. These stories told of uncertainties as these women lived out the tensions. The gradual coming to an understanding of the human condition was their way of coping.

Re-discovery of self

After visiting their husbands in the nursing home, these women returned to an empty house. There was no husband to welcome them into this space. There was no-one with whom to share their day, yet each husbands' presence seemed pervasive. Personal belongings were scattered throughout the house; clothes in the bedroom; shoes at the back door; photographs on the wall; all reminders of a life spent together. Bernice described how her husband's presence lurked in her thoughts.

> *Sometimes I get asked to attend this and that.*
> *May be a concert and I think, I won't bother.*
> *But then I think, I must go as Allan would*
> *have wanted me to go.*

The incompleteness in the lives experienced by these women, was filled by an ever present understanding of what has been lost. Bernice recalled how the presence of Allan in a nursing home has constricted many possibilities from reaching fruition for example, she no longer contemplated holidays away from Allan.

Whilst the literature acknowledges loss, it dismisses the ongoing and challenging nature of loss. The stories revealed how loss was experienced in terms of prevailing presence. The hedge in Alice's garden was now a reminder of Allan. The past was not something to be packaged away but remained as marking memories of what was revered.

These women appeared to be able to dwell in the recollection of memories. The memories of being with their husband allowed these women to connect with them to create a feeling of presence. In these memories there was a discovery of self. They discovered themselves in light of what they were. Bernice related how she supported her husband as he made all the decisions in their family. Placement into a nursing home called forth a new way of being, *'I make the decisions now'*. Now Bernice must make decisions on behalf of Allan, decisions about his care.

Frances' everyday taken-for-granted way of being was shattered. However, she felt the presence of Harold. Her habitual body took over.

> *It took me about two weeks to settle down and realise that I wasn't going to be woken up at night, it was funny, I found myself waking up and pacing the floor. Wide awake and he wasn't there and you know, I would be thinking of him.*

These women discovered their ability to talk with and help others in similar situations. Bernice met other wives who had placed their husband into the nursing home. Talking amongst themselves, sharing their experiences and their individual stories, built a sense of community. Bernice felt understood; she was not judged; she could talk with ease; she felt no sense of guilt in their company. They all shared a solidarity, a belongingness where their inner feelings were free to surface.

> *Talking to others and the difficulties and experiences they have, helps me sort of sort things out for myself. I talk about what I do when I visit, it is interesting to know what they do. Sometimes when you visit he (Allan) goes off and does his own thing and does not even say goodbye. You kind of exchange and laugh about things, to the nurses too. They sometimes will have time to sit down and talk to you* (Bernice).

Also, Bernice was able to offer advice to family and friends about what to do when they visited Allan. Sharing these feelings could transform expressions of insecurities to signs of hope towards new meanings and new relationships.

> *I talk to a lot of my friends about Allan. It helps me to know they go and visit him, because I know that helps him, he likes seeing people. When I visit, sometimes he says, Hello, cheerfully and he goes a bit confused after a few sentences. but it doesn't matter. It gives him a bit of...it keeps him somehow a person.*

There was an awareness of the significance of the women's relationship with their husband and significant others. There was the discovery of the closeness of the family. Each woman sought the support of family members and felt comforted.

> *The family were actually more keen for him to go there than I am. In fact I backslide a bit. I sometimes say I could have him back. Oh no, no, no way they say. In fact I think that it was really through them that I stuck to my guns* (Alice).

> *My son said I think it is the best thing he (Allan) goes into a home, you can't manage any longer* (Bernice).

> *My son said, what happens if he becomes agitated at home? You just will not be able to cope . You cannot go on any longer* (Frances).

These women rediscovered themselves as they found a new way of being in the world. Current literature addresses this existence as a 'quasi widow' experience, consisting of phases. The stories revealed the possibilities and tensions of these changes rather than attempting to categorise the experience into discrete stages.

Placement also offered these women an opportunity to reconstitute a sense of self. Alice looked forward to *'getting her health back'*. Frances anticipated having time for her ceramics. Finding a project for these women gave a sense of continuity to life and a sense of purpose. Having a purpose gave direction to an otherwise futureless existence.

> *A lot of purpose was suddenly taken away. It is the hardest (thing) I think which anyone could feel. I always thought that because he comes from a very long lived family that I would go first. I need to stay alive to look after him and now I just hang on to him because he like seeing me still* (Bernice).

> *What I am doing now is sort of pulling up the threads together again of my past life which I had just put aside for about five years* (Alice).

This new life-journey, as it took many directions, was one of self transformation. The experience of placing their husband into a nursing home offered the promise of self-discovery for each of these women. Discovery of their limitations and their capabilities. Each woman had re-discovered a sense of self through their ability to adapt and embrace the challenges which laid ahead.

In order to reveal the possibilities that placement brings, nurses need to value differences whilst recognising the communal nature of admitting one's spouse into a nursing home. By careful listening, nurses can reach a deeper understanding of the struggles inherent in the experience. These understandings can provide a starting point from which all related nursing practice within the context of admitting one's spouse to a nursing home can be considered. Research is meaningful for nurses themselves as a reflective practice. As we think about different ways of handling situations, alternatives are revealed. We become aware that we have the power to choose our actions. This study is not a final authority rather, it is suggestive in composition; evocative, rather than conclusive. This research and that which follows can lay the foundation on which other studies can let the voices of married women who place their husbands into a nursing home be heard.

Chapter Seven

PERSONAL REFLECTIONS ON THE STUDY

It was a dark grey
desolate day,
a day for lonely hotel rooms
and cold eyed strangers
and funerals—
then you walked into my life
and filled my aching emptiness
with warmth and love—
you did not stay long,
but rainbows never do—
I only know
the glow of our friendship
has lit my world—
thank you—

(Witcomb 1989).

This chapter draws upon my journal writings as I experienced this research. Doing phenomenology is hard work. I strived to achieve a harmony between the research approach and the question at hand. As this study lead me from a place of certainty to uncertainty, I experienced the ambiguity and tensions in our lived-world. Phenomenology called me away from the categories towards a place of openness. Hermeneutics, once sounding so unfamiliar, has opened new doors to self-understanding. The hermeneutic reflections of the text moved fluid-like, to and fro, as the women and I attempted to make sense of the experience. This process helped us remain close to the phenomena.

The stories dwelled in me as I read and re-read the text of the conversations, trying to re-capture the essence of the experience. van Manen (1990, p. 44) aptly describes this experience,

> ...one must meet with it, go through it, encounter it, suffer it, consume it and as well be consumed by it.

I used conversation as a way to enter the lived-world of these women. As I entered into conversation with each woman I hoped to develop a relationship characterised by trust and respect. Through relating openly we were able to explore meanings. The stories of these women linger in me. My questioning of their Being continues as I reflect on shared moments during the conversations. As I lived in the text of the conversations, I was reminded by van Manen (1990, p. 16),

> ...that the lived experience is always more complex than the result of any singular description, and that there is always an element of the ineffable to life.

A phenomenological study is an edifying experience. As a nurse, I will return to the profession with courage to question current nursing practices. The prescriptive tones of the words 'should' and 'must' I will now use with caution. My experience as a nurse has allowed the emergence of the understandings within this research. The understandings were revealed as I lived the project. I acknowledge that as the narrator of the stories, I am also part of the text itself. It is their-my story.

A phenomenological study is a transforming experience. I entered this experience having worked in a nursing home for two years. Now, as I return to nursing, I will be more deeply aware of what this experience means. Recently, a colleague told of how she had placed her mother in a nursing home. She spoke at length of how understanding the staff were towards her. I pondered on what made it possible for her to feel cared for and understood.

During the conversation with these women, I struggled to remain close to the lived experience and asked "Can you tell me how you felt?". I blushed as I heard a stern voice state, "Of course, I felt dreadful". My concern dwelled in the nature of my questions.

I started this journey with apprehension, wondering how these women would relate to me being a much younger person. My concerns were unjustified as these women freely talked about their experiences. Indeed, they talked at some length about their lives with their husbands prior to admission to a nursing home. I felt this verbalising was important to them as these reflections allowed them to come to the realisation of what they were now experiencing.

A friendship developed between myself and these women. Bernice expressed our closeness by giving me a book written by her husband. The other two women offered friendship by sharing afternoon teas during the conversations and afterwards by sharing the pleasure of their gardens with me.

I met with these women in separate debriefing sessions where we talked about what the research experience was like for them. The following comments are the voices of these women.

> *I really looked forward to the next visit, to talk about how I felt. I really feel you have become a friend. It has been good...*(Bernice).

> *I feel like someone is interested in what I say. I haven't really talked to anyone about it before. I feel you understand* (Frances).

> *At first I wondered how it could help, but I realise nurses need to know what it is like. It was good for me, it made me make sense of things I really had not thought about before* (Alice).

This study has provided me with a place to pause and reflect on my practice; my work has dwelled in my life. I no longer understand research as something academics do, but as an expression of a continual quest for meaning. By 'doing' phenomenology I have gained inner freedom and desire to continue on a path that leads to greater understanding of myself and others. This is a journey that will never end.

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APPENDIX

PLAIN LANGUAGE STATEMENT FOR PARTICIPANTS

The lived experience of married women who place their husbands into a nursing home
Investigator: Trudy Hills RN

The purpose of this study is to increase nurses' understanding of the experience of married women who place their husbands into a nursing home. Information will be gathered in the media of audio-tape.

The stories you tell me will be tape recorded and we will discuss your feelings about your experience of placing your husband into a nursing home. These tapes will not be shared with anyone else and when I have transcribed them I will give you a copy for your own interest and validation.

The topic of each story has the potential to be very sensitive and may arouse unpleasant feelings. Should the situation arise that you become distressed during our sessions together, I will undertake to cease recording and give you the option of withdrawing from the research. Additionally, you are also free to withdraw your consent and terminate participation in this research at any time.

Any questions concerning the research can be directed to Trudy Hills of 4 Stoke Street, New Town, Tasmania; Tel: (002) 287656.

I (the participant) have read the information above and have been given the opportunity to ask whatever questions I desire and all such questions have been answered to my satisfaction. I agree to participate as a volunteer in the above named research, realising I may withdraw at any time. I agree that research data collected for the study may be published, provided no real names are used.

_____ _____
Participant Date

_____ _____
Researcher Date