

# **AS A NURSE IN THE FAMILY:**

**Three women's stories of what it means for a female nurse to be  
a caregiver to a family member who is ill,  
elderly or with an enduring illness**

**by**

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## **ABSTRACT**

In this research three female registered nurses relived their experiences of being caregiver to a family member who was ill, elderly or with an enduring illness and explored whether they chose, or felt obligated, to assume the role of caregiver because they were nurses.

This research was an exploratory descriptive study utilising narrative as inquiry and the method of story-telling. It is women-centered, taking into account the unpaid role of caregiving within families most often fulfilled by women, due to habitual gender bias. The stories of the participants Marie, Polly and Frances (pseudonyms) were audiotaped, transcribed and analysed using core story creation and emplotment.

At the end of each story emerging themes were identified and compared for similarities and uniqueness, then simplified through the use of diagrams. Four main themes were identified and renamed to highlight research findings – these were the culture of nursing, silence of the nurses, emotional cloudiness, and the natural role of the nurse.

Through this study it is hoped that nurses will be more aware of the impact their caregiving roles have had on their lives. The importance in acknowledging the effects of caregiving, relevance of informing employers to promote supportiveness, implications for workforce development and recognising the loss of objectivity in caring when emotions are involved, are identified in this research. Further indepth research about these concepts would be a valuable contribution to the nursing profession and ideas for future research have been identified.

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# **Chapter One**

## **Introduction to the research project**

The focus of this research study is to explore how nurses perceive what their role in their family is when a family member is ill, elderly or has an enduring illness and requires care. Caring for family members is an everyday role performed by many people, however, this study will focus on family members who require more than domestic care. The idea that nurses experience significant expectation by family members who are ill and infirm originates from my personal experience. Supporting this are the anecdotal conversations with registered nurse colleagues, which highlight a possible 'burden of caring' for the registered nurse in his/her own family.

A literature search related to this phenomenon yielded limited results. Research has demonstrated that the caring role within families is more likely to be fulfilled by women (Angus, 1994; Chinn, 1991; Covinsky, Eng, Lui Li Yung, Sands, Seghal & Walter et al, 2001; Davies, 1995; Finch & Groves, 1983; Glass & Davis, 1998; Hoffman & Mitchell, 1998; Robinson, 1998; Teutscher, 2003; Twigg & Atkin, 1994; Ward, 1993). Taking into account that the nursing workforce is predominantly female and that the caregiving role is more likely to be fulfilled by women this study was limited to female registered nurse participants, to help explore the impact of familial caregiving on the nurse.

Using narrative as inquiry, and incorporating a women-centered qualitative research approach, the experience of nurses involved in caring for their own family members

who are ill, elderly or with an enduring illness was explored. During the course of the research project, I also examined whether the nurse chose to take on this role, felt obligated to, or acquired it by virtue of being 'the nurse in the family'.

## **Background to the study**

Nursing is often referred to as the 'caring profession' (Leininger, 1984; Watson, 1979, 1985). What interests me in relation to this caring is the realisation that for many nurses this is a role or responsibility they carry long after the end of a shift, often providing nursing care to a family member who is ill, elderly or with an enduring illness after finishing their nursing work for the day. Through conversations with nurse colleagues I have become aware of how many nurses are committed to caring for family members who are ill, elderly or with an enduring illness; a role they have either chosen to do, felt obligated to do, or have acquired by virtue of being 'the nurse within the family'.

My interest in 'what it means for a nurse to be a caregiver to a family member and how nurses perceive what their families consider are the roles and responsibilities of the nurse family member in regards to elderly or ill relatives' stems from my own experiences in helping care for a chronically ill sibling for the last twenty-two years. This interest is further inspired by the realisation that many of my colleagues are in similar situations, though their circumstances may be different. Several colleagues recounted their experiences of looking after family members who were ill, dying or with an enduring illness and how the role of being the nurse prevented them from 'grieving' or being involved in 'care delivery' in the same way as other family members.



## **My family caring role**

The idea of questioning the role of the registered nurse's caring for a family member originates from personal experience. In the 1980s as a second year student nurse, my understanding of what it meant to be a nurse at, and outside of work, came to the fore. During this time my then twelve-year-old brother was diagnosed with a malignant brain tumour with a prognosis of three years life expectancy. Following surgery and a three-month course of radiotherapy my brother returned to the family home, pale, thin and with a permanent bald patch and scar at the back of the left side of his head. What resulted from this 'cruel tumour' and subsequent surgery was profuse thought blocking and severe epilepsy with the difficulties and dangers associated with constant seizures. Throughout the ups and downs over the next few years my 'wisdom'<sup>1</sup> was called upon to make decisions about treatment; when doctors should be contacted; what ointments should be applied; which symptoms were medication related and which could be hiding something more sinister and undiagnosed lurking beneath.

Throughout these years one particular conversation I had with my brother stayed with me. He had reached the grand age of twenty-two (well outside his life expectancy) and was very ill physically. The possibility he might die soon had become a reality. During his illness my brother had not asked for much, though he had lost his opportunities for a normal life such as attending school, playing sport and enjoying being with his friends. His determination and independence shone through in that he chose not to acknowledge that he had cancer and refused to have any further investigations or hospital based treatments after the initial surgery and radiotherapy. As he lay at home in a poor

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<sup>1</sup> As perceived by the family, although I considered myself at this stage novice in almost all aspects of nursing.

physical state he asked me if I would promise to care for him at home and not let him die in hospital, which was his greatest fear. My affirmative response was not hesitant, for I was a nurse. And it was what nurses did – caring for people. For me the implications of how I would cope with caring for someone I loved so dearly, how I would deal with all the family personalities, strengths and weaknesses, and manage to make rational, sensible decisions that were right, were pushed to the back of my mind. I would do anything for my brother, especially if I could help decrease his suffering. I was honoured that he felt comfortable in asking me to provide his nursing care if needed. I sensed a feeling of silent relief within the family. Someone was going to take charge, someone who ‘knew’ what to do when decisions had to be made, someone who would provide direction. In many ways this was a turning point in my ‘coming of age’ as a nurse.

### **Being a ‘real’ nurse**

As the years passed I began to realise what it truly was to be a ‘nurse’. Queries about minor coughs and colds, ‘knowing’ what to do if someone had a temperature; expectations that I would know every medication and its side effects off by heart were all part of how family members perceived what nurses did and knew about health issues. Now, as an experienced nurse of twenty odd years and belonging to the so-called ‘sandwich generation’ (Anderson, 1999; Morrissey, 1997; Spillman & Pezzin, 2000) between aging parents and dependent children, I have a growing awareness of my responsibilities both within the home and the work environment. As part of an aging workforce which statistics show has a mean age of forty-three point nine years (Ministry of Health, 2004), the realisation that many of my nursing colleagues are in, or have experienced, similar situations has been highlighted. From conversations with

colleagues it became apparent that many nurses feel that it is an expectation by other family members that they will take 'charge' and provide or organise the 'caregiving' that is required within one's family. This role is often taken on without much thought or resistance, a role that is recognised as the responsibility of the nurse within the family. This, in turn, has inspired me to 'hear' nurses' stories of their lived experience in caring for a family member, whether it be through a period of illness, nursing a dying relative, or caring for a family member with an enduring illness such as epilepsy, schizophrenia, multiple sclerosis or brain injury.

In hindsight when I reflect back on my experiences over the last 23 years of being both a nurse in the workforce and a nurse caregiver for my brother many previously unacknowledged dilemmas and experiences are brought to mind. Firstly, that from the beginning of my nursing career I was more than willing to perform or take control of organising the caregiving for my brother, a decision on reflection that seemed naturally to be mine and one that holds no regrets. However, within the roles and responsibilities of the nurse family caregiver there have been times over the intervening years when the stresses and pressures have seemed overwhelming and the desire to have someone else 'take over' or be responsible for the organising, advocating, liaising and ensuring everything is 'okay' has been desirable. While reflecting on these times a sense of gratitude prevails towards my younger sister and a need to acknowledge the many hours of caregiving and organising she has provided over the years, contacting me, informing and updating as required and seeking intervention when feeling out of her depth in assisting with caregiving for my brother, which in turn has decreased the burden of care I have often felt. It has also prevented me from feeling alone in the caregiving role.

Over the years the impact of my caregiving role on my own family, how they perceive this role and the resulting consequences on our family life have on many occasions been brought to the fore. The art of ensuring everyone's needs are met and the need to prioritise what and whose needs are most important is ongoing. For me, this can be best portrayed by a situation four years ago when my youngest child turned five and started school. Several weeks later my brother was badly burnt while having a seizure, resulting in hospitalisation, the need for a skin graft (at a city hospital away from where we lived) and assistance in performing most activities of daily living, not to mention psychological support and assistance in pain management. Working fulltime nursing, studying, running a busy household and travelling most days to assist with caregiving, as well as travelling out of town with my brother when he had his skin grafts meant that I could only provide limited support for my youngest son during his first months at school. As seems the norm at times, the family survived and the routine of family life gradually returned to normal, but for me the feeling that I had not been there as I would have liked to have been for my youngest child at an important time of his life will always remain – the choice I made.

Throughout the process of completing this research and through the re-telling of the three participants' stories many more memories have been brought to the fore and new insights or perspectives highlighted. Resulting from this is a new awareness of the true impact of the caregiving role for the nurse in the family involved in providing care for a family member who is ill, elderly or with an enduring illness.

## **Situating the research**

For this study I used a narrative, women-centered approach with the aim of enabling nurses to tell the stories of their lived experiences. Narrative or story is the chosen form of inquiry because for many nurses it is a part of their everyday working life, whether during shift handover, in clinical discussions with other professionals, educating clients and family or part of establishing a therapeutic relationship with clients (McEldowney, 2003). In the words of Sandelowski (1991, p.164) “narrative forms reveal individual’s construction of past and future life events at given moments in times”. Ricoeur (1986, 1991) describes stories as being particularly suited as the “linguistic form in which human experience as lived can be expressed” (as cited in Polkinghorne 1995, p.7).

This study is women-centered in that it is based on the notion that the majority of caregiving is done by females and, as the nursing profession is predominantly female is appropriate. I have chosen to use a woman-centered approach rather than exploring in depth issues of feminism within this research project, although I have included a brief definition of the underlying values and assumptions associated with feminism as an acknowledgement of the principles relevant when considering the roles of nursing and caring for family members that women perform. Glass and Davis (1998, as cited in Harker, 2000, p.38) state that “the underlying values and assumptions associated with feminism include the reciprocity involved in the relationship between nurse and patient, the ethic of care, and the importance of the experiences of women’s social and personal worlds”. Both feminism and nursing value the subjective experience. Subjective experiences can be recorded and shared through story-telling. Through this process it was hoped participants would reflect and evaluate why it is they have taken on certain

roles and responsibilities within their families and what effect such roles and responsibilities have had on them. I posed the question, is the role taken on through choice, obligation or by virtue of being a nurse, part of the 'caring profession'? It is envisioned that through the process of hearing these stories insights into what it means for a female nurse to be a caregiver to a family member who is ill, elderly or living with an enduring illness will be explored and examined.

### **Aims of the study**

The overall aim of this study is to explore the role of the female nurse in the family when a family member becomes ill, is elderly or is living with an enduring illness and requires care. In addressing this question several sub-aims will also be explored. These are 1) to examine whether the family nursing role is taken on by choice, through a sense of obligation or acquired because of family expectations (perceived or real) and 2) to explore how caring for family members who are ill, elderly or with an enduring illness impacts on nurses, their health, their work and in turn on workforce development.

This research also raises issues in relation to the burden of care on female nurses. It will make a contribution to the literature on nurses as caregivers to family members outside the work environment. Research findings may assist in workforce planning, taking into account that the average age of female nurses, not only in New Zealand, but also in other parts of the world is 43.5 years (Gottlieb, Kelloway, & Martin-Matthews 1996). This equates to the same age group who are more than likely to be providing care for family members (Convinsky, et al, 2000; Gottlieb, et al 1996).

## **Overview of research study**

This thesis consists of seven chapters. The first chapter has outlined the reasons for the study, the research question, the personal significance to the researcher, justification for undertaking the study and aims of the research.

Chapter Two will outline the literature search centered in four sections. The first section will look at the concept of caring and nursing. As this research is women-centered the second section identifies issues in relation to women as caregivers and nurses. This will be explored in regards to being a women and societies' and families' expectations of the female role. Section three will discuss the concepts of burden, obligation and choice incorporating the effects of belonging to the 'sandwich generation'. Section four will explore literature in regards to family caregiving.

In Chapter Three the chosen methodology of narrative as inquiry will be detailed. This will include examining narrative as a form of qualitative research, story-telling as a research method and story-telling in nursing. This chapter will conclude with a discussion on reflexivity, congruence and rigour in narrative inquiry when doing qualitative research.

Chapter Four will detail the research process. My position as a nurse researcher and caregiver within the research will be discussed. Issues in regards to ethics, confidentiality and identifiability, selection and recruitment of research participants and the right to withdraw from research will be examined. The process of recording the

women's stories, data collection and analysis using core story creation (Emden, 1998b) and the identification of themes using emplotment (Emden, 1998b) will be detailed.

I have chosen to title Chapter Five *Experiences Re-membered and Re-told*. This chapter will be presented in three sections – one for each participant's story. Marie's story – 'Who cares for the caregivers?'; Polly's story – 'It's about caring for one's own' and Frances's story – 'Knowing you've done your best'. Themes from each participant's story are identified and then explored more fully in Chapter Six.

Chapter Six explores and discusses in depth themes identified as common to all three participants' stories. Themes have been clustered and re-named. These are: nursing and family culture; the silence of the nurses; emotional cloudiness and the 'natural role of the nurse'. A section in relation to multiple caregiving roles has been incorporated due to the fact that nurses not only perform multiple caregiving roles at work but also at home.

The final chapter will provide a conclusion of study findings, the implications for further research, an evaluation of the study's initial aims and it will evaluate whether the study has achieved these aims.



## **Chapter Two**

### **Review of the literature on women and nurses as caregivers**

In this chapter a review of the literature on the chosen topic of female nurses caregiving for family members who are ill, elderly or with an enduring illness will be detailed. Using the electronic database CINAHL (Cumulative Index to Nursing and Allied Health Literature) several literature searches were conducted. It became obvious at the beginning of the literature search that there was an abundance of information available about nursing and caregiving. The keywords of 'nursing', 'family' and 'caregiving' were used to locate articles about nurses providing care to family members who may be ill, elderly or with an enduring illness. As already identified in Chapter One a literature search of data in relation to nurses as caregivers for family members yielded limited results.

Searching for information about the role of the nurse in caring for a family member who may be ill, elderly, or with an enduring illness revealed limited results. Articles on 'women in the workplace' (Covinsky et al, 2001; Tetuscher, 2003; Ward, 1993), 'caregiver characteristics' (Covinsky et al, 2001) and what is defined as the 'sandwich generation' (Anderson, 1999; Mintz & Weinberg, 2002; Morissey, 1997; Spillman & Pezzin, 2000), described some aspects of caring for a family member, but not the dual role of being a nurse and caring for a family member.

To assist in locating research completed in New Zealand examining the role and experiences of female nurses caregiving for family members who are ill, elderly or with

an enduring illness, a search of New Zealand Nursing Journal Index 'Kai Taki' (1999 – 2003) was completed. A recent article written by Teutscher (2003) focused on the dual roles of being both a nurse and a caregiver for a parent. It was the only relevant article located.

A search of previously completed research work from the Graduate School of Nursing and Midwifery at Victoria University of Wellington located two studies of interest. Collins' (2000) study examined 'The experience of living with a family member who has a mental illness'. This study included topics such as the burden of caregiving for families, and the effects on children and support networks, but not the specific role of the registered nurse caregiving for a family member who may be ill, elderly or with an enduring illness. Kersey (1999) researched the role of nurses as partners in care with careguardians and issues that arose when the responsibilities of providing care and the balance of power shifted between nurses, family members and caregivers in rest homes or institutions, but once again, not the dual role of providing nursing care outside of work.

An interesting article located in CINAHL was Robinson's (1998) study of the effects on women when chronic illness is present in the family. This provided some insights, particularly with regard to the roles women take on and the consequences of burden of care, issues which will be discussed in more depth later in this chapter. Information related to the sandwich generation defined as "... people being squeezed between the demands of their children and the responsibility they feel to assist their aging parents" (Anderson, 1999, p. 18), had been researched to some extent. Aspects of research

findings in relation to people's experiences in this group may be relevant to similar situations in which nurses find themselves. As noted by Morrissey (1977, p. 1), "This care is still something families expect to do and want to do, but it requires sacrifices of time, money, energy and peace of mind".

The review of literature did, however, identify several main themes or concepts that will be explored more fully in this chapter. These include: expectations of women's roles (Angus, 1994; Boland & Sims, 1996; Bowers, 1987; Davies, 1995; Marshall, Barnett, Baruch & Pleck, 1990; Ward, 1993); obligation or desire to care (Angus, 1994; Morrissey, 1997; Twigg & Atkin, 1994) and family functioning when illness is present or caregiving is required (Boland & Sims, 1996; Bowers, 1987; Robinson, 1998; Ross, Rideout & Carson, 1994; Tetuscher, 2003; Yea-Ing Lotus, 2000). To assist in reviewing the literature related to the research question 'What does it mean for a female nurse to be a caregiver to a family member who is ill, elderly or with an enduring illness?' these key themes are presented as four sections. The first section explores the literature related to the notion of caring and nursing. The second section will look at women as caregivers and nurses. The third section will discuss burden, obligation and choice. The final section will look at nurses as family caregivers. The themes may overlap and intertwine at times.

Issues about the financial costs of women's caregiving work through reduction of hours of employment and declining of promotions and pay equity in relation to gender, have all been identified in previous research (Angus, 1994; Briggs & Oliver, 1985; Covinsky et al, 2001; Gottlieb, 1996; Jeon & Madjar, 1998; Robinson, 1998). These issues will

not be discussed in detail in this study. This is an area that requires more in-depth research. The impact of caregiving work performed by nurses for family members and the subsequent impact on workforce development within the profession will be discussed in relation to the research participants' stories, but once again, this is an area that needs to be researched in greater depth than is possible in this study.

### **Caring and nursing**

Over the years much literature has been published about caring in nursing by nurse theorists (Benner 1984, Gadow, 1980a; Leininger, 1984; Watson, 1985). The writings of non-nurse theorist Noddings (1984) along with nurse theorists are outlined briefly in this section to help define what caring is. When studying different philosophies on caring, the teachings and philosophies identified by Benner and Watson underpin the teachings and theoretical frameworks of many nurses today. When examining the notion of what caring means in relation to nursing, the relevance of their teachings in influencing my own nursing education and philosophies was brought to mind. As there is a wealth of literature available on caring I decided to focus on those nursing theorists who were familiar to me and whose teachings I could relate to (Benner, 1984; Watson, 1985). I have also incorporated definitions from non-nurse theorist Noddings, whose work has been centered on the concept of caring, and who I feel describes the concept in a way that resonates with my own understandings (Noddings, 1984). It is not the aim of this study to debate or discuss the vast array of caring literature in depth, but, for the purpose of acknowledging caring as part of nursing and in the context of caring for a family member, the fundamental principles will be briefly discussed.

Although Noddings (1984) is not a nurse her description of the concept of caring as being based in receptivity and that “the one caring ‘feels with’ the other and ‘receives the other’ completely” (p. 30) resonated well with my own concept of what caring is and so is included in this defining process. Watson defines caring as “the ‘vanguard’ of nursing and considers that “caring involves the will to care, the intent to care, and caring actions. These actions can be positive regard, support, communication, or physical interventions of the nurse” (1985, p. 84). The notion of what constitutes caring as described by Watson is the basis for how I define care in relation to the aims of this study, that is to explore the role of the female nurse in the family when a family member becomes ill, is elderly or is with an enduring illness and requires care, whether this be in the form of ‘positive regard, support, communication or physical interventions’ of the nurse family member. Although Watson talks about the will and intent to care I would debate that those often in the caregiving role of caring for family members acquire it and do not choose it for themselves. Issues around the will and intent to care are addressed in this research in relation to burden, choice or obligation to care and how research participants felt they acquired their caregiving roles and is the first subsidiary aim of this study to explore if a family nursing role is acquired by choice, obligation, or through perceived or real expectations of the family.

Gadow (nurse theorist) defines caring as “... the essence of nursing [it] is the nurse’s participation with the patient in determining the unique meaning which the experience of health, illness, suffering, or dying is to have for that individual” (as cited in Chinn, 1991 p.3). Taking Gadow’s idea of ‘unique meaning’ into account may be significant when attempting to answer the question of whether nurses feel obligated to care for

family members who are ill, dying or have an enduring illness and how the care provided for family members may be different from care provided at work. Within these definitions it becomes apparent that caring consists of more than providing physical care. It incorporates an holistic approach that in turn influences how the experience will be, not only for the caregiver, but the care-receiver as well. This in turn highlights some of the difficulties that may arise such as ethical dilemmas, the effect on family relationships and loss of objectivity when providing care to a family member with whom emotional connectedness is present before the caregiving/nursing relationship begins. Taking these concepts into consideration the second subsidiary aim of this research study will center around understanding how the family nursing role may impact on participants' ongoing relationships with family, their health, and their commitment to work and the implications of this for workforce development.

It is interesting to note Baumgart and Larsen (1992), define nursing in relation to caring as having "its roots in a maternal ethic of care that emphasises service, dedication, and self-sacrifice – attributes that comprise the traditional attributes of women" (cited in Ross, et al 1994, p.44). More importantly, Ross et al, state in relation to this "... consequently, the provision of care assumes a heightened importance in the lives of nurses who are mandated to care both within the context of their families and their professions" (p.45). This identified 'heightened importance of care' is relevant when looking at issues in relation to nurses' caring for family members and expectations of those within the family (and possibly the profession) that it is their duty as nurses to care for their own ill family members.

“Caring, as Leininger describes it, includes two major groups of components, (1) the activities and processes necessary to assist and support a person and (2) the accompanying attributes or emotions such as empathy and compassion” (Leininger, as cited in Chinn, 1991, p.170). These are components that one would argue are essential in nursing practice. Yet as noted by Vezeau and Schroder “both Leininger (1977) and Watson (1979) assert that caring is nursing’s essence and yet one might ask how it is that caring is what defines the profession” (1991, p.111). This is also supported by Gadow’s (1980a, as cited in Chinn, 1991) reference to caring being the essence of nursing. These all encompassing definitions of what theorists constitute as caring, appear to incorporate all the attributes of what nursing can be defined as, and so it is fitting to assert that caring is really nursing’s essence while acknowledging the importance of other roles nurses perform such as teacher, educator, technician, counsellor and so on, nurses provide care – its what ‘we’ do.

In contrast, non-nurse carers Twigg and Atkin (1994), in their study of ‘Carer’s perceived policy and practice in informal care’ defined care as “... involving a feeling of being responsible for the cared-for-person” (p. 9) and in cases where the “the cared for person has no need for physical help, the sense of ‘being responsible ’is the primary element in caregiving and, we would argue, represents the core feature that underlines all care-giving” (p.9). Identifying responsibility as a core feature of all caregiving in turn helps one question whether it is this sense of responsibility that is the basis of caregiving for nurses within their own family, or is the need to care because it is the essence of what nursing is, as highlighted previously. Does this sense of responsibility

obligate the nurse to the caring role? This topic will be explored more fully in the section on burden, obligation or choice.

Findings from the National Health Committee set up in New Zealand in 1998 identified that carer work was most often unrecognised and unpaid and that family members or others who live close to the person requiring care took responsibility for taking the role on. These findings can be supported by Briggs and Oliver's (1985) study which identified that the emotional and psychological effect on the carer from caregiving situations and varying levels of dependency had a flow on effect for those providing care. It is interesting to note the study also identified that the financial implication of caregiving was not the most important thing for those providing care.

Within all these definitions of caring, understanding what it is and how we come to care can best be summed up by Benner, Wrubel and Lazarus; "Caring cannot be controlled or coerced, it can only be understood and facilitated. Caring is embedded in personal and cultural meanings and commitments" (1981, p. 171). Is it this caring that we 'do' as nurses that places us at the forefront of caring for family members? As noted by Farran and Keane-Hagerty (1991), it is usually a family member who takes on the role of caregiver. If caring is not coerced, one must ask what is it women, and women who are nurses, may do without choice, when one's family member requires care because they are ill, elderly or with an enduring illness? In this research project through the re-telling of participants' personal experiences these questions will be addressed. With this in mind the next section will examine the role of women as nurses and caregivers and the role of the female nurse within the family when a member requires caregiving at home.



## **Women as nurses and caregivers**

“Gilligan (1982), notes that women’s identity is defined in a context of relationship and judged by a standard of responsibility and caring” (cited in Ross et al, 1994, p.44). The review of literature related to women and caring showed that women are the “overwhelming majority of unpaid caregivers of the chronically ill” (Ward, 1993, p.4). Davies identified that caring “is done almost exclusively by women...” (1995, p.17), as did Hoffman and Mitchell (1998). Covinsky et al, found that “daughters of patients were more likely to reduce work hours than sons” (2001, p.712). Teutscher’s (2003) study supports this finding. Finch and Groves (1983), noted “It would be women who would carry out, unpaid, the work of caring for those who were unable to care for themselves at home”. Throughout this literature it becomes evident that the role of caregiving within families for those who may be ill, elderly or with enduring illness is a responsibility predominantly filled by the women within the family.

Yet caring for one’s own family member may present difficulties. Benner and Wrubel (1989) note in relation to family caring that “the health care worker may not be able to perform as well for a family member as for a stranger. Memory is disrupted, and thinking processes can be chaotic due to fear and distress” (p. 173). Teutscher (2003), identifies “... this duality of roles [as caregiver and family member] may compromise care” (p. 14).

Much research in relation to women and the effects of caregiving on the caregiver’s health has been published (Benner & Wrubel, 1989; Davies, 1995; Marchi-Jones,

Murphy & Rosseau, 1996; Robinson, 1998; Ross, et al, 1994) with the resulting effects of burnout, stress and isolation having been explored in depth. Robinson (1998), a nurse who works with families experiencing difficulties with chronic illness's conducted a grounded theory study which examined 'What happens to and for women when a chronic illness enters the family'. References to Robinson's findings have been incorporated throughout the research project. In Robinson's (1998) study it is evident that women take on the major caregiving responsibilities, as well as the role of keeping family life intact, usually to the detriment of their own health, often leading to overwhelming illness burden with the resulting impact of precarious life balance. It is interesting to note that although the women in Robinson's study identified the burden of the caregiving they did, it was "a key family belief acknowledged by these women that women are the caregivers, the protectors" (Robinson, 1998, p. 278). Robinson also found, after working alongside some of the families, that although they developed more of an understanding of the burden of illness care "... the woman remained the pivotal person around whom the family organised it's life, and thus, her overall sense of being responsible was not diminished" (1998, p. 285).

Although, as identified in Robinson's study, the responsibility for caregiving is mainly taken on by women within the family, it is important to acknowledge the findings of Angus's (1994) study which focussed on the analysis that much of women's work remains invisible and undervalued and that paid activity in the public sphere is seen as work, whereas activities pursued in the private sphere of the home are overlooked and the responsibility involved in caring at home is not work. In relation to balancing working and caring Angus (1994) found that often the benefits obtained from working

with other women "... served to bolster and sustain them" (p. 30). Angus also noted "the satisfaction of successfully providing support to others is a powerful intrinsic reward for women" (Wharton, 1993; White, 1993; Wilson, 1991; cited in Angus, 1994, p. 30). With nursing identified as a female dominant profession, these findings not only have relevance for women who mainly work alongside other women, but also highlights that they are working in an occupation in which demands are placed on them for attention and nurturance, which is often the case in the home environment. One would question if in turn, does this 'powerful intrinsic reward' then promote strength of spirit to assist women in the caregiving they perform outside of the work environment, no matter how many demands are continually placed on them?

Gottlieb et al (1996) found in their study of predictors of work-family conflict, stress and job satisfaction among nurses that "in sum, it would appear that relations at work are on the whole more stressful than supportive, in part because nurses are so heavily taxed by their job responsibilities that they have little opportunity to support each other" (p.102). Factors such as current work environment, type of nursing and supportiveness of employers (Gottlieb, et al, 1996), also play a role in perceived support. In contrast, Ross, et al (1994), found in their study of nurses' work and home lives the respondents had a sense of working in isolation on the job, and expressed much more satisfaction with the support they received from their spouses and children than with the support of peers and supervisors. However, these findings do not take into account whether the 'nurse in the family' is actually performing the role of caregiving for a family member who is ill, elderly or with an enduring illness. Gottlieb et al (1996), identified the more nurses "... perceived their co-workers as supportive and the more they viewed their

employer as responsive to their family demands, the more satisfied they were with their jobs” (p.111). In my own experience I would argue that often it may be the nurses themselves who are to blame for the perceived lack of support as work colleagues, and no doubt some employers, are often not aware of the caregiving role performed by many nurses outside of their work situation. On reflection it was not until I began discussing my research topic with work colleagues that I became aware of how many nurses were or had provided nursing care to a family member who was ill, elderly or with an enduring illness. One would question is this because nurses feel it is their duty and that there is an expectation to fulfil this role, that it is often something they keep to themselves?

Neal (1990) notes that few studies have examined any aspect of the relationship between types of occupations and the ability to balance work and family responsibilities. He also notes that “in light of the preponderance of women in the nursing profession in North America, and the substantial amount of occupational stress they experience, it is surprising that so little attention has been paid to the nature and antecedents of the conflict between their work role and their family role” (cited in Gottlieb et al, 1996, p. 101). Ross et al, (1994), examined the relations between nurses’ work lives and home lives, concentrating on the tensions and conflicts that arise from their dual caregiving role, though not necessarily for ill family members. As previously identified Teutscher (2003) is one of the few nurses who has written about her experiences and the difficulties associated with providing care for a family member who is elderly.

In summary, literature (Angus, 1994; Covinsky, 2001; Davies, 1995; Gilligan, 1982; Robinson, 1998; Teutscher, 2003; Ward, 1993) has demonstrated that it is predominantly women within the family who take on the caregiving role and as previously noted in Gilligan's findings a women's identity is defined by the context of relationship and in turn judged by a standard of responsibility and caring (1982). This caregiving can in turn produce its own anxieties and difficulties due to emotional ties. The type of nursing work performed and whether nurses chose to share their personal lives with colleagues all played a role in the perceived support of colleagues and employers. This brings to the fore the question of whether nurses feel that there is an expectation that the caring work they choose as an occupation must also be their role within their family when someone is ill, elderly or with an enduring illness and requires care. Do they have an obligation to care or is it by choice and if they do provide caregiving for family members do nurses identify with the burden of care that may result? These issues will be explored in the next section.

### **Burden, obligation or choice?**

One of the aims of this study was to explore whether nurses who are family members choose to become caregivers or acquire the role and responsibility by virtue of their chosen profession. The formal or informal burden in relation to caregiving, has been researched in depth (Gottlieb, 1996; Mintz & Weinberg, 2002; Robinson, 1998; Teutscher, 2003; Yea-Ing Shu, 2000).

Yea-ing Shu (2000) found that literature related to patterns of caregiving when family caregivers face competing needs "demonstrated that coping behaviours of caregivers are

potential mediators of caregiver burden and stress” and “that competing demands of paid work and caregiving led to poor work outcomes and increased caregiver burden” (2000, p. 41). If this is so we must consider if the learned coping behaviours or responses of nurses (often working in crisis) are what enables them to fulfil the caregiving role over a long period of time without question or acknowledgment of the stress it places them under. The assumption that nurses who take on a caregiving role for ill, elderly, or family members with an enduring illness, will in turn be affected in their caregiving in their work role, can be supported by Mintz and Weinberg’s (2002) findings. They identified “the stress of caregiving can have an impact on literally every part of your life, and can impact not only on your ability to be a good caregiver, but your ability to be a good worker” (p.7). With these findings, the importance of nurses acknowledging the role they perform outside of work and informing their employers of the extra stress they may face, highlights the value of these actions.

The expectation that women will take on care, no matter what, is evident from the literature researched (Covinsky et al, 2001; Teutscher, 2003; Twigg & Atkin, 1994; Ward, 1993). Ward (1993) spoke of an habitual gender bias that women will provide care because it is the natural thing to do and suggested “... we have the socially constructed model that places caregiving in the center of women’s concerns” ...[and]... “despite evidence that supports a range of choices about caregiving, the assumption that women will provide care (and that they need not exercise choice) is the bedrock of chronic care” (p. 8). Although women more often than not provide this care, a review of the literature has illustrated that it is most often without choice (Angus, 1994; Robinson,

1998; Twigg & Atkin, 1994; Ward, 1993). I would concur with Twigg and Atkin (1994, p. 10), who explain this obligation as:

Caring is embedded in relationships of obligation such as marriage, parenthood, kinship in which people feel responsible for spouses, children or parents, and obliged to give care. These are not voluntary relationships, and these feelings of obligation have consequences for their lives.

Ward (1993) spoke of the notion that care at home was often called family care, which in turn implies all members shared the role equally, but the reality is that women overwhelmingly did and still do the majority of caregiving work and even when it is shared with males women did more for longer. Literature (Chinn, 1991; Covinsky et al, 2000; Robinson, 1998; Twigg & Atkin, 1994; Ward, 1993; Ward & Carney, 1992) has demonstrated that emotional entrapment and societies' experiences have pressurised women into accepting the role of caregiving for ill, elderly or family members with an enduring illness. Ward's (1993) study concluded that for many women it was difficult for them not to take on the caregiving role without being accused of familial treason and there is an expectation and a powerful public assumption that women want to take care of family members who may be ill, elderly or with an enduring illness which in turn denies them the exercise of choice. As summarised by Angus "women are bound to unpaid work by emotional and ideological obligation" (1994, p. 34). Chinn (1991, p. 228) noted:

ironically, when it comes to caregiving, persons often perceive that they do not have a choice as to whether or not they will become caregivers. In reality,

choosing the caregiving role is influenced by both societal conditioning (especially for women) and by unconscious psychodynamic forces.

This brings to the fore questions about how it is for the female nurse who works in a 'caring' profession? Through this research project issues about whether nurses felt that they had a choice in the caregiving role; whether they felt their families assumed it was the natural responsibility of the nurse family member and whether they felt obligated to provide care because they were a nurse or because they were a female in the family were all explored. As stated previously, one of the few articles located in regards to nurses caring for family members outside of work was Tetuscher's (2003) article about caregiving for an elderly parent. As discussed in the last section, one would assume this is a role frequently taken on, but not researched in any depth, possibly due to lack of acknowledgment by nurses themselves of the role they often perform in caring for family members beyond nursing work.

McBride (1998) examined, to some extent, how dimensions of nurses' lives at work spill over into their lives at home and vice versa, but Teutscher's (2003), account of being a nurse and caring for a parent is one of a few articles that provides some insight into difficulties associated with this role. Teutscher identified that it is a role that "... may be willingly (or grudgingly) given" (2003, p.14) and that it is "... usually a daughter who is in the position of being a nurse caring for her parent" (p. 14). Of particular interest is that Teutscher (2003, p.14) identifies that

a) "... duality of roles may compromise care"; b) "Objectivity in nursing may be lost when a daughter's emotions intrude on the caring relationship"; c) "Having



professional knowledge and practising as a nurse may interfere with the normal relationships and spontaneity with the family”; and d) “... parent- nursing work is often demanding and may negatively alter the shared life experience of patient, carer and wider family”

Teutscher’s experience can be best summed up in her words: “There is no doubt the motivation to care for a parent by a nurse/daughter is a noble one” (2003, p.14). Yet as already identified, often it seems one does not have a choice, particularly if one is female and a nurse. Thus insight has been provided into some of the difficulties and expectations of the nurse-carer that differentiate them from those who are not nurses and the performing of caregiving roles for family members.

As demonstrated through the literature identifying issues related to burden, obligation or choice there is an expectation that women will fulfill the caregiving role when required, more often than not without choice. If women choose not to take this role on, pressure from families and society may force them to unwillingly concede. Although not researched in depth issues in relation to effects of caregiving on work roles has been noted. In this study the research participants’ stories will compare how they have found the caregiving experience in relation to being a nurse and caregiver for a family member who was ill, elderly or with an enduring illness, and whether issues as identified by Teutscher (2003) are similar. Comparison of identified issues will be explored with research findings in Chapter Six. Although it appears limited research has been done on the caregiving role nurses may perform for family members outside of work, research into the effects on family relationships when the caregiving role is taken on has been explored to some extent and will be discussed more fully in the next section.

## **Family Caregivers**

As noted previously, with the exception of Tetuscher's (2003) article on being a nurse caring for a family member, literature in relation to nurses caring for family members who are ill, elderly or with an enduring illness appear to be limited. However, in this section articles identifying patterns and consistent outcomes noted from those involved in the family caregiving experience are identified and explored.

Maturana (1992) defined family "... as a social system drawn forth in the emotional domain of love. It is a group of persons constituted under the passion for living together who have a network of relations and conversations" (cited in Robinson, 1998, p. 274). In response to Maturana's definition of family I would argue that family members do not need to be living together to be considered as 'family'. In my experience the caregiving role taken on by nurses for family members who are ill, elderly or with an enduring illness is often fulfilled from some distance creating other difficulties and stresses that require even more time, energy and money from the caregiver.

Overwhelmingly, literature has demonstrated that women place family caregiving ahead of their own needs, often to the detriment of their own health, resulting in poor physical and mental wellbeing (Angus, 1994; Browning & Schwirian, 1994; Robinson, 1998; Vezeau & Schroeder, 1991). However, it is interesting to note that literature in relation to the resulting impact of family caregiving has also demonstrated that patterns evolve within family caregiving that show women are frequently reluctant to relinquish the caregiving role they have taken on (Boland & Sims, 1996; Brubaker, 1983; Ward, 1993). Boland and Sims (1996) found that "as caregivers become proficient in

performing tasks of care, they become less willing to share this care with others” (p. 58). Robinson argues that “... women [have] been pushing their own experiences with illness into the background as one way of protecting family members from the influence of chronic illness” (1998, p. 284). Ward, (1993) spoke of women internalising society’s pressure so deeply they resisted help. She supports this with an example common to nursing where nurses speak of the difficulties they experience trying to “... convince weary wives and daughters to get some relief from caregiving that those wives and daughters cannot allow an alternative, even when it’s shown to work well” (Ward, 1993, p.6). Through the research participants’ stories it is hoped to explore the notion that when nurses themselves are providing the caregiving to family members who may be ill, elderly or suffering from an enduring illness, whether or not they feel the same pressures to protect family members. Are they more willing to share the burden with this knowledge of reluctance to let go of the caregiving role when it has been part of everyday life or when it comes to personal caregiving do nurses acknowledge these identified outcomes of chronic caregiving?

Robinson’s examination of family dynamics in caregiving for chronically ill members highlights that “... ordinary arrangements of family life are characterised by inequity that consistently disadvantages women” (1998, p. 257). This can be supported by Drover and Keran’s findings that “the contemporary family is still largely constituted by a gender division which defines certain kinds of work as domestic, female and unpaid, while other kinds of work as public, male and paid” (1993, p. 18). With the advent of more women in paid employment attitudes to gender division and roles may be slowly

changing, although literature suggests caregiving will always be regarded as 'women's work'.

Robinson (1998) also notes that when family caregiving reaches crisis point, to the extent that it affects the woman's ability to provide care, it is not other family members, but the woman herself who seeks help for herself and the family. Vezeau and Schroder (1991) spoke of interpersonal family conflicts that often arose from excessive demands from caregiving which in turn created stress and exhaustion for the caregiver. In acknowledging the role of the nursing family member and their experience, family members in turn shift the balance of power from being partners in the caregiving role, which then changes the family dynamics, sometimes resulting in bitterness and resentment. This is supported by Briggs and Oliver who identified, in experiences of looking after disabled relatives, that when family members left the caring work to one main member this lead to "...enormous bitterness and resentment" (1985, p. 114).

Teutscher's (2003) account of caring for a parent discusses some of the ethical dilemmas for the nurse / daughter in relation to other family members. These include the passing on of information that may breach the patient/parent rights and the need for nurses to be aware of how their emotional responses in the decision making process can affect the care given. Teutscher did identify that "it may be necessary to establish with the parent and family that the daughter's nursing knowledge and experience give weight to her care observations and affect the decision-making" (2003, p. 15). This may result in both positive and negative outcomes for the nurse caregiver and in family relationships.

In summary, literature related to family caregiving has demonstrated that this is a responsibility more likely to be left to the female in the family. Resentment and bitterness may result from this responsibility, along with poor physical health and mental wellbeing for the women. Yet when the family reaches crisis point it is often left to the female caregiver to seek help. Also highlighted is the fact that a caregiver's immersion in their role, may result in a reluctance to relinquish that role even when their own and the family member's health may be affected and alternatives for caregiving are available. Tetuscher (2003) identifies some of the ethical issues in regards to decision making that may create problems for the nurse caregiver in relation to care provided and family decisions.

## **Conclusion**

This chapter explored the concepts of how caring can be defined in relation to nursing and what that caring entails. It identified that caregiving requires the caregiver to be involved in all aspects of the care-receiver's life. It is holism to the truest extent, it cannot be controlled or coerced. However, this raises issues in relation to women and whether women who are nurses have a choice in taking on the caregiving role. As noted in the section titled 'Women as caregivers and nurses' women comprise the majority of unpaid caregivers, a role often dictated by habitual gender bias. As identified by Ross et al, findings that "the provision of care assumes a heightened importance in the lives of nurses who are mandated to care both within the context of their families and their profession" (1994, p. 45) and thus demonstrates how for those who are female and a nurse it is a two-fold expectation to provide care - a natural obligation to care.

Differing views on supportiveness from employers and work colleagues have been discussed, with literature identifying the type of nursing the caregiver is employed in playing an important role. A lack of research in relation to nurses caregiving for family members who are ill, elderly or those suffering with an enduring illness would suggest it is a part of their lives that nurses choose often not to discuss. This is supported by my own findings from anecdotal conversations with colleagues.

There is no doubt, as suggested by literature in relation to burden, obligation and choice, that caregiving, whether it is performed through choice or obligation is stressful, with long-term effects on health, work performance, family relationships and dynamics. As previously discussed, findings in relation to the reluctance of female caregivers to relinquish this role when help and support were organised is significant. The idea that women feel the need to protect other family members from burden or stress provides justification for this thinking and behaviour, often without regard to the detrimental effect on their own health and well being.

Through this literature review salient points or identified emerging recurrent findings have been briefly explored. However it is evident that literature in relation to nurses caregiving for family members and the impact of same on those nurses and family dynamics is limited. Through this study researching 'What it means for a nurse to be a caregiver for a family member who is ill, elderly or suffering from an enduring illness?' it is hoped that its findings will contribute to this paucity of information currently available. Leading on from this the next chapter explores the methodological underpinnings of the research project and the method used to complete the research.

# **Chapter Three**

## **Narrative as inquiry**

### **Introduction**

This chapter will examine the methodological underpinnings of the research study. The chosen methodology of narrative inquiry will be discussed, with the method used being explored. Story-telling and the use of story-telling within the nursing profession will be detailed, I will discuss how it has been used in this research project to re-tell the three female participants stories of their caregiving experiences for a family member who was ill, elderly or with an enduring illness. As noted by Berg (1989) qualitative research attempts to capture people's meanings, definitions and descriptions of events. This study will be women centered, acknowledging the underlying principles of feminism, that is, valuing the subjective experience and incorporating the issues of reciprocity in relationships, the ethic of care, and the importance of the experiences of women's social and personal worlds (Glass & Davies, 1998). Although issues in relation to feminism will not be explored in depth reflexivity is considered a central tenet of a feminist methodology and in addressing requirements of qualitative research will be explored along with congruence and rigour in this chapter.

McEldowney (2003) ascertained that a range of methodologies such as autobiography, biography, life history, oral history and life story all fall within the range of methodologies classed as narrative inquiry. Stanley (1993a) defined biography as "writing the life of another" and autobiography as "writing the life of one's self" (p. 41). Minichello, Aron, Timewell and Alexander (1991) defined case history as having "as its central goal, the eliciting of the fullest possible story for it's own sake" and case

study as trying “to utilise personal documents, oral or written, for a theoretical purpose” (p. 156). In this research project biography or life history through the art of story-telling was the method selected. In McEldowney’s study of nursing teaching and life experiences she identified that “life story narrative inquiry enabled a depth and richness to emerge in the interpretation...” (2003, p. 5) of the data. One of the key elements of life story narrative inquiry as identified by McEldowney is that it sits within the interpretive paradigm, that is, through the research process of interpreting and reinterpreting of material by the researcher this then gives data meaning. She defines the “...whole interpretive process [as] one of the key features of life story” (2003, p.8).

Sandelowski (1991) states “A narrative framework affords nursing scholars a special access to the human experience of time, order, and change and it obligates us to listen to the human impulse to tell tales” (p. 165). Over the years much debate has taken place in relation to whether narrative or storytelling can truly be classed as a scientific research method (Benner, 1984; Lather, 1991; Reed, 1995). Indeed, it is only in the last decade that nurses themselves have begun to recognise its importance in relation to nursing practice and defining nursing as a science (Benner, 1984; Reed, 1995). Polkinghorne (1995) defines narrative inquiry as referring:

... to a subset of qualitative research designs in which stories are used to describe human action. The term narrative has been employed by qualitative researchers with a variety of meanings. In the context of narrative inquiry, narrative refers to a discourse form in which events and happenings are configured into a temporal unity by means of a plot (p. 165).



The use of plots in analysing research data will be explored more fully in the next chapter.

Narrative has been defined in simpler terms as storytelling. However, Riessman (1993) differentiates between the two defining “‘narrative’ is an encompassing term of rhetoric whereas ‘story’ is a limited genre” (p. 41). Yet I would argue they both achieve the same purpose, that is, to record events and experiences to enable others to share in that event or experience. Clandinin and Connelly’s description that “... people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them and write narratives of experience” (1994, p. 416) helps to define and clarify the process as used in this research project. In this research study the stories of three female nurse caregivers are described and recorded as narratives so their lived experiences can be shared with others who may be or have been in the same or a similar situation. Through this process I wish to capture the essence and meaning of their unique experience. It is hoped this in turn will help contribute to the lack of knowledge in relation to nurses’ caregiving within their own families and it’s potential impact on participants ongoing relationships with family, their health, their commitment to work and the implications of this for workforce development. Within this research project aspects of my own story may be incorporated at times. Therefore it is important to explore further how the researcher situates themselves within the research.

## **Situating oneself within the research**

The self/researcher is inevitably in the text, and as noted by Ribbens and Edwards, “we have often chosen to research topics to which we have a particular personal attachment, based upon our individual experience and knowledge” (1998, p.5). The idea for this research project arose through my experiences as a nurse caring for a sibling with an enduring illness. McEldowney (2003) in her interview about life story and narrative inquiry in nursing and midwifery identified that “we come to our research with key interests in mind and some experiences that help locate us alongside our participants” (p.8). Being involved in the process with the research participant relates well to the partnership concept nurses use, working alongside and with clients in their everyday practice. Clandinin and Connelly (1994) emphasize the importance of recognising one’s own voice in an inquiry where the aim is to capture the participant’s voice and experience. Stanley (1993a) acknowledges that reflexivity is a central tenet of a feminist methodology. The principle, as described by Stanley, can be applied to the women-centered approach used in this research. That the researcher locates herself in the process and in turn the subjectivity of the researcher becomes part of the research process. Stanley’s findings are supported by Tierney (1997) who believe that researchers are now able to resituate themselves within the texts and have the freedom to reconstruct their relationships with research participants. This recognition is particularly important when using ‘human experience’ methods such as narrative inquiry (McDrury & Alterio, 2002; McEldowney 2002, 2003; Sandelowski, 1993). In the last few decades with the beginning awareness, acceptance and acknowledgment of qualitative methods such as narrative inquiry, comes the recognition of nursing as an art

and a science, which can be portrayed so beautifully in the form of story-telling – an area explored more fully in the following section.

### **Story-telling and story-telling in nursing**

“Story-telling is a feature of many non-interview, normal conversations” (Minichiello et al, 1991, p. 117). It is part of everyday life and the way we communicate. Stories may consist of biographies, autobiographies, case studies and histories about life events (Polkinghorne, 1995) and it is one of the first discourses we learn as children (Riessman, 1993). People tell stories in different ways, but essentially the function of story-telling is to pass on our knowledge and information or to describe an experience. It is a way to order and organise one’s experience (Riessman, 1995). Clandinin & Connelly (1994) suggest that people live stories and by telling stories people then have the opportunity to reaffirm how the experience was for them, modify the story and create new stories. Through these processes stories lived and retold are a way to educate the self and others, one of the aims of this study.

Stanley (1993b) describes narrative as being linear in progress with a beginning, middle and end. This is also supported by Minichiello et al (1991), Polkinghorne (1995) and Riessman (1993). Stanley (1993b) acknowledges that the way in which a story is told or structured results in different ‘voices’ being heard and thus different meanings may be taken from the stories told. However, I would debate Stanley’s description of stories being linear in progress, particularly when reflecting on story-telling between nurses and clients. *For me it is an ever-evolving circle that may begin with an aim or objective, but may change direction or course depending on the communication form, listening skills or invitation to participate between parties.* As noted by Stanley, the retelling of

stories by participants/readers and those passing the information on can all be influenced by the way the story is told and the meaning or essence taken from that story. When one considers examples such as oral nursing hand-overs, the story can be classed as never-ending and forever changing as the story is told from one shift to another, as also noted by McEldowney (2003). Even when clients are discharged or stories of previous care given are retold they may be given different meaning depending on the inclusion or exclusion of pieces of information and what is deemed important by the story-teller. In relation to research interviews Riessman identifies that locating stories is often a “complex interpretive process and where one chooses to begin and end a narrative can profoundly alter it’s shape and meaning” (1993, p. 18). This concept is important when addressing the telling of research participants’ stories as the researcher needs to be aware that what is relayed as the participants’ experience is true to the meaning as conveyed by the participant themselves, and is recorded as such.

Story-telling has been identified as the best way to share experiences of practice in many different fields of the human sciences (Benner, 1984; Clandinin & Connelly, 1994; McDrury & Alterio, 2002; McEldowney, 2002, 2003; Koch, 1998; Lumby, 1993; Reason & Hawkins, 1998; Stanley, 1993). Reason and Hawkins note that through the bringing of “... these stories alongside each other it is possible to ‘sense’ the underlying essence which they share” (1998, p. 89). This research project involves the reflecting on and analysing of the stories of three women nurses to enable them to share the essence of what the caregiving experience has meant to them and how it may have affected / influenced their nursing practice. By bringing their stories ‘alongside each other’ it is

hoped to identify common themes, while acknowledging the uniqueness and individuality of each narrative.

For nurses storytelling is an art we use daily in our practice of caring. It is what we do while caring for our clients, educating our clients, at handover and when discussing aspects of our practise with other nurses. Boykin and Schoenhofer (1991) stated that “the use of the story of the nursing situation preserves the integrity of nursing knowledge and enhances understanding and knowledge of nursing” (p. 246). My own experience and awakening about story-telling in nursing arose when commencing academic study, which involved the critiquing of different nursing journals. The enjoyment and understanding from relating to nurses’ exemplars of their practice experiences highlighted the evolving awareness of the need for nurses to share their experiences, or stories, with others and to record those stories. The importance of story-telling within the profession has been further enhanced for me as a clinical lecturer when educating student nurses about the importance of journalling and reflecting on practice to identify what they did and why they did it.

Benner (1984), when discussing nursing in relation to recording exemplars from practice, identifies that nurses have traditionally not been good at recording and defining their practice and its associated knowledge. She argues that if nurses wish to have nursing recognised as a science that the telling of stories about practice is an important tool to advance the cause. In keeping with the universal trend in helping nursing to be recognised as a science and art, nursing curricula in New Zealand (Christchurch Polytechnic Institute of Technology, 2004), has incorporated in its

competencies the need for student nurses to journal and reflect continually on their practice. This, in turn, teaches nurses the importance of recording their experiences, thus helping to contribute to the science of nursing, and in turn, define how it is we know and what it is we know. With the more formal practices of reflective journalling and recording of nurses' stories, nurses can reflect and learn from the experience while contributing to the science and art of what it means to be a nurse and, as suggested by Benner (1984), help nursing to be recognised for what it is.

Heinrich (1992) describes stories as having "... the power to inspire, mentor, inform or caution novices, and to validate and honour the practices of more seasoned nurses" (p. 141). However, in my experience, I have found stories have the power to inspire, mentor and inform all nurses (even the most seasoned) and stories or exemplars from novice nurses have the power to encourage experienced nurses to reflect on their own practices and changing trends in nursing.

Nurse educators Diekelmann (1988) and Hedin and Donovan (1989) describe storytelling as a way of relating intellectual theory with subjective feelings. Many of the proponents of storytelling as a research method highlight the importance of the unspoken healing and nurturing that results from being able to express, recount and acknowledge the impact lived experiences have had on our lives, particularly as part of the nursing profession (Boykin & Schoenhofer, 1991; Heinrich, 1992; Sandelowski, 1991). Storytelling is how we make sense of our experiences (Bruner, 1990; Mishler, 1986a). Riessman found that "individuals recapitulated and reinterpreted their lives through story telling" (1993, p. vi). Through this thesis project, it is envisioned that by

telling the stories of their lived experiences, research participants will be able to reflect on what the experience has meant to them as a caregiver to a family member who may be ill, elderly or with an enduring illness and how it has changed their lives. It is hoped it will enable them to feel they have been heard and nurtured as the result of being able to tell their story, a benefit of storytelling as identified by Sandelowski (1991).

#### Story-telling as defined by Churchill and Churchill (1982)

... includes dimensions of both intimacy and distance – intimacy in that the self as person is involved, and distance in that the method encourages the use of alternating rhythms, moving from a personal view to a broader one of putting the event into another or a new perspective. This alternating rhythm is a necessary feature of the practice of professional nursing and is beautifully portrayed by use of story (as cited in Boykin & Schoenhofer, 1991, p. 246).

Churchill's description of what can be achieved by the act of story-telling justifies its use in the recording of female nurses' experiences as caregivers for family members. It resonates well with the concepts of intimacy and distance and the difficulties and issues that may arise in this process as previously identified by Robinson (1998) and Teutscher (2003). It is indeed an art, being both a family member and nurse caregiver to a family member who is ill, elderly or with an enduring illness. However, within the story-telling or narrative form of research, as part of the research process, issues of reflexivity, congruence and rigour must be addressed if the research is to be considered trustworthy, issues that are discussed further in the following section.

## **Reflexivity, Congruence and Rigour in Qualitative Research**

Polkinghorne (1988) talks about difficulties that arise when completing research from a human science perspective relating to epistemology (knowing). He states "... human science can no longer only seek mathematical and logical certainty. Instead, it should also aim at producing results that are believable and verisimilour" (p.161), that is, that have the appearance of truth or reality. Any research project must acknowledge issues of reliability and validity. "In narrative research 'valid' retains its ordinary meaning of well grounded and supportable" (Polkinghorne, 1988, p.175). Koch and Harrington (1988) noted the development over the last decade of the terms of congruence and rigour rather than validity and reliability in relation to qualitative research. Congruence is concerned with continuity and consistency throughout the research, while rigour is about the scientific quality of research (Koch & Harrington, 1998). However, Sandelowski (1993) spoke of the importance of recognising the "... artfulness of qualitative inquiry" and of the need to soften "our notion of rigour to include the playfulness, soulfulness, imagination, and techniques we associate with more artistic endeavours" (p.8).

When research is of a subjective nature, as in narrative inquiry, the researcher must demonstrate that the research is trustworthy, that is, the degree to which the results reflect the truth; and dependable. Gillis and Jackson (2002, p. 216), defined dependability as "the stability and the trackability of changes in the data over time and conditions". For qualitative research to demonstrate rigour it must show subjectivity in that readers can locate and track the positioning of the research; uniqueness, that is the extent to which the subject or case experience is individualised, and transferability in



relation to the fittingness of study findings to other settings, populations or contexts and finally credibility through the accuracy of the description of the phenomena under study.

Throughout the research project congruence and rigour need to be addressed and it is essential if one wishes to produce quality research (Koch & Harrington, 1998). Within this research process these concepts have been addressed through a literature search (as documented in chapter two) in relation to the research question and by acknowledging these concepts and how they have been addressed throughout the project in areas such as data gathering and analysis.

If these issues of reflexivity, congruence and rigour are to be met the researcher needs to address how the research question then informs the methodology. In this study the research project involves the recording of the lived experiences of three female nurses in caring for family members who are ill, elderly or with an enduring illness. To ensure issues of subjectivity and uniqueness are attended to in meeting the requirements of congruence and rigour narrative inquiry, using a women-centered approach, was the chosen methodology. The listening to and recording of research participants' stories of how the experience has been for them is part of this process. Positioning the voice of research participants, and hearing their stories, demonstrates rigour in methodologies (Koch & Harrington, 1998). Within this research participants' voices are identified by the use of italics when data has been presented directly from the transcripts of their lived experiences as re-membered and re-told.

Clandinin and Connelly (1995), in their research on personal experience methods, speak of issues of 'voice' that arise between the researcher and the participants, that is, recognising the text or data for what it is and having the confidence to inquire about research data rather than merely summarising and interpreting others. In research, issues around voice and the need to "... consider the voice that is heard and the voice that is not heard" (Clandinin & Connelly, 1994, p.424), as part of the research process it is important to revisit the transcripts and audiotapes, to identify the unspoken meaning or the layers of the story as it unfolds, a process that evolves as the research progresses.

While interviewing research participants I became aware, when initially listening to audiotapes on completion of the first set of interviews, of crucial times when the participants' 'voice' may have been unheard due to my inexperience as a researcher. Participants may have been acknowledging a sensitive or relevant point when through my 'sharing', or interrupting, new issues or experiences have been remembered and thus the story-telling focus changed. The importance of that unspoken thought, feeling or experience and the need to let the silences be, has become more apparent as I consider what the participant is sharing with me. There is an awareness of the need to let the richness of the data tell the story. The ability to listen and to let the data tell it's own story is an important skill as noted by those involved in the human experience research method (Clandinin & Connelly, 1994; Koch, 1996; Riessman, 1993; Sandelowski, 1991; Stanley, 1993b) and a process which the researcher needs to be aware can influence research findings. This will be discussed further in chapter four in issues around researcher bias.

In this thesis through identification of the processes used for sample definition and obtaining of research participants, congruence and rigour have been adhered to. At commencement of the research process, criteria for inclusion in the study was established to provide clear definition (Appendix1). The criteria set stated that participants needed to be female Registered General and Obstetric Nurses; Registered Comprehensive Nurses or Registered Psychiatric Nurses. The female had to be of European/Pakeha descent recognising different cultural structures within families, roles and responsibilities. The female nurses selected were or had been a caregiver for a family member who was ill, elderly or with an enduring illness. As previously mentioned, participants were restricted to female nurses due to the overwhelming amount of literature that states the caregiving role within families is predominantly filled by women. Due to the constraints of this research project sample size was restricted, but did provide the opportunity for nurses who worked in different fields of nursing and lived in different locations of a region to participate. Wadsworth notes “the purpose of sampling, be it in qualitative or quantitative research, is to produce either a sample which is representative of a chosen population or which may ‘illuminate a situation, get insight or collect information about a particular event’” (1984, p.197).

In the following chapters, congruence and rigour when analysing data and disseminating results will be addressed at each appropriate stage, bearing in mind Polkinghorne’s thoughts that “narrative studies do not have formal proofs of reliability, relying instead on the details of their procedures to evolve an acceptance of trustworthiness of the data” (1988, p. 177). Koch and Harrington, (1998) argue that there is a need for those doing qualitative research to incorporate reflexivity within the

research - in other words to continually ensure that readers are aware of what is going on throughout the process. They speak of the need for ongoing self-critique and self-appraisal, which in turn is shaped by the politics of location and position. Koch and Harrington consider that if reflexivity is adhered to, that is, the research project is well signposted and readers can follow through the participants' and researchers' text themselves, this then contributes to ensuring the text is believable or plausible, in other words, meeting the standards of rigour. Stanley (1987), defines reflexivity as "a central tenet of a feminist methodology, whereby the researcher documents the production of knowledge and locates herself in this process for '... the subjectivity of the researcher herself is part of research production'" (cited in Ribbens & Edwards, 1998, p.49). At the commencement of this research process, as the researcher I demonstrated reflexivity by situating myself in relation to justification for this research and my own personal experience. I identified that, although the idea for the research question originated from my own personal experience and dilemmas in caring for a family member with an enduring illness, I did not wish this research to include an autobiography of my lived experience. However, the need to acknowledge the influence of my own experiences and how they may impact on the analysis of the research data must be discussed – that is locating oneself within the research (Koch & Harrington, 1998; Stanley, 1987).

Sandelowski identifies that "... qualitative research is about art, or, at least, as much art as science, and the nature of narrative data are the mainstay of qualitative work is inherently revisionist" (1993, p.3). She also argues that as participants' stories constantly change and as the researcher and participants are both stakeholders in the process, it is difficult to adhere to the principle of member checking as enhancing the

rigour of qualitative research. In this research project participants were given transcripts of their interviews to revisit their stories as recorded before the next meeting. This process allowed them to 'correct' their story if they felt it was not a true account, and provide the opportunity if they wish to delete or correct any part (Emden, 1998b).

Member checking, or validation, is the process whereby researchers check with research participants that interpretations of data obtained from interviews, and subsequently transcribed, is as the participant described their experience. Throughout the project researchers continually validate data for clarification or elaboration with participants. This process often results in discrepancies in what participants remember saying and transcripts returned for verifying. An important point that Sandelowski (1993) makes in relation to this is that research participants often change their stories from one telling to the next as new experiences and the very act of telling itself cause them to see the nature and connection of the events in their lives differently. The idea of empirically validating the information in one story against the information in another for consistency is completely alien to the concept of narrative truth and to the temporality, liminality, and meaning – making function of stories (p.4). This is supported by Polkinghorne's (1995) findings about interview-based data, that participants' recollection and present perspective of events is selective and influenced by the interviewer and that the significance and meaning of the event changes over time.

## **Conclusion**

This chapter has outlined the methodology of narrative as inquiry as a scientific form of research. The importance of the method of story-telling in recording human experiences and story-telling as part of nursing culture has been discussed. How this research project

using the qualitative methodology of narrative inquiry meets the need for reflexivity, congruence and rigour has been detailed, along with the importance of acknowledging researcher bias and the researcher positioning themselves throughout the process – a concept that is explored more fully in the next chapter.

# **Chapter Four**

## **The research process**

### **Introduction**

The previous chapter provided justification for the research question, issues in relation to personal significance, current literature available about the research topic and detailed the methodological underpinnings of the research study when using narrative inquiry. This chapter will outline the research method used; researcher position, and an outline of the process involved prior to commencing research along with my account of issues that arose throughout the research process. Issues that arose around selection of research participants; ethical issues; identifiability and confidentiality taking into account reflexivity, congruence and rigour will all be addressed. The method of data collection and the process used for analysis of data will be detailed. In conclusion a summary of the main issues will be highlighted. As already detailed, the research process involved the recording of three women's stories or biographical accounts of their experience in caring for a family member who is ill, elderly or with an enduring illness based on the research method of narrative or story-telling using a women-centered approach.

### **Position of the researcher**

In the first chapter I outlined my justification for the chosen research topic of caring for family members who may be ill, elderly or with an enduring illness and whether nurses felt that they had a choice or were obligated to take on this role. Due to issues of identifiability and in a quest to prevent members of my own family from becoming unwilling participants in this research project I did not intend my own story or

autobiography to be included. However, I soon realised it was impossible to complete this research without centering or placing myself (as identified in Chapter three) within the research, that is, declaring my bias as the researcher.

Researcher bias, as defined by Gillis and Jackson (2002), is the “... *systematic distortion of research conclusions*” (p. 298). They also state that when researcher bias is not addressed, the reliability of research findings could be considered highly suspect. This is supported by Minichiello et al, (1991) who state bias is inherent within the research and is considered part of the research process. Thus, by recording my perspective as a researcher it minimises the bias and situates me as researcher within the research. Clandinin and Connelly (1994, p. 418) suggest “... in personal experience methods we must acknowledge the centrality of the researcher’s own experience: their own tellings, livings, relivings, and retellings”.

Discussion with my supervisor about ethical considerations in relation to recording my own autobiographical story took place throughout the research project. The importance of placing or centering myself by outlining my personal situation brought home to me the sensitive nature of my chosen research topic and what I was asking of those who volunteer to be part of the research project. For me this research was to be based on three women’s stories of their experience in caring for a family member who was ill, elderly or with an enduring illness. While acknowledging my own experience, I did not wish it to be about me or my present situation. As part of the ethical process required when completing the research, written consent (Appendix 8) was obtained from my brother who was mentioned at the beginning of the research process and whose illness



planted the seed for the focus of the research question. Stories from the researcher's personal experience may be incorporated in findings throughout the text with these being acknowledged at all times. Through this process the researcher then meets the research requirements in regards to rigour, that is, signposting to readers 'what is going on' to ensure the text is believable and plausible as suggested by Koch and Harrington (1998). This process also helps to address some of the ethical requirements when completing research, with other ethical considerations being detailed in the following section.

### **Ethical Issues**

Before the research project commenced a research application overseen by the thesis supervisor was presented to the Victoria University of Wellington Human Ethics Committee for approval. The research application was then presented to the local Regional Ethics Committee where final approval was granted to actively begin the research (Appendix 9). As pseudonyms were to be used throughout the project and any identifying factors were changed, identifiability was minimised as much as possible.

### **Issues of Confidentiality and Identifiability**

As previously discussed pseudonyms (selected by research participants) were used to ensure that identity was protected. All information related to geographical area was removed from data transcripts and appendices. A confidentiality form was signed by transcribers (Appendix 3) prior to word processing of audiotapes, along with an agreement that all data was to be locked away when not in use. Pseudonyms (once again selected by research participants) were used to protect participants' family members from also being identified. Transcripts were returned to research participants to validate

after each interview with changes incorporated as requested. Due to my name being on the research thesis identity of my brother and other family members may be disclosed.

## **Recruitment and Selection of Participants**

In discussion with my thesis supervisor it was decided this research project would incorporate up to four female nurses' stories of their experiences caregiving for a family member who is ill, elderly or with an enduring illness. Participants were recruited through a flyer outlining the research project, displayed at local hospital and community health centres (Appendix 7). Permission to display flyers was gained from the General Manager of the local District Health Board (Appendix 5). Information on the flyer contained the researcher's name, phone number and e-mail address and it asked potential participants to contact the researcher through one of these means. At the time of advertising there was a chance that some participants may know me, or be known to me through working in the same organisation.

Flyers requesting research participants were displayed in three wards of the general hospital where I worked including the surgical ward which I worked in on a part-time basis. Flyers were also placed in the acute inpatient mental health unit and the community mental health centre attached to the same hospital. These were areas I was working in as a clinical lecturer, but had previously worked in for many years as a staff nurse and team leader. A flyer was also placed in the community health centre in the town where I lived, which incorporated nurses working in meeting the physical and mental health needs of people within that community. Most staff working in this centre were known to me or had worked alongside me at various stages of my nursing career.

I was hesitant about the response I might receive and this was further exacerbated by the fact that, as ethics approval was only gained three weeks before Christmas, I was asking participants to partake in research around a time traditionally recognised as the busiest time of the year.

The first participant recruited was Marie. Marie was sitting in the staff room where I was about to display my flyer. She asked to read the flyer and then stated she would take part, much to my surprise. I suggested to her that she may wish to think about it and I would contact her next week to see if she still felt the same and if she wished to take part I would meet with her and discuss details and procedures. She was happy with this and wrote her name and address in my diary.

As I was leaving the area where Marie worked I noticed a nurse with whom I had discussed my research project a couple of months earlier. Polly was in the filing room writing up clinical notes. During our previous discussion Polly had shown an interest in sharing her story and we had discussed the fact that she would meet the criteria for inclusion. I was unsure when I approached Polly to discuss participating whether this would seem like coercion, and whether Polly would feel pressured to take part. I was aware Polly had a heavy workload and was a very busy person outside of work, however I was also aware of Polly's strong work ethic and the desire to advance nursing knowledge at every opportunity and I was keen to record her story. I approached Polly to discuss my research and gave her a copy of the flyer to read. She indicated she was still keen to take part, but was going to be very busy over the next few weeks and suggested that I contact her between Christmas and New Year when things may be a bit

quieter. I was pleased and excited that Polly's story would be recorded, although mindful that Polly's busy life may lead to her changing her mind prior to our first meeting.

The third research participant was located when I realised I had not displayed a flyer in the community services part of the large base hospital. I was teaching nursing students who were working in this area and was asked by a nurse working there how my research was progressing. Annie, who was also in the room, showed an interest in the chosen topic and indicated that she would like to take part. As there were other people present at the time I reiterated the facts about identifiability and confidentiality, but that I would drop off the participant information sheet for her to read so she could make an informed choice. I dropped off the sheets later that day. Annie contacted me that night, keen to take part, and we arranged a meeting time for the following week to sign the consent to participate form and go through any queries she wished to have answered. Unfortunately after meeting with Annie and her signing of the consent form I became aware that Annie was not actually a registered nurse at the time of caregiving, but was due to commence her nursing training. This meant Annie did not meet the inclusion criteria and had to be excluded from the study. Both Annie and myself were disappointed at this outcome, particularly as Annie was enthusiastic about sharing what was a very personal and sensitive story.

For the next week I did not receive any phone contacts from people wishing to take part, and the thought I may only have two research participants' stories to record was a possibility. However, as I was working in several roles in different areas of the hospital,

I had contact with many people throughout my working week. Numerous people approached me expressing an interest in the research project and informed me that they were thinking about taking part, but due to heavy work commitments and busy lives, they were unsure whether they would have the time and indicated they would contact me if they decided to take part. I decided I would 'let things be' for a week or two to see what happened. It is interesting to note from my experience the number of people who seemed to be willing and more comfortable to approach me personally on an informal basis rather than by formal phone contact or e-mail. In hindsight I wondered whether some of the nurses who had contact with me through my work roles and had shown an interest in partaking in the research, but were unsure about making a commitment, felt more comfortable talking about the project in an informal way. During this time two nurses, known to me, indicated they could possibly take part. The first nurse, Kate, felt that before she could participate she would need to discuss this with her husband. I felt when talking to Kate that this was a sensitive issue that could potentially cause problems if Kate did take part in the research. Subsequently, I decided that I would let her re-contact me if she felt it was what her husband and her wanted. Kate did not make further contact and I felt this may be related to the fact the caregiving role for the ill family member was still relatively new and was ongoing. I had noted that with all other research participants their caregiving roles had been performed years earlier and they were able to tell their stories in retrospect.

The last research participant to be recruited was a nurse I had known for many years who had stated a few weeks earlier that if I didn't receive the required number of research participants I was hoping for she would be willing to tell her story, as she had

cared for both her parents through their illnesses. Frances had not seen the flyer displayed and stated she would have offered to take part earlier if she had. This offer to participate was accepted as time was moving on and I knew Frances had taken on a major caregiving role within her family and she appeared comfortable about sharing her story.

It is interesting to note that during the period when I was nearing completion of the second audiotaped interviews with the three research participants I was approached by five further nurses offering to take part in the research. I was both surprised and taken aback by this. Through this response came an awareness that there are a lot of nurses keen to share their stories, but also that nurses value their privacy and their private lives. The second point of note for me as a researcher was that the timing for recruitment and length of time flyers were displayed may have hindered the recruitment process. This also reaffirmed my belief that many nurses do carry a caregiving role for ill, elderly or family members with an enduring illness that is not disclosed and nurses do want to tell their stories.

My research project would incorporate the telling of three women nurses' stories of the caregiving role they had fulfilled for an ill, elderly or family member with an enduring illness while also incorporating extracts of my involvement in caregiving for my brother who suffers from an enduring illness. During the research process a number of nurses nominated or suggested to me that a particular person would be an ideal candidate to take part in research. Often they would offer to ask them on my behalf, while taking on the gate-keeping role without being requested to do so. From the rigorous ethics

application process the issues of confidentiality and identifiability came to mind, along with the importance of participants wishing to take part without coercion, particularly when considering the sensitive nature of the research topic. Taking this all into account, I decided the best option was to obtain participants via the flyer, as first outlined in the research proposal, except in Polly's situation where I approached her due to previous conversations. In relation to Frances taking part in the research, she mentioned she had not seen the flyer displayed, but was aware of my research project from personal discussions and was keen to participate.

### **Right to Withdraw**

As with all research, participants may find that after initially agreeing to participate in a study, that at certain stages throughout the process that they may decide they no longer wish to take part. Following initial phone contact each participant was given a copy of the Information/ Participant sheet (Appendix 1). This was part of the process to ensure all participants were fully informed and were aware of the right to withdraw from research at any time. This sheet also contained information, my contact number and e-mail address to enable any participant to contact my thesis supervisor if they had any further questions. In the initial process, when signing the consent to participate form (Appendix 2), participants were made aware of the statement that said they could withdraw at any time and if they chose to do so any information provided already would be returned to them.

In line with acknowledging the sensitive nature of material, participants were informed before commencing the research that through reflecting and analysing their experiences

unresolved issues may surface. If required, I would assist participants requiring further help to find appropriate services for their needs. It was also clearly stated that this would be at the participant's initiation. None of the three research participants requested this service during the time they were involved in the research project, although Marie did acknowledge after reading the first transcript "it seems real now" and spoke of it bringing things back to the surface. When offered Marie declined assistance to connect with support services as she felt she did not require input and she would be okay.

### **Analysis of audiotapes**

In this research project each research participant and the researcher met twice to record the research participant's story. All sessions were audiotaped with participants having the option of having a copy of the audiotapes if they wished. Schwartz and Jacob (1979) "pointed out that there is greater analytic depth (when audiotaping) because the anecdotal information and the ambiguity of the response is still available to the researcher" (cited in Minichiello et al, 1991, p. 134). Prior to commencing audiotaped sessions with the research participants I prepared prompts or guidelines (Appendix 4) to identify areas of focus for the study in answering the research question. However, once discussion about the research project and question had begun it was hoped that participants would feel comfortable enough to tell their story without direction from the researcher. As noted by Brannan (1988) and DeVault (1990) "during the interview itself, I adhered to several tenets of the technique to listen to the women attentively and let the interaction follow the themes the women raised" (cited in Ribbens & Edwards, 1998, p. 49).



Each session was then transcribed. Transcripts were given to participants to read, make comment on and to clarify if they wished. Within a fortnight of receiving each transcript, participants were contacted to organise a time when we could meet to explore issues, themes or queries that may have arisen from the reading of the transcript. Sandelowski (1993) notes that

Research participants often change their stories from one telling to the next as new experiences and the very act of telling itself caused them to see the nature and connection of the events in their lives differently. The idea of empirically validating the information in one story against the information in another for consistency is completely alien to the concept of narrative truth and to the temporality, liminality, and meaning-making function of stories. (p. 4)

These findings are supported by Mishler (1986a), Stanley (1993a), and Polkinghorne (1988). In this research project after returning the first transcript to each participant follow-up phone contact was made to check with each participant about how they were getting on reading their transcripts and to arrange the next session. Both Polly and Frances identified closely with their experiences as recorded in the transcripts and only requested some minor changes. However, Marie stated *"I think I may have become a bit muddled and confused when talking about caring for Dad, as I was under so much stress at the time, I needed to clarify some things when we next meet"*. As identified by Polkinghorne (1995) and Sandelowski (1993) this is to be expected when narrative as inquiry is used. At the next interview Marie identified that parts of her caregiving role were 'a bit of a blur' due to her mental state at that time. When we completed the second interview, Marie corrected some dates and times of events and clarified her feelings and experiences of when her Dad was admitted to hospital in his last days.

When validating transcripts with the other two research participants, Polly felt on reading both the transcripts from her interviews that they provided a true picture of the caregiving roles she had performed and how she felt in relation to them, while Frances felt that both transcripts provided a clear account of her caregiving experiences as she remembers them.

Immediately after each story-telling session field notes were written. I then listened to the audiotapes and noted points of interest. Prior to the second interview with each participant transcripts were read several times, I identified major themes or recurring concepts that appeared to be emerging. At this time any queries or areas identified which required further exploration or clarification at the next meeting with research participants were recorded. I requested that participants do the same prior to arranged meetings.

### **Analysing the data**

Data analysis can be defined as “the process of systematically arranging and presenting the data in order to search for ideas and to find meaning in the information collected” (Minichiello, et al 1991, p. 320). As I contemplated the best way of analysing the data while being ‘true’ to the stories told by research participants, I decided to record a shortened version of each woman’s story of her caregiving role with family members, followed by the highlighting of themes identified in the story. To assist me in this process I decided to use the method described by Australian nursing scholar Emden (1998b) in her article on ‘conducting a narrative analysis’. Emden’s (1998b) work described the processes of ‘core story creation’ and ‘emplotment’ as previously

documented by Mishler (1986) and Polkinghorne (1988) in relation to the analysis process when doing narrative research.

The first stage in Emden's (1998b) process is to create a core story. "Core story creation is basically a means of reducing full length stories to shorter stories to aid the narrative analysis process" (p.35). In core story creation all unnecessary duplications of words and sentences that detract from key ideas are removed.

Emden (1998b) devised eight steps or moves to clarify how she used the process. In this research these steps as outlined by Emden (1998b) were used to create core stories for each participant. The first step involved reading the full interview several times. Notes were taken immediately following each session with research participants and audiotapes were listened to within twenty-four hours of each session. When texts had been transcribed they were then read through while listening to audiotapes, with comments recorded beside transcripts. This process was completed several times over a two-three week period to enable a good "grasp of the contents" (1998b p. 35). The next step involved the deleting of any questions or comments from the text that I, as the researcher, had made. Further to this all key words that may detract from key ideas (from sentences or groups of sentences) were deleted. Step four required the re-reading of the remaining text to ensure it made sense. The next step involved repeating the two previous steps several times "until satisfied that all key ideas were retained and extraneous content eliminated, returning to the full text as often as necessary for rechecking" (1998b p. 35). Step six centered on identifying "fragments of constituent themes (subplots) from the ideas within the text" (Emden 1998b p. 35). Identified

themes were manually recorded on paper for each participant's story. Following on from this process was a moving of the themes or subplots together to create a coherent core story or a series of core stories. In this research project, as each participant spoke of several caregiving experiences they had with different members, all three participants ended up with more than one core story. The final step Emden (1998b) described was focussed on member checking, returning the core story to research participants to provide them with the opportunity to correct/develop or delete any part that they felt didn't ring true or that they did not wish to have recorded. As previously discussed within this project when participants read their core stories the only requests they made were to change minor details due to the sequence of events or dates and time frames being incorrect. During the process of listening to the women's stories and subsequently the reading of the transcripts, it became obvious that the stories told by the women did not follow a linear fashion and the process of extracting how the experience was for them without omitting important data was crucial to honouring their experiences. As noted by Riessman, "obviously, the agency of the teller is central to composing narratives from personal experience, but so are the actions of others - listener, transcriber, analyst and reader" (1993, p. 15).

The second stage of data analysis on completion of the core stories is the process of 'emplotment' as described by Emden (1998b). Emplotment involves the identifying of one or more main ideas or emerging themes, that are called plots. Polkinghorne describes emplotment as a "dialectic process that takes place between the events themselves and a theme which discloses their significance and allows them to be grasped together as parts of one story" (1988, p. 19). It is up to the researcher to

'clarify' and decide the course of action that they may use when plotting or using the process of emplotment. In this research project themes or plots were identified and then colour coded using fluorescent sticky papers. This process was completed using the procedure of 'tacking' or 'moving back and forth' (Polkinghorne, 1988) between proposed plot structures (or themes) using the principle of "best fit" (Emden, 1998b). Once plots were identified and colour coded these themes were then manually recorded under distinct headings. At the end of each participant's story themes or plots were clustered together and then expanded on and represented in diagrammatic form for visual clarity. The emplotment process was then applied to all three participants' core stories "... searching back and forth across stories, comparing and contrasting these distinguishing or important features, to see if they were common to more than one story" (Emden, 1998b, p. 37). In Chapter Six a diagram highlighting common themes from each core story along with themes unique to each participant's experience is presented. The cluster themes have been re-named and given titles relevant to the nursing culture and experience as identified by the researcher and then commented on in more depth. Polkinghorne (1988), noted that it is important when using the emplotment process to be aware that the emplotment of events into story form is something we do without being aware of the process, but being aware of the experience of the reality it may produce.

### **Issues that arose in data collection**

Due to time constraints contact with each research participant consisted of several phone conversations, initial meetings to sign consent and talk through the research process and two pre-arranged interviews held at venues of the participants' choosing. As mentioned previously, follow-up phone calls were made several times to check out

progress, problems or matters arising. As the participants were all known to the researcher on a professional basis this made the process of establishing rapport easier. The processes of audiotaping were completed without any problems. The first transcriber found it difficult to transcribe audiotapes due to several other commitments. This was hindering the research process so a second transcriber was employed and audiotapes were transcribed without difficulty. Both transcribers signed confidentiality forms.

No major issues arose in data collection, however, two areas highlighted researcher naivete. The first area I had erred in was that although I planned to tell three women's stories of their caregiving experience to ill, elderly or family members with an enduring illness all three participants had more than one experience to share as they had all been caregivers to more than one family member. As it was not possible to single out any one experience, in essence this exploratory research project developed into the story-telling of seven caregiving experiences by three female nurses for family members who were ill, elderly or with an enduring illness. Although this involved more work as a researcher, it added a richness and depth to the research through the detailing of the impact different caregiving roles had for the research participants for different members of their families.

The second issue that was not foreseen due to researcher inexperience was the length of time required to organise and complete procedures. All aspects of research work from arranging story-telling sessions, to contacting research participants; awaiting the transcribing of audiotapes; and the waiting for participants' feedback of transcripts, took

much longer than envisioned. The importance of reading and re-reading and letting things 'be' over a period of time to enable one to 'hear' the true meanings of participants' experiences were all concepts that appeared foreign to me at the beginning of the research project. An awareness of the importance of not rushing the processes developed as the research progressed.

## **Conclusion**

This chapter has detailed the research process used. It has addressed issues of researcher bias, acknowledging the researcher's own experience. Issues in relation to how ethical approval was obtained from the appropriate committees; the use of pseudonyms in the quest to prevent identifiability of research participants and their family members, and the recruitment of research participants were addressed. The method of data collection using audiotaping was explored. The process of transcribing and reviewing the transcripts with participants was discussed, acknowledging that research participants often change their stories from one telling to the next. As noted, this process was much more time consuming than first envisioned. The data analysis process of core story creation and emplotment, as described by Emden (1998b), was detailed and explained in relation to this research project. The process used to identify themes, and then core themes, from research findings was outlined. Issues that arose during data collection were identified and discussed.

This now completes the detailing of processes that are necessary when undertaking research, covering such areas as aims, justification, current literature available on the

topic, methodology and the research method used. Chapter Five will share the special and unique stories of the three female research participants as re-membered and re-told.



## Chapter Five

### Stories re-membered and re-told

This chapter will detail/discuss the recording of the three participants Marie, Polly and Frances's caregiving experiences for relatives who have been ill, were elderly or suffering from an enduring illness. Marie's story will detail her experiences of caring for her father prior to his death from cancer. Further to this experience is the story of caring for her mother over the last fourteen years. Marie's story concludes as she reflects on the resulting impact on her own health. Polly's story tells of the caregiving culture of her family and details the caregiving experiences which enabled her father to die at home; her experience with caring for her mother (albeit briefly) and how she felt about her mother dying in hospital; caring for her brother who suffered from depression, and, the experience of caring for her estranged husband during the last few weeks of his life as he was dying of cancer. Highlighted within Polly's story is the impact resulting from the outcomes of those experiences. The third participant, Frances's stories revisited her caregiving experiences as she looked after her parents over a thirteen year period. These involved initially caregiving for her mother following trans ischemic attacks (TIA's) and strokes. Further to this her story discusses her caregiving for her father up until the time of his death from a similar illness.

Throughout the re-telling of the participants' stories, to enable the reader to identify direct quotes taken from the transcripts, these have been written in italics with changes to wording, when necessary, for the purpose of ensuring the quotes make sense. To examine the caregiving roles in more depth and to help identify and acknowledge the

differences and uniqueness of each caregiving role, I have broken the stories down into separate 'core stories' followed by a section in relation to the personal effects of caregiving. On completion of each participant's story I have detailed a section titled 'Emerging Themes'. Depending on how the experience has evolved for the research participant stories have been broken down into sections. At the completion of each participant's story emerging themes have been identified and discussed, then illustrated in diagrammatic form for visual clarity. In Chapter Six emerging themes from all three research participants' stories will be compared and explored in more depth. Once again these themes will be presented in diagrammatic form, demonstrating themes common to all three participants stories and themes identified as unique to each participant.

### **Marie's Story – 'Who cares for the caregivers'**

Marie is a comprehensively trained nurse who is in her forties. She trained initially as a general obstetric nurse, and then five years later, she completed her psychiatric training. She currently works in the psychiatric nursing field. Marie began her nursing training at age seventeen. The decision to go nursing resulted from her family upbringing which Marie states *"wasn't that great"* due to her father being an alcoholic. *"He used to drink all the time and things and I've always wanted to understand alcoholism and how I could help him, if there was anything I could do and of course I quickly found out there wasn't much I could do, but it had to be something he decided on himself"*.

Marie's decision to complete her psychiatric training was also influenced by her desire to find out more about her father's alcoholism. Through working in the psychiatric field Marie feels it has enabled her to have an *"insight into my whole family"* and how her father's *"alcoholism impacted on all of us in different ways."*

Marie is one of five children; she is the second youngest child and has two brothers and two sisters. Two family members live overseas; one lives fairly close to Marie, while the last sibling lives in the same town as Marie's mother. Marie is the only nurse in the family. Marie was known to the researcher on a professional level prior to her involvement in this research project.

### **The caregiving role**

Marie volunteered to take part in this research as she had been a caregiver for her father from late 1989 to 1990 and up to the time of his death from cancer. This caregiving role lasted approximately twelve months with an increase in the input required in the last couple of months, leading to Marie's Dad requiring full time care for the last three to four weeks prior to his death. Marie's mother is still alive and following her husband's death she has become quite dependent on Marie. Marie has continued to be involved in the caregiving role for her mother to varying degrees over the last fourteen years.

While listening to Marie's story, it became apparent that although Marie had been involved in providing care for both her parents, the expectations of family members in regards to Marie's role, Marie's feelings about the two different roles and the support available while providing care all differed. In caregiving for her father Marie felt that the family were willing to share the role although she took responsibility for co-ordinating and liaising when required and felt supported by the family, whereas with her mother who required long term caregiving the responsibility and majority of care was left to Marie. The lack of insight Marie had into the effects on her own health and how this was handled by work colleagues and employers was another consequence of the

caregiving role that was highlighted during the story-telling process and on review of the transcripts.

### **Caring for Dad**

As mentioned previously Marie's father died in 1990 from cancer. At the time of his illness Marie's mother was living with her father and Marie and her elder brother lived in the same town. Marie chose to care for her father even though she described her upbringing as "... *horrible*" due to her father's alcoholism and on occasions subsequent physical violence towards her mother. Marie describes her father as having a "... *hell of a life*" resulting from being a prisoner of war in Italy; suffering tuberculosis; depression and post-traumatic stress disorder. He chose to self-medicate through drinking to help cope with life. In the last six to seven years of his life Marie's father stopped drinking and smoking on medical advice as he was diagnosed with chronic leukaemia.

During the last twelve months of his life Marie was involved in helping provide some care for her father on a daily basis. She describes this as "*I probably got used to being there to help with him*" and talked about the "... *little things...*" like her father "... *wouldn't shave, and he wouldn't let her (Mum) do it, but he would get me because I was a nurse*". During the last year of Marie's father's life he became confused at times and towards the end suffered from paranoia, possibly due to cancer metastases.

Although Marie's father had been diagnosed with chronic leukaemia many years previously, his eventual death from lung cancer was only diagnosed officially two weeks prior to his death. However, Marie describes knowing her Dad was unwell for the twelve months prior to his death. "*Mum and I knew, like I told her a year before he*

*died, you know, to be prepared because I think, thought that he had been really unwell, and that he had cancer. You know when you just know when you're a nurse".*

Marie described the caregiving role in relation to her father as *"... it just seemed like a natural thing, that I sort of took it on, but there was always a lot of pressure from the family all the time, like what do we do next, what shall we do now this is happening, and it would always come back to me because I had more knowledge than them, knowing how to deal with some things, or whether he needed to see the doctor or whatever, and when he was in hospital, just before he died, like, it was the family expecting me to talk with the doctors about him and all that sort of thing. My mother was just so distressed that she wasn't able to talk to doctors and things".*

Several weeks prior to Marie's father's death his confusion and paranoia resulted in him being admitted to hospital in an emergency type situation. For Marie this admission resulted in being the most distressing and stressful time in relation to her caregiving role resulting from experiences with health professionals involved in his care. Marie described the situation of organising a doctor's interview with the consultant and her mother to talk about things and of telling the consultant of her desire to take her father home to die. Unfortunately the consultant who was filling in for her father's regular consultant misdiagnosed Marie's father's illness with an alternative diagnosis of Senile Dementia, stating *"He could be like this for twelve months or so" and "the family should consider putting him in a nursing home."* At this point the family had been taking turns to ensure someone was with their father twenty-four hours a day. Marie stating *"I just knew that he was on his way out and we wanted to make sure someone*

*was always with him.*” Marie had been caring for him from eleven o’clock at night till seven in the morning, going to work and then sleeping in the evening, prior to returning to the hospital. During the day Marie’s mother would sit with her father, with Marie’s siblings sharing the evening shift. Marie felt that *“family-wise, I think we shared that quite well.”*

For Marie this new diagnosis created feelings of self-doubt *“... so, yeah. at that point I really doubted myself, because I thought what the hell was going on here?”* This self-doubt resulted in Marie not staying over with her father that night, but requesting nursing staff to place bedrails on her father’s bed due to his semi-conscious state and confusion, resulting in attempts to climb out of bed. For Marie this experience was totally disempowering with uncertainty about what direction the family caregiving should take. The following day Marie’s brother questioned the consultant about her diagnosis and in Marie’s words *“blew the s... out of her”*. The consultant apologised profusely and stated *“Your father probably has only got about twenty-four hours to live, so get the rest of the family.”* This situation not only caused much distress for Marie and her mother, but also took away the opportunity for Marie and the family to take their father home and provide end of life care.

This episode indicates the lack of acknowledgment by the consultant to Marie’s expressed desire to take her father home to die and was compounded by the fact as Marie described *“she never came and apologised to me or anything.”* Marie’s request that bedrails be placed on her father’s bed had been ignored, with him subsequently having a fall and tearing his skin resulting in him being covered in steri-strip dressings.

Marie felt during the last few days of her father's life he did not receive adequate pain relief and she had to advocate for him by requesting one of the nursing staff to get the doctors to chart adequate pain relief for him. *"Finally on the last day he was completely unconscious and one of the nurses said to the family 'Oh do you think we should give him an injection of morphine now, perhaps?' You know, I mean pain relief's not just for the patient, it's for the family as well."* Marie's siblings arrived from overseas and her father died within the following twenty-four hours with his wife and five children present.

During his hospital stay Marie spoke of a nurse who was on night shift who used to let her read her Dad's file, *"I think just because she knew I was a nurse and that I wanted to understand everything that was happening with him."* Marie spoke of the last few weeks of caregiving for her father as being a *"... bit of a blur"* and *"becoming distressed."* *"Along with my mother, I wasn't sleeping and things, so I actually took time off work and got some sleeping pills and things for me and my mother."* Throughout the time Marie was involved in helping care for her father Marie describes *"colleagues at the coalface as supportive"* and stated in regards to her family *"I was always supported you know, anything that I came up with."* Following Marie's father's death Marie had a short period of time off work and then returned to her full-time job. She stated in relation to caring for her father *"... it didn't really impact on work."*

### **Caring for Mum**

As previously mentioned Marie's mother is alive and now in her late eighties. At eighty-five she married a man who has a major disability. Since her first husband's death in 1990 Marie's mother has become quite dependent on Marie. Marie has been

involved in the caregiving role to varying degrees with her Mum over the last fourteen years. This dependence was further exacerbated by numerous ongoing physical health problems – two hip replacements; a major myocardial infarction; hiatus hernia; perforated stomach ulcers and, more recently, short-term memory loss.

When Marie's mother initially became unwell Marie lived in the same town as her. As these health problems were chronic Marie felt the situation was different to caring for her father. She describes feeling "... *that (the family) tried to lumber quite a bit on me ... there was only my older brother living in the same area.*" Marie stated "... *I really felt the pressure, she'd (mother) always be on the phone when something was going on. My brother, he just kept his nose out of it. He was quite good at saying no.*" Marie's health began to suffer to the extent that she was diagnosed as suffering from depressive illness with generalised anxiety. Marie stated, in relation to the caregiving role she had been performing for her mother, "*I think I just, I had been trying to do too much really. What with helping her and things and like I use to maintain the section and everything. It got to the stage one day when she rang to ask me to help her install call minder on the telephone, I just wanted to say 'F... off I'm having a nervous breakdown for Christ sake.'*"

At this time Marie felt that for her own health, and the need to decrease her mother's dependence on her, that she needed to shift away, which she subsequently did. "*I had sort of dug myself into hole.*" At this stage Marie's mother was living with her new partner. Marie has helped organise support services as required over the last few years. Currently Marie's mother " *...has a nurse who comes in every week to assist with*



*bathing and someone comes in and does the housework and she has all sorts of aids around the house for her hips and things". For Marie shifting was a distressing time "...she wouldn't even speak to me the night before I left. I think she felt that I was abandoning her when she had become quite dependent on me. They were trying to get me to come around and do a lot of stuff in the house that she couldn't keep up with and I had to put my foot down and say well no I can't keep doing this."*

Prior to moving "I sort of dealt with things a lot, but since things have happened with Mum and we've both lived here, my sister's been pretty supportive and things, and done as much as she can...". However, even with support Marie identified that she felt there was more pressure on her being the nurse, "... *I've always been the one that's been expected to talk with doctors ... and then having to try and explain that to the family.*"

However, when Marie's mother did become really unwell in the last few years and there was a possibility she may die, Marie and her younger sister travelled long distances each weekend to help care for and support their mother. Of interest was Marie's description of the chaos that developed when her sister, who lived in Australia, came home for a week because her Mum was in hospital and there was a chance she may possibly die. "*She kind of just took over things, and it was really distressing for me and my sister. She was like a control freak really. It was almost like a sense of guilt on her part and she was sort of saying, 'I can't thank you enough for all the help and support that you've given Mum with Dad and oh she's been sick and things...' We were relieved when she left to go back, it's probably a lot easier her not being here.*"

Although Marie spoke about her sister travelling with her to help care for her Mum when she became really physically unwell, before this Marie described feeling as if *"the rest of the family weren't really there"* to help. In regards to future caregiving roles for her mother, due to the detrimental effect the stress of the caregiving has had on Marie's health, Marie stated *"... I think she'd probably need to go into a rest home really, although my sister's quite keen for her to come and live here at her house. I don't think I could cope with that myself. With full-time working and things I wouldn't be here to look after her all the time, but you know, between us we might be able to do it"*. Although Marie lives some distance from her mother and partner she states, *"I try to keep in contact as much as I can and I sort of help them out financially quite a bit"*. In relation to moving to a different town from her Mum, Marie stated, *"... it's been quite good, good to have a bit more of an independent life, without feeling that you've got to be responsible for everything"*. For Marie the cost of caregiving has impacted enormously on her own health and work situation. This is examined in the next section.

### **Caring for herself**

Through the process of relaying her story of the caregiving roles she had taken on within her own family Marie began to discuss the ongoing effects on her own health. She initially described an episode of suffering from a major depressive illness just before shifting away from the town where her Mum lived (four years after her father's death). However, in the second session when Marie and I met she acknowledged that in hindsight her unwellness stemmed from after her dad's death. *"Now that I look back on it, it was an enormous pressure really, providing the care. After my father's death, I was struggling at work for at least six months. But like, you know, I just had the regular amount of time off. I had a week or so off on bereavement leave, but it was like I was*

*functioning on automatic pilot*". Marie felt it was more than part of the grieving process. *"It was more than that for me, I think I didn't recognise it at the time, I just tried to work my way through it, and eventually, about six months after, I started to feel like life was getting back to normal"*. What was highlighted in Marie's story-telling of her caregiving experience was the effect of and the trauma resulting from the consultant's misdiagnosis, which not only created feelings of self-doubt for Marie, but the resulting effects which she describes as *"...I'd just about run out of energy, basically, after what happened with that doctor in the interview"*. For Marie the accumulation of a long period of stress and responsibility meant she had reached her limit.

When Marie first became unwell she booked in to see a counsellor stating *"I thought I needed to have a look at what's been happening here"*. She attended twelve sessions with the psychologist who felt Marie's illness was *"... pretty much a reaction thing, because we looked at things I had had happen leading up to it – just a whole lot of accumulative stresses, one after another"*. Marie felt at this time when she became unwell she lacked support from both her family and her boss at the place where she worked. In relation to her family, Marie stated, *"... they weren't aware and they didn't understand at all really, because you know they had no perception of depression at all."* She described her experience with her boss at this time *"I had a couple of weeks off work ... I had this dreadful boss at work that was ringing me and saying 'When are you coming back, when are you coming back, we need you here?' She used to ring and hassle me every couple of days and I mean I had severe anxiety. I just forced myself to go back to work and basically worked my way through it..."*. Marie felt in hindsight the

area of nursing she worked in had a bearing on her depression describing it as *"the most stressful and awful place to work"*. When asked whether she would think about leaving nursing she stated *"...not really. I've been struggling with depression on and off for years really and anxiety disorder. I mean it's such a strange thing to look at the profession and job that I've gone into ... and I've been struggling with those things"*.

Since shifting Marie has held several different positions with her new employer. Throughout this time she has continued to suffer from depression and anxiety and described episodes of experiencing panic attacks at work. The majority of Marie's colleagues are aware of her illness, with Marie stating, *"people were pretty supportive, I have some close workmates, two in particular that I, sort of, work the same shift as me"*. In regards to her work function over the last two years Marie felt that *"I managed to do most things adequately and do my work and things, but only just"*.

Over the last decade Marie has had both positive and negative experiences with employers and colleagues in regards to dealing with her illness. Last year when Marie became really unwell with depression and anxiety things came to a head. *"I was having too much time off and things, and that was okay, and then I just crashed, and ended up having to be off work for seven weeks"*. Prior to this crisis Marie had not informed her bosses or work colleagues in the clinical area about how unwell she really was. She stated in regards to her boss *"Well all she knew was that I was on stress leave"*. In regards to work colleagues Marie stated, *"you try not to take it to work really don't you? Or as much as you can, so you can do your job, but by the same token it's really good if you've just got a couple of close friends that you're working with on your team"*.

*that you can confide in” and in Marie’s situation she spoke of her experience last year following the crisis where “one team member was really supportive and helped me a hell of a lot when I wasn’t sort of quite at the level I should be back to, but doing okay...”*

Following the crisis resulting in Marie having an extended period off work was a ‘sick leave review’ described by Marie as organised as a *“forum to help you to see what can be done ... like counselling or anything”*. To an extent this was a supportive arena and Marie felt it enabled her to say some things she needed to say, but for Marie a comment from her manager devastated her *“... he got really angry and said ‘Well Marie, you just have to be here at work, you know. We can get that straight’”*. Marie stated *“... I was still unwell at the time and my self-esteem was so low and it was just badly planned ... that was the one time that I really felt that I wanted to kill myself after that”*. Following on from this Marie was offered supervision sessions with a psychiatrist whom she felt comfortable with and supported by. Since this forum Marie has had only a few sick days and stated, now, in relation to taking sick leave, *“I’m absolutely shit-scared”*.

Marie feels if she had been suffering from a physical illness rather than a mental illness she may have been treated differently. *“No-one would have been moaning”* and felt that staff generally feel *“that there’s a problem with the stigma, because you’re frightened to inform them (employers) of too much really, aren’t you if you’ve got problems with mental illness of any kind. So people tend ... oh I can imagine lots of people that have come into work within our company, that haven’t even declared that they’ve had*

*problems with it". The majority of Marie's teammates are now aware of her illness "it's quite open within the team that I work with and a few people out of the team know."*

Marie described in relation to supportiveness of employers and the work environment over the years that she felt *"... it varies, it really depends on who the bosses are, and what team you're on and what support you've got around you, it's all quite individual really ... a lot of people don't have a full understanding of your history and where things have come from, and the types of stresses that led you to arrive in the position you're in"*.

On reflection Marie feels the depression and anxiety that she currently still suffers from stems back to the effects and pressure of the caregiving roles she has carried in her own family for both her mother and father, a role that she has been involved in for over fourteen years - a role that was both chosen and acquired.

### **Emerging themes from Marie's story**

Within the context of these three 'core stories' several main themes are highlighted. These themes are detailed in this section, but explored more fully in the next chapter in conjunction with emerging themes from other research participants' stories. These themes have not been grouped or recorded in any particular order.

**'Knowing' / Advocating** were the first themes identified. Marie talked about knowing her father was unwell, prior to him being diagnosed with cancer and trying to prepare her mother with the knowledge that her father may be dying. Throughout the data expectations by family members of the 'knowledge' that they thought Marie should

have was evident. Although Marie spoke of the role of advocating as being the natural thing to do, she also identified with the pressure she felt from family members to perform this role in both caregiving experiences. As Marie belonged to a big family the co-ordination, liaising and responsibility for caregiving required someone taking charge, an expectation that Marie identified the family perceiving as her role. However, when Marie reached crisis point towards the end of her caregiving experience with her father and felt unable to advocate due to feelings about self-doubt and judgement Marie's brother stepped in and took over the role briefly, albeit in a less constructive way. Although the family had some awareness of the impact on Marie's health their lack of knowledge and understanding was highlighted by the family's expectation that Marie take on the same role over a longer period of time for her mother, with less support from other family members. The role of communicating between health professionals and intervening when needs weren't being met appeared by family members to be considered to be the role of the nurse in the family, a role that Marie acknowledges she took on without discussion or any formal choice.

**Dependency** was the second theme identified. Within Marie's caregiving experiences both parents became dependent on Marie to organise and provide the help and support they required in meeting physical, emotional and domestic needs. Marie's father's dependency can be highlighted by the 'shaving incident' when he requested that Marie shave him rather than her mother, who was both capable and willing to perform this task and, although this was a small task, it highlights the significance of the request in relation to how family members perceive what the nurse family member's role is. It is interesting to note that once Marie's father had passed away Marie's mother appeared to

become more dependent on Marie for input in every aspect of her life; physical, emotional and domestic. This would suggest that the family caregiving role for the nurse within the family is extended to incorporate filling the void left when a family member dies and the possible need of family members left behind to slip into the 'sick' or 'requiring care' role. For Marie the dependency her mother exhibited and her continual requests for input resulted in Marie deciding to shift to a new town so she was not as accessible and to preserve her own mental well-being. This enabled Marie to continue to have input into providing care, but with limitations into how much and how often.

**Acknowledgement / Responsibility and Relinquishing the Role** were identified as themes when Marie talked about sharing the caregiving role and the fact that family members appeared to have the choice to opt out or to be involved often only when a parent was in crisis health wise and death was a possibility. For Marie it was a responsibility she carried at all times with no choice about when and for how long she would have such a responsibility, though Marie did acknowledge at the beginning it "*... just seemed like a natural thing...*" to do. Although Marie talked about the pressure and responsibility of caring, it was interesting that when her mother became ill and her sister, who had previously had little contact with her mother, returned from overseas for a week to help provide care it created more stress. Marie describes both her and her younger sister feeling "*... relieved when she left to go back*" and "*it's probably a lot easier her not being here*". Robinson (1998) talks about those who have been responsible for the caregiving role over a long period of time being reluctant to relinquish the role, a concept that will be explored in more depth in the next chapter.



The need for acknowledgment of the role being performed, not only by family members, but by health professionals involved alongside the nurse, was of importance to Marie within the caregiving role. This was particularly evident in relation to Marie's experience when her father was hospitalised and the effect that both acknowledgment and lack of acknowledgment by health professionals had on Marie. In Marie's experience when providing care for her mother, she described this as more of an expectation by family members, with little acknowledgment of the role she played, until her mother reached crisis in her health state. When Marie herself became unwell she talked about her family's lack of awareness and understanding and of family members having no perception of depression and the implications in regards to her own health. Acknowledgment in the work environment appeared to vary, but in turn this could be a reflection of what Marie chose to disclose about her caregiving roles or health to colleagues and employers.

**Self-doubt** in relation to Marie's knowledge and judgement was highlighted for her when her father's illness was mis-diagnosed at a vulnerable and sensitive time for all family members. Although Marie was comfortable caring for her father, and expressed a wish to do so, this misdiagnosis resulted in Marie questioning her role, assessment and judgement skills. For Marie this self-doubt resulted in her feeling as if the last of her "*...energy had been used up*" and it was all becoming too much. Consequences of this self-doubt included feeling disempowered, a decrease in self esteem and feelings of distress for Marie. Highlighted throughout Marie's story of her caregiving experiences was a lack of insight of the impact not only on her own health, but on her ability to

function at work properly and a lack of insight by family members into the effects on her health.

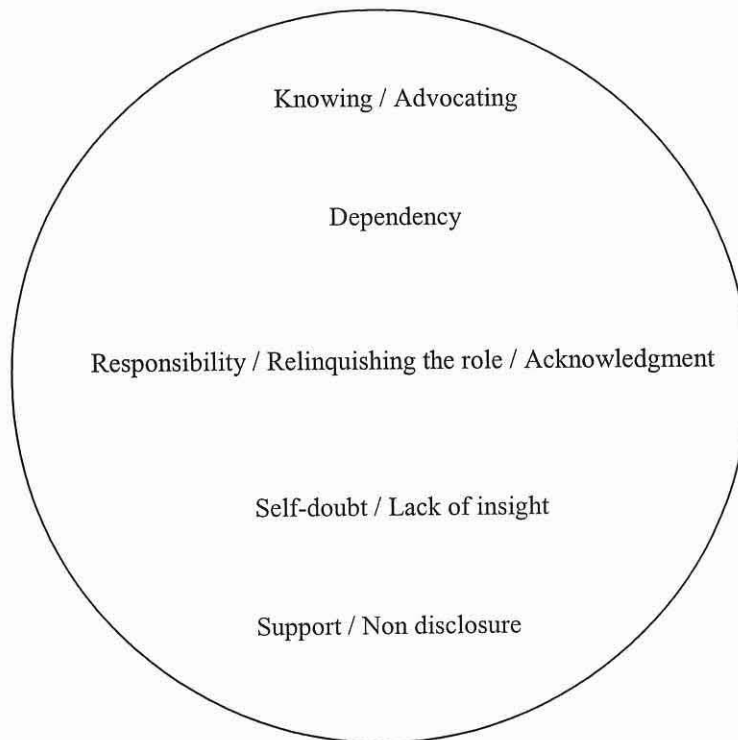
**Support and Non-disclosure** – The transcripts reflect the importance of support within the family, particularly in regards to decision making. For Marie she felt in her caregiving roles family support varied, feeling the family “*shared this quite well when caring for Dad*” to stated feelings of abandonment when caring for her mother. Issues in regards to the ‘pull’ of a violent, abusive father and the impact this had on family dynamics/relationships and the chronic ongoing nature of caregiving for her mother may have contributed to the family’s abandonment, as perceived by Marie.

Within the work environment support by colleagues and bosses was seen as important. However, it became obvious it was often an unrealistic expectation, particularly as Marie didn’t make it known to those she worked with, of the input and energy required by her for the caregiving roles within her family outside of work. The so called ‘silence of nurses’ and the reasons why they choose not to disclose information about their personal lives to colleagues or bosses, even when it is having a detrimental effect on their health, is an issue that has major implications, thus it requires further exploration. Of particular concern is that health professionals working in the ‘caring profession’ feel that the caring work they perform for family members is something you just do, often with a lack of acknowledgement or insight into the impact such work has on all aspects of one’s life.

**Implications of Caring** – When reading transcripts and discussing data with Marie it became obvious that through telling her story she achieved some clarity about the

effects of the caregiving role on her. Marie described how a year after her father died, *"it all just sort of came crowding in..."*. She also disclosed *"... now that I look back on it, it was an enormous pressure really"* and in hindsight *"I probably needed to have quite some months off work and never did – I sort of worked through it the best that I could"*. For Marie the depression and anxiety she began to suffer within the year following her father's death continues to be an ongoing problem fourteen years later. Whether the depressive illness is a direct result of Marie's caregiving roles and associated stresses may remain unanswered, but an acknowledgment by Marie regarding future caregiving roles/options for her mother that *"I don't think I could cope with that myself"* and the change she feels in responsibility since shifting to a new town emphasize the effects caregiving for family members who have been ill, elderly and suffering from an enduring illness has had on her.

**Figure 1 : Diagram identifying themes from Marie's Stories**



Emerging themes identified from Marie's stories of her caregiving experiences are shown in the centre of this circle.

### **Polly's Story – 'It's about caring for one's own'**

Polly is a 60 year old comprehensive nurse who currently works full-time in the psychiatric field. She has trained as a teacher, commenced her training as a psychiatric nurse at age twenty-one, bridged to comprehensive via completion of general nursing training in the 1980s and completed her Bachelor of Nursing degree in the 1990s. Throughout her working life Polly has had many varied jobs, including management and clerical work and has left nursing several times as she has felt it was "*... burning me out*", only to return, stating "*... but I always come back to it*". She validates her choice to work in the psychiatric field as she compares it with general nursing "*... it's something you're doing to the person, as where with psychiatric nursing you have the experience of getting to know the person*".

Two major factors influenced Polly to choose nursing as a career. The first was, when nurse aiding at age seventeen at a psychiatric hospital, "*I felt these people are treated worse than criminals and they've done nothing wrong ... I think it was just in the back of my mind, that it intrigued me, psychiatric nursing and I think that's why I went back*". The second factor that influenced Polly was "*...when I was twenty my father was dying and I stayed home so he was allowed to come home and die. It was sad, but a wonderful experience*". What was particularly unusual about this was that it was during the 1950s when people were normally cared for and died in hospital. Polly says, "*it was wonderful to see that he could go on every day as long as he could, independently, without it having to be a medical thing. He was dying, but it was lovely to have him at home*".

In relation to how this has influenced Polly's working life, she describes nursing as: *"a way of life that you choose, it's not just a job ... it's not just a job that you do at work, unfortunately. You've got to say to yourself, now listen I'm off work now, but you tend to do what you shouldn't do, that is be the caregiver all the time and forget about yourself. But I think that it does become a way of life..."*

### **Family History**

Polly is of European/Pakeha descent. She is the middle child in a family of seven children. She has three older sisters, two younger brothers and one younger sister. The children are all close in age with approximately fourteen months between each child. Polly states, *"I think that's better too, because if you grow up close together in age like that you've got your rules and you care for each other because you're used to living with each other. So the family's very important to you because I think you rely on your family more. You don't have to have friends when you're young, because you've got all your family looking after you, haven't you, so your family are your friends as well"*.

Polly was brought up in the country and, with the exception of a ten year stint working overseas has remained in the same region. Many of Polly's siblings still live close to her. In Polly's family two of her sisters are also nurses with a third sister commencing, but not completing her training. Both Polly's parents are deceased.

Polly was married to Robbie for eighteen years before they separated ten years ago. From that marriage they had two children who are now in their early twenties. After the separation Polly brought up the children with input from Robbie via weekly phone calls and visits several times a year. Robbie had been married before and had three children

from his previous marriage. These children did not live in the same country. Polly stated that although Robbie was a *'drinker'* they remained good friends, had regular contact and Robbie would stay at her house several times a year when he came to visit.

Polly identifies with strong religious beliefs that she feels have influenced her life in many ways including her decisions to care *"... like if you've been brought up with – you help other people; he's my brother concept that influences you too"*.

Polly has her own home, which she shares with her son and her daughter's two dogs. She was known to the researcher on a professional basis prior to participating in this research project.

### **Caring roles**

Polly had volunteered to take part in this research project to share her story of caring for her estranged partner and friend Robbie. However, during this process Polly also talked about caring in relation to her father (as previously mentioned), her mother who died in hospital and her brother who suffered from depression. To understand and value the impact that these caregiving experiences have had for Polly I have incorporated them into Polly's story, albeit in varying depths, as the main focus will be on the caregiving role Polly had in relation to Robbie.

### **Caring for Mum – Mum's Culture**

From the beginning of her story-telling Polly spoke of a culture of *"caring for one's own"* and described how her mother had always cared for family members including her father when he was dying. *"I guess it's a way of life isn't it? It becomes part of*

you". Polly's assumptions that it becomes a way of life can be supported by the influence of this caring culture within Polly's family as highlighted by the fact that all three of Polly's sisters chose to go down the nursing 'caring' pathway. Polly also stated in relation to this caring *"It's terribly upsetting when you can't care ... Mum died in hospital. She shouldn't have really, but however"*. This statement by Polly demonstrated a feeling of letting her mother down and not honouring the culture within the family.

### **Caring for Shorty**

Shorty was Polly's younger brother. He also spent time overseas when Polly was overseas so had always been a presence in her life. Polly had been involved over the years in caring for Shorty who suffered from alcoholism and depression. Polly stated one other sister in the family who was not a nurse *"... always took responsibility for Shorty"* so between them they looked out for him. She describes herself as probably being the *"... most constant person in his life"*.

Several years ago Shorty became depressed and Polly arranged to take him to see a psychiatrist. Polly planned to attend the appointment as a family member to support Shorty and to help advocate as she worked in the psychiatric field and knew the majority of the staff working in this area. She describes this experience, *"I said to the doctor, look you should get someone else in (health professional) and he said no you come in because you've got all the knowledge on it you know. They would have made him stay in hospital, but because Shorty said, "Well I can come home with you can't I? I'll stay with you", and I said "oh yes of course you can, but had it been someone else he would have gone in (to hospital) because he was really depressed"*.



Polly's brother was not admitted to hospital, instead returning to his own home and during his depressive phase he disappeared into bushland with his remains being found a long time after his disappearance. For Polly she describes this as *"a terrible experience"* and how it *"took a long time to get over, because **I thought I help other people, but I can't help my own**".* In hindsight Polly stated, *"When I look back if I hadn't been Shorty's sister and taken him to the doctor... someone else would have taken responsibility for the caring and decision making".* When it's *"...somebody that you know, you know what its like, you think, oh god they're going to be locked up. I thought, now, he'd have to go there, and I couldn't imagine him, and I thought, well no, he could come with me. But when I first went, I really thought the doctor would say, he'd go into hospital, he'll have to go into hospital – he didn't. I am not blaming anyone, but then I think, well, I should have perhaps insisted"*.

Within this caregiving experience the ethical dilemmas faced by nurses providing caregiving for family members are highlighted. Although Polly had organised the psychiatrist appointment for Robbie and gone with him to provide support and to advocate, she found herself in the position of taking responsibility for the decision making in treatment planning with no recognition by the psychiatrist of the impact that loss of objectivity can have when caring for one's family members. The resulting impact when unexpected difficulties arise in the caregiving situation and subsequent implications for the nurse caregiver relationships/dynamics with other family members was not foreseen or acknowledged by the psychiatrist or Polly at this time. As identified

by Polly would the treatment option chosen by the psychiatric have been different if Polly was not a nurse and involved in helping care for her brother?

Shorty's death for Polly not only resulted in shock and grief over his loss, but feelings of self-doubt and questioning of her judgement. The responsibility that goes hand in hand with the caregiving role is highlighted by one family member's reaction to Shorty's death as identified by Polly. *"One sister blamed me. She thought that I had, that I didn't know what I was doing. Well she was probably right in a way, she probably was right. But the others didn't see it that way. They saw it as a family thing, you know, you help one another"*. This in turn raises the question of 'emotional cloudiness' that may affect the pathway chosen to provide care when it involves a family member and the long-term consequences that may result for the nurse/family caregiver. As identified by Teutscher (2003) in her study that the *"choice to care for a family member is a noble one indeed"* (p. 14).

### **Caring for Robbie**

As previously mentioned the main focus of Polly's story is the caring she provided for her estranged husband Robbie whom she had remained good friends with. A couple of times a year Robbie would come to visit Polly and their two children. On his last visit Polly described her thoughts on seeing Robbie. *"I thought this man's dying, you know, he didn't know himself. I knew he wasn't well. I took him to see the doctor"*. Four years previously Robbie had been treated for cancer of the larynx, but prior to travelling had received a clearance from his doctors. Following the G.P. visit with Polly he was diagnosed with cancer of the lung and prostate. Polly states *"... it was a shock really, but I guess I was more prepared... because I was a nurse"*.

On receiving this diagnosis and, knowing Robbie was dying and would not be able to travel home, along with the fact his mother and older children were overseas and would not be able to care for him, Polly made the following choice. She describes this as *"...they (hospital staff) didn't know what to do with him, but I thought that he could come home and stay with me and I would do what I can for as long as I can, so he could die at home if he wants to. Because you know all children have the right to have their father there and go through that grieving, and coming to grips with it. Robbie would never have asked, but I just said to him, 'Would you like to come you know'".*

Polly saw caring for Robbie as an *"opportunity to continue to rebuild the relationship"* between Robbie and his children. She states the *"children were upset about taking Robbie home to care for him (daughter 21, son 17). They didn't understand, but it was a wonderful opportunity because when Robbie had left, when the marriage broke-up, there was a lot of ill feeling with the children, that he had left them"*. Polly subsequently took Robbie home and cared for him over a three to four week period in her house. In the last few days leading up to his death Robbie was nursed in the local hospital with the aid of Polly and his children. Robbie's three children from overseas arrived in time to spend the last day with Robbie prior to his death.

In her role as caregiver for Robbie Polly faced many challenges. These included her children's reaction to her caring for Robbie at home *"... like the children, my daughter and son couldn't understand why you would want to do something like that – why would you want to help someone, look after them, virtually have to feed them, see them so sick*

*and be awake half the night...".* Polly's caregiving role also involved having to advocate for Robbie when he was informed of his diagnosis in an unclear manner. Polly describes this, *"he was rather horrified at the way he was actually told in the end. I mean I had some idea being a nurse, but they (doctors) are not very clear about what they tell people ... we had the misfortune of having two different doctors and the doctor came in and he said, 'you have got lung cancer'. The room was full of visitors. They pulled the curtains around, everyone could hear, and then walked out".* Polly describes being *"appalled that everybody else heard"* and the manner in which Robbie was told. The next day she contacted the doctor and said, *"how you told Robbie that you think he has cancer..."* and the doctor said, *"oh I understood that he understood already".* This was a particularly difficult situation as Polly stated Robbie had difficulty with this as *"he thought he was going to get better".* Polly was left to deal with the emotional aftermath of this incident.

One of the unexpected aspects of Polly's caregiving role for Robbie was the reaction and judgements made by other people in relation to Polly's decision to care for Robbie although they had been estranged, and, because of some of his past behaviours such as being a heavy drinker. This both surprised and astonished Polly. *"A lot of people were horrified. I never thought of anything different, because I thought, you're not going to get back home. I had to; his daughter would have had to look after him otherwise. Actually I got a lot of criticism from people in the community. Even the social worker who had to be involved, she said "Oh I don't know why you're doing this" and I said "Well it doesn't matter, you don't know why".* Polly also spoke of Robbie's mother's

reaction to her caring for him. *"Robbie's mother was actually a bit horrified. She thought I wouldn't look after him properly".*

Polly felt her work colleagues were generally *"... very supportive. There was only one person who said 'Well you know, after the rough deal he gave you, I don't know why you're...' but the majority of people were okay"*. Polly also described an incident where she was stopped by a woman in the street who was a complete stranger to her and who questioned her decision to care for Robbie. As Polly reiterated *"he was a friend, although we had parted as a couple, and he was the father of the children. And there is a bond isn't there when you ... and he's a human being too. We have to respect human beings"*.

During this period Polly described her employers as *"very supportive. I had about a month off. They gave me sick leave ... they were very good. I didn't even have to get a doctor's certificate"*. When Polly was caring for Robbie her work colleagues were aware of the situation, however, Polly spoke of how in her different caring roles over the years she has chosen not to disclose her roles in depth. As Polly stated *"well you didn't take your home life to work did you? And you don't talk about it, and in my day that was it. Work was work and home was home. We were not allowed to discuss it, but today it's different isn't it, or it should be"*. Polly felt in relation to work colleagues, *"We turn a blind eye, because we often see people struggling, and we just don't go there, do we?"* Polly identified several factors that she felt contributed to this lack of support as *"... years ago you had to live in the nurses' home and that was very supportive ...but now you are all individuals, you go to work with your colleagues, but*

*then you go home again". Polly spoke of the lost tradition of informal reflection, "we used to do that orally. We were in nurses' homes. We supported one another and we gave one another supervision, without knowing what we were doing. We'd all rush back and, oh this happened and that happened and you do this. I tell you it's marvellous and the girls don't get that now because they don't live in the nurses' homes". Nowadays it's different. "Where is the opportunity to talk? I mean working in primary nursing, you're on your own, and you're not sharing. Lots of times when you work with someone else, you're making little comments and you're picking up (notice things were wrong) wouldn't you? But you don't, because it's primary nursing now. Nursing has become too isolated in a way". However, Polly felt that in regards to one of her workmates she had worked alongside for a long time "I can read her and she can read me. We know because we've worked together".*

During Polly's story-telling the opportunity for reflecting on her caregiving roles and how this may influence future caregiving came to the fore. In relation to caring for Robbie Polly described this as *"... I felt good about it. I had got over the bitterness of the marriage break-up – it showed that I truly had got over it because I didn't mind doing it one bit".* Polly spoke of the experience as *"getting a lot from caring for someone who was dying"* and *"... there's something, no I don't know what it is, but as you get older, your life experiences, you learn don't you? You couldn't do it perhaps when you were young, because you haven't had the life experiences to understand".*

However, in relation to the caregiving role for a family member suffering from psychiatric illness Polly felt *"I could be involved, but I think if it was psychiatric I*

would make sure somebody else was there to make those decisions". Polly talked about mental health issues and family members and, in her experiences, the impact of being involved in caring. *"It spoils the family relationship"* and *"they don't forget, and they don't forgive"*. She also felt there was a lot more expectation on family to provide *"community care"* now for mentally unwell relatives. Polly summed this up as *"I mean I would deliver care, but I wouldn't make decisions about where the care was. I'd step back from there, and if they (the professionals) said that it was alright, I would offer my services"*.

### **Emerging Themes**

The main themes highlighted within Polly's stories of her caregiving roles are identified below. As with other participant's stories these themes will be explored and compared in the following chapter.

**Nursing/Family Culture:** Polly described being brought up in a culture of *"caring for family, and caring for one's own"*. This family caring culture was highlighted by the fact that Polly's three sisters all chose to go down the caring nursing pathway. The influence of this culture can be seen in Polly's caring for different people, wanting to get to know the people she is caring for, and her return to nursing on several occasions after working in different occupations. It can be summed up by her own definition, *"nursing is a way of life"* and feeling that her mother should not have died in hospital. For Polly her family culture of caring influenced all aspects of her life and was important in helping her to remain strong in times of uncertainty. She spoke of being brought up with the concept of *"he's my brother"* and looking out for people. However, within this family caring culture it is also important to note that although

Polly had several sisters who were nurses the main responsibility for the caregiving for her brother Shorty when he became unwell was taken on by Polly and her sister who had not completed her nursing training. This was possibly due to her field of expertise and issues of accessibility.

**Advocating / Knowing:** Advocating was a role often acquired through expectations of family members that the nurse family member would have the knowledge to deal with the situation. In her caregiving experiences Polly spoke of the need to advocate for both Robbie and Shorty when dealing with doctors. On reflection, however, it was Polly's feelings in regards to advocating for people locked up in psychiatric hospitals when she was seventeen that influenced her decision to go nursing, and in turn, her role as a nurse. The concept of 'knowing', and the expectation by others that you should know because you are a nurse, were both highlighted in the text. Polly spoke of knowing that Robbie was dying before he visited the General Practitioner (GP) and when visiting the psychiatrist with her brother the expectation that her nursing knowledge and experience would assist in treatment planning. As demonstrated in Shorty's story this expectation and lack of acknowledgement of the emotional aspects involved when caring for family members by the psychiatrist resulted in Polly's knowledge possibly being disadvantageous to treatment outcomes.

**Responsibility:** In Polly's caregiving role for her brother Shorty she spoke of sharing the role with another sister, although she took responsibility for organising contact with the specialist when required. As previously noted, although Polly had two other sisters who were nurses they did not play a major role in caregiving or decision making and the



sister who did share that role was not a nurse. In relation to caring for Robbie, Polly was clear about the fact that, for her, it was a natural choice that did not require any consideration. However, the responsibility Polly felt in caring for Shorty and the subsequent tragic outcome have affected Polly to the extent that in future caregiving roles for family members she has identified that although she would help provide care she would not be responsible for the decision making in regards to professional treatment planning.

**Judgement / Self-doubt / Self-Blame:** For Polly the death of her brother while suffering from depression has impacted and will continue to impact on all aspects of her future caring and highlighted the responsibilities and ethical dilemmas associated with providing care for loved ones. Feelings of self-doubt, in relation to judgement and the questioning of whether one could have done things differently, are constant thoughts for those who have cared when outcomes have not been positive. In Polly's situation this was compounded by one family member blaming her for 'not knowing' what she was doing. Judgement by people (professional and non-professional) about Polly's decision to care for her estranged husband in the last weeks of his life resulted in Polly being questioned by many different people as to whether Robbie "*deserved*" to be cared for by her. For Polly she was clear that the decision she made was the right one and "*the natural thing to do*". However, in relation to the decision making and caring for her brother Shorty, Polly identified a loss of objectivity, which in turn resulted in feelings of self-doubt and self blame, a cost of her caregiving.

**Support / Non-disclosure:** Polly described feeling supported by work colleagues and bosses when they were aware of her caregiving roles, as evident by the time off she was given to care for Robbie. The District Nurses provided physical support for Robbie when requested by Polly. Although Polly spoke of feeling supported by work colleagues and employers in her caregiving roles she also talked of not discussing these roles or the responsibilities she carried outside of work. In explanation Polly stated *“you don’t take your home life to work”* and that she felt *“nursing has become too isolated...”* so there is little opportunity to share. Polly also spoke of nurses *“turning a blind eye when they saw colleagues struggling at times”*.

**Impact of caregiving:** When reading the transcripts of Polly’s stories in relation to caregiving the influence of Polly’s family culture played a major part in her decision to care. Through her experiences Polly identified the positive aspects of caring for Robbie when he was dying and how her nursing career may develop in this direction. In her role of caring for Shorty the shock and grief that resulted from his unexpected death has impacted on how Polly would consider her caregiving role with a family member in future. Polly stated that it is still a role she would perform, but with limitations on the responsibilities she would carry. Polly’s statement that *“ nursing is a way of life you choose, it’s not just a job ... it’s not just a job that you do at work unfortunately”* sums up both the positive and negative aspects of being a nurse. Polly identifies that although the choice is made to become a nurse, once that choice is made it involves providing care, whether it be at work or home, and there really isn’t a choice when it comes to the family caregiver role as it is acquired because you are a nurse and it’s part of the nursing culture.

**Figure 2 : Diagram identifying themes from Polly's stories**



In Figure 2 emerging themes from Polly's caregiving stories are represented in the circle.

### **Frances's Story – 'Knowing you've done your best'**

Frances is a 46 year old psychiatric nurse of European/Pakeha descent. On leaving school Frances worked in the clerical field for two and a half years prior to commencing her community nursing training. The decision to go nursing was influenced by her desire to travel overseas and, as she describes it, "*I thought it would be a useful skill to have*". On returning from her overseas experience she decided to train as a psychiatric nurse and has continued to work in this field, in different roles, since completing her training twenty years ago.

Except for time spent overseas Frances has lived her whole life in the same rural area. She is married with a supportive partner. Frances is the youngest child from a family of six children, three girls and three boys, and as described by Frances in relation to the caregiving roles in her family "*we were fortunate as a family ... that the six of us all lived locally*" - an unusual occurrence with today's mobile population.

Frances volunteered to share the story of her role in caregiving for her mother over a long period of time, but within her story evolved another – that of the caregiving role she played for her father. With this in mind I have chosen to divide Frances's story into three sections, that is, 'caring for Mum'; 'caring for Dad', and 'moving on'. As to be expected parts of the stories may overlap or intertwine.

Frances was known to the researcher on a professional basis prior to participating in this research project.

## Caring roles

### Caring for Mum

Frances's caregiving role initially began when her mother, at 67 years of age, had a major stroke and was given a poor prognosis, not being expected to live long. However, Frances describes her mother's recovery as wonderful. From the beginning Frances describes *"working as a family"* and *"putting a system in place for home with a few minor physical alterations"*.

This worked well until a few years later, when Frances's mother had several TIA's and strokes, resulting in deteriorating physical health and her requiring more support and assistance. As Frances describes it *"there was the professional care and the family care"*. During this period Frances's father was vital in providing a supervisory role, while the family organised professional care filling the gaps with a family roster system. *"We had a whiteboard in the kitchen which we used for communication between family members, as neither parent had good short-term memory"*.

From the beginning the family members decided to have a family meeting *"we decided we needed to have our space as well, so Mum and Dad were open to employing someone..."*. This system worked well with family providing all the care over the weekends until a further deterioration in Frances mother's health to the stage she required *"someone to stay overnight"*. The family organised *"professional help four nights per week and the family did the next three nights"* as stated by Frances *"so we just did a roster and we worked out what the need was"*.

Frances was responsible for writing up the roster and felt this was a job she acquired “... *because I’m an organised person*” and not because she was a nurse. She did, however, take on the role of liaison and advocating which she describes as “*being a nurse, talking to health professionals and GP appointments and that sort of thing – that was left to me, because I think I had working relationships, anyhow, with my job and I knew some of the staff within the hospital system and it makes it so much easier when you know them. You can talk to them and get advice or direction and support*”.

During the next few years as Frances’s mother’s health deteriorated the family continued to care for her with professional help and the use of services such as district nursing and physiotherapy. Although Frances’s mother’s needs were intensive enough that rest home care would probably have been an easier option Frances stated, “*we (as a family) decided to do this. We knew that it was Mum’s wish, but the other part of that equation was that Mum probably towards the end needed to be in care, but Dad wasn’t open to her going into care and as a family there was no way we could part them. You know, even though it was getting quite hard and stressful – it was part of what we did*”. Throughout these times Frances was supported by her husband and describes the situation as “*there were no qualms about it. On my three nights he would come and sleep over and we will do the same for his family if needed*”.

The care provided by Frances’s family for their Mum can be summed up in Frances’s words, “*as the family saw it, they were really good parents to us as kids and adults, but it was our turn now, because your roles reverse really, and it was our turn to repay*

*that, and we were able to do that. I think the fortunate thing was with our family we did work in together and we all had the same goal”.*

When discussing with Frances how co-ordinated and effective the system that they had organised to share the caregiving responsibility for their Mum was it was suprising to hear Frances state “... *apparently some families have no idea, but I didn’t realise that, I thought it just came naturally, the desire, the culture to care for one’s own”.*

One situation that did arise in relation to her mother’s caregiving was when Frances and her sisters went overseas on a pre-arranged holiday. Prior to the holiday Frances’s mum had been hospitalised with the plan for her not to be discharged until they returned. However, during this time she become ill with pneumonia and, in consultation with her brother who was listed as next of kin, the physician decided to commence her on antibiotics to try and keep her alive until the daughters returned from overseas. Frances was taken aback by this decision and recounted a discussion with her brother as “*And like I said, but you shouldn’t have said that we’d, we wouldn’t want our Mum to suffer anymore, you should have just...*” and he stated “*Oh, but you would never forgive yourself being away and coming back*” and I said “*yes, it would be okay for me, it would be okay for me to come back and say, hey your mother’s died, because we knew we’d done our best and cared for her. So that was, I was really taken aback. So it wouldn’t have been my decision. I would have thought all the family would have thought that, but because we were away, he (my brother) thought, oh no she can’t die while were away, but to me she could have*”. On reflection Frances stated that she did not feel her brother’s decision to keep her mother alive until she and her sister returned

from overseas was the family waiting for her to make a decision about what to do because she was a nurse. Frances's mother died seven years after her first stroke, with the caregiving role fulfilled by the family in varying degrees over those seven years.

### **Caring for Dad**

Shortly after Frances's mother died her father had a stroke. He had previously had health problems. "So it was like, for our family, thirteen years of caregiving for our parents. It was a long time. Dad's stroke wasn't as dense, but his recovery wasn't as good initially, so we did the same for him basically. He was originally quite good and then he had little TIA's, not unlike Mum, and just deteriorated". To some extent the family had been providing some care for their father prior to their mother's death and as Frances noted "it's like when you're caring for one, it's just as easy to care for two almost, and that was part of the package". Although there were similarities in the caregiving roles the family performed Frances describes her parents as different personalities requiring different input from the family. This was highlighted by Frances speaking of *"one of the difficulties experienced was in trying to ensure Dad still enjoyed his hobbies like going to the races and the pub and as he got more frail and more disabled, that really became a huge effort, but one sister took that on board to drop him off and pick him up, but it was quite stressful..."*.

During the time Frances was involved caregiving for her father as well as working full-time she had several other major commitments and, on reflection, recounted thinking *"... oh my god, what have I taken on? I said to my husband, 'I will need your support' and he said 'well what sort of support will you need' and I said 'I don't know', but I did in the end. I said 'look if you can cook all the meals...'".*



Frances continued to work full time over the thirteen years she was involved in providing care for her parents. During this time she did not take any sick leave to care for her parents and stated “... *it was never offered and I never asked for it*”. When asked about supportiveness of work colleagues Frances stated, “*unless I was asked about it, I never talked about it. Some more distant work colleagues were aware of my role due to living in a small community and through a connection to some of the services like physio and district nursing that the family was utilising. I suppose I didn't come to work and tell them about it. You don't talk about it (your caregiving role) unless people ask. I never spoke about it, because I thought, you know, everyone's got their um, you know ... well I didn't see it as a problem. But because they're busy...*”.

In relation to her bosses during this time Frances stated, “*I don't think they would have been aware of the detail, the roster, the involvement and the time commitment. And because I was never really off sick myself and never took sick leave for caring for my parents, it was never highlighted I suppose to them. And if people didn't ask, I didn't offer really*”.

Frances felt that through her job in the community she had “*greater flexibility to check on her parents*” if needed.

Frances spoke of several stressful situations that arose during her father's illness and the impact of these on the family. The family members were continuing to care for their father using the combination of family support and paid help. The first difficult situation related to Frances being contacted by the local GP who she used to liaise with in regards

to her father's health. She said, *"it's time to do something you know, about the need to look at placement due to his deteriorating physical and mental health"*.

On reflection Frances describes this as *"I think the hard part was we knew that he didn't want to (go into care). And we tried to support that at home and it took someone here (the GP), because you are emotionally involved. I don't think you can. You don't see it objectively and it took her (the GP). That was a lot of steps removed, to actually say that and also being a professional. If it had been someone else, perhaps I may not have taken any notice. But it's your GP saying 'hey you know, this needs to happen'. You don't want to see it and you're still working hard as a team, as a family to support him, but you know he's getting slower and frailer and all of that, but because you know, deep down that he doesn't want to go and you don't want to make that decision"* The GP suggested Frances's father needed to have a psychogeriatric assessment with the view of placement in the local psychiatric hospital. Frances describes this, *"I had to co-ordinate our family meeting and that was terrible, that was terrible, to actually think that my father was going to be in there (the psychogeriatric unit) for assessment, but I could see it needed to happen. So as a nurse, that was very much part of it, you know, the GP liaised with me"*. The psychiatrist who was a work colleague was supportive and Frances stated she was *"just absolutely wonderful"*. However, the day the assessment was to take place Frances's father became physically unwell, resulting in admission to the General Hospital. *"I was relieved for my father that he didn't have to go through all that, but I know that they're (staff at the psychiatric hospital) absolutely wonderful. But I thought, oh, this is the worst day of my life, having to put my father into a psychiatric hospital for a psycho-geriatric assessment"*. In relation to this arranged admission

Frances felt some family members thought she may have been behind the decision to have her father admitted to the psycho-geriatric unit. *"I think some of my brothers and sisters may have thought I was behind it more than the GP..."*. In summary Frances felt *"the responsibility and knowing the system that was probably the nurse coming out, and while the GP was involved with me, it was terrible as a family to think that our father may have been going to end his days in there. There are so many connections with our family with psychiatric hospitals, so I don't know why it was so devastating, but that's how I felt at the time. I was relieved in a sense that he ended up in a medical ward. He would have hated being in a psychiatric hospital and the family were quite traumatised at the thought of a psycho-geriatric unit"*. This situation identifies one of the ethical dilemmas faced by those as a member of the family and as a nurse, when although there may be an awareness of a family members deteriorating health, it requires a health professional who is not emotionally involved to take over and make decisions about care planning and treatment. The need for nurses to acknowledge the 'emotional cloudiness' or loss of objectivity and how it can affect decision making about caregiving when you are both the careprovider and a family member is demonstrated. The effect this decision making has on family relationships and the difficulties that may arise are also highlighted.

One of the most stressful times was when Frances's father was readmitted to hospital *"and this was at the beginning of the end", but we didn't know that. We didn't know how long he was going to live. He wanted to go home. We were given relative relief in the local rest home, but one family member in particular thought Dad wanted to go home to his house, not just the town we lived in. It was devastating. It was just a huge*

*thing for that particular family member to think he didn't get his wish. I was prepared to take annual leave if I knew it was going to be three months or so. We just didn't know that he was so unwell at the time and he only did last three weeks. I felt terrible about it - which was probably the nurse coming out in me. That was quite a sad thing for our family I suppose. I think that it was always a regret for that family member, that we, that she didn't insist that we did take Dad home and care for him. This was like full time, one hundred percent... like someone would need to be in the house, whereas my father was in the house with our mother... and we knew she was really unwell and it was only a matter of time". Frances's father died within a few days of being transferred from the general hospital to a private hospital in his home town.*

### **'Moving on'**

*"After our parents died it was a gap, but it was like, I knew personally and I think all the other family members knew, we did our best for them and we had no regrets basically. I look back now and think how did I do it? It's like when you have to do something, you do it and you get on with it. And when it seemed overwhelming, that's how I used to break it down, just one day at a time. You just feel absolutely exhausted or think oh my god, how did I do that?"*

Throughout the caregiving roles Frances performed for her parents she stated *"I never felt totally responsible, because there were five others. The co-ordination was fine. I never felt I couldn't hand it over to someone when I got tired. I suppose I must have got tired, but just kept doing it really. You just needed to do it at the time. You just do it. As*

*a family, I don't think any of us – I can't speak for everyone, but I don't think any of us would have any regrets... we know that we've done our best"*

In relation to future caregiving roles for her husband's parents Frances felt *"I'd do the same for them, because my husband was so wonderful with my parents, so I'd like to return that for his. And that wouldn't be a problem"*.

### **Emerging Themes**

**Family Caring Culture:** Within Frances's caregiving roles the togetherness of her family and the shared responsibility was evident. Frances's expectation and the assumption that all families perform the same roles when required - *"apparently some families have no idea, but I didn't realise that, I thought it just came naturally"* - emphasizes the culture within her family, that it was their role. The fact that Frances's brothers and sisters shared this role equally was highlighted. Within this caring culture dilemmas about where and what type of care should be provided arose. Frances spoke of the dilemma faced by family members when their mother was unwell and different treatment options were offered. Ethical dilemmas about her father being assessed in a psychiatric hospital and whether to care for him at home at the end stage of his life were particularly traumatic for the family. For Frances this was exacerbated by the emotional cloudiness that arises when one is not only a family member, but a health professional involved in the caregiving role.

**Advocation / Liaison:** Throughout the time Frances cared for her parents she was the person who advocated and liaised with health professionals. She felt this was directly related to the fact that as she was a nurse working in the community and she had

working relationships with most of the health professionals, including knowledge of how the system worked. It made it easier for co-ordination. Frances described family members feeling that this was her role and they were happy for her to take control.

**Responsibility for Decision Making:** Although Frances's family shared the caregiving roles for her parents, when crisis resulted or a major decision needed to be made the family looked to Frances for direction. They believed she had played a major role in decision making with other health professionals. Initially Frances did not seem to be aware of the connection and responsibility that appeared to be her role by virtue of being the nurse, but on reflection, she can recall the feelings and trauma they evoked. These involved decision making about organising a psychiatric-geriatric assessment and possible admission to the local hospital and whether to take her father home when he was very unwell physically and required full-time nursing care or to place him in hospital care. Her brother's decision to keep their mother alive until she returned from an overseas holiday, a decision she could not understand, highlighted her assumption that all family members would think like her and make decisions similarly. Although not directly responsible for making caregiving decisions alone, Frances's knowledge and guidance was sought by family members.

**Support / Non-disclosure:** Because Frances's family shared their caregiving roles Frances felt supported by her brothers and sisters. Her husband played an equally important role in the caregiving, supporting Frances and physically assisting with her parents. Support was also provided by physiotherapists and district nurses, but not by employers or colleagues to any major extent, though this was possibly due to Frances's

non disclosure of her caregiving roles. Throughout the thirteen years Frances provided care and support to her parents she spoke of not disclosing her role with colleagues or employers. Frances stated *"unless people asked I didn't tell them"* and spoke of her colleagues all being busy people. As Frances managed her caregiving roles without taking sick leave she did not discuss this with her employers, though she felt that as she lived in a small town they would have possibly been aware of it. They did not approach or discuss it with her. Frances was never offered sick leave to enable her to perform caring duties.

**Loss of Objectivity / Lack of Insight:** In relation to family caregiving Frances spoke of the situation with her dad when it took the GP, someone not emotionally involved, to point out to her the degree of his failing health and the need for re-assessment. Frances described this as *"... because you are emotionally involved... you don't see it objectively. You don't want to see it"*. This highlighted a possible emotional cloudiness that appears to become part and parcel of the caregiving role when it involves relatives or significant others.

**Figure 3 : Diagram identifying themes from Frances' stories**

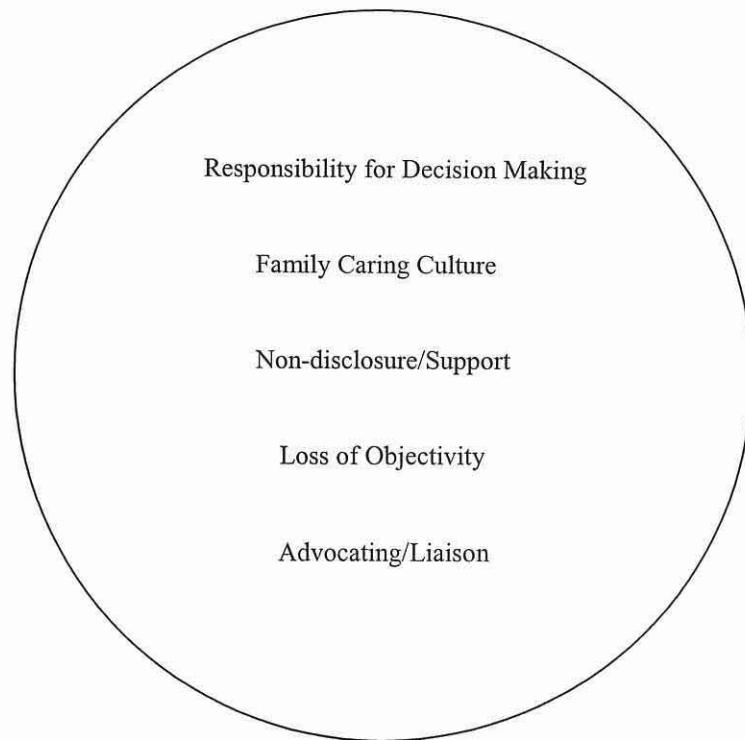


Figure three represents the emerging themes identified within Frances's caregiving stories.

### **Conclusion**

This chapter has incorporated the stories of three female nurses retelling their experiences of caring for a family member who is ill, elderly or with an enduring illness. Emerging themes within each participant's story have been identified and then presented in diagrammatic form for visual clarity. The following chapter will explore, in more depth, core themes common to the participants' retold experiences.



## **Chapter Six**

### **Exploration of core themes**

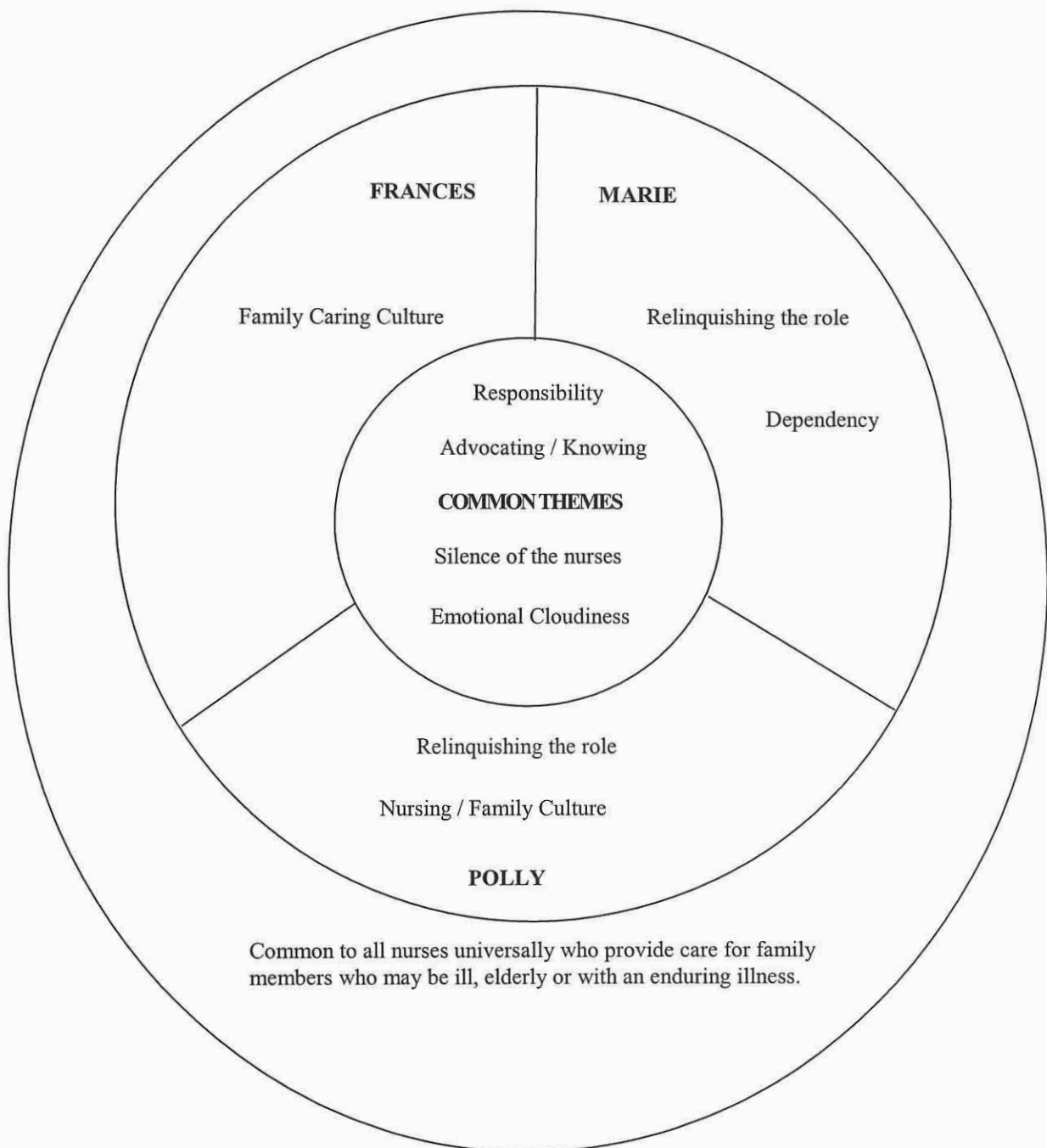
In this chapter I have identified and renamed the main themes that are common within all three participants' stories and will explore their meaning in relation to findings from the literature search detailed in Chapter Two and throughout this research project. Due to some identified themes being interrelated I have clustered common themes under several main headings to highlight research findings. These themes have not been listed in any particular order of importance.

- 1) Culture – incorporating the principles of nursing culture and family culture.
- 2) 'The Silence of the Nurses' – incorporating the themes of non-disclosure of caregiving roles and support.
- 3) 'Emotional Cloudiness' – incorporating the areas of loss of objectivity; self-doubt; judgement, self-blame and ethical dilemmas.
- 4) The 'natural' role of the nurse through the nurse's eyes – incorporating responsibility; advocating, liaison and knowing.

As previously mentioned, through the telling of participants' stories it became apparent that all three participants had been involved in multiple caregiving roles. The impact of and differences of these roles are discussed at the end of the chapter. In the previous chapter the caregiving stories of Marie, Polly and Frances were relived and retold. At the conclusion of each story the main themes were identified, summarised and presented

in diagrammatic form for visual clarity. The diagram below illustrates common themes from the three stories.

**Figure 4 : Common themes identified in the stories of all participants**



While in the process of developing this diagram it was suggested to me by one of the supervisors involved in the overseeing of this research project that I identify where I am

situated in the diagram. However, without going through the process of telling my caregiving story (autobiography) in full detail and identifying my emerging themes I did not feel I could truly justify placing myself alongside the women who have retold their personal caregiving experiences to enable me to complete this research project. Yet, when discussing research findings, I have found myself reflecting on my own experiences and the sense of having similar experiences or expectations and behaving in a similar manner in my family nurse caregiver role as those disclose by the three research participants. Although I have identified themes common and unique to each participant's stories as identified through the process of emplotment (Emden, 1998b), when considering themes I had classed as unique to each nurses caregiving role and looking at where I myself was situated and what themes I associated with my role I became more aware of what the research findings truly identified. In reality each theme identified is common to all nurses and within the caregiving roles that nurse family members perform there is an expectation by family members that they will provide care - they will advocate and take responsibility for organising, decision making and providing knowledge. All nurses base their care on the culture of caring that is part of being a nurse – the essence of the profession. The caring culture that is passed on through our families is what may possibly lead towards choosing the occupation that is based around caring - nursing. To illustrate this in diagrammatic form I have incorporated my findings by drawing a third wider circle encompassing all the themes identified that represent all nurses universally, as within each participants, and my own stories to varying degrees. Themes identified are able to be located or resonate with experiences remembered and retold in all stories. As noted by Polkinghorne (1988, p. 167) when completing research “The researcher’s experience with many narratives

allows him or her to produce a description that includes comparisons and contrasts *within the story under consideration and between this and other stories*". Polkinghorne also states "yet the uniqueness of the particular narrative being described by the researcher is as important as the feature it has in common with other stories" (1988, p. 169). Within this project although comparisons have been made about the themes identified in each women's stories, this does not undermine the value, significance, uniqueness and individuality of those experiences. In the following sections discussion around the four re-labelled themes will be documented.

### **Culture of nursing / Family culture**

Within the participants' retelling of stories the cultures of nursing and family were identified as factors that were instrumental in influencing the nurses in their caregiving roles. Suominen, Kovasin and Ketola defined culture as finding expression in learned, shared and inherited values in the beliefs, norms and life practices of a certain group, *guiding their processes of thinking, decision-making and action*. Past events and the anticipation of future are both reflected in culture (1997, p 186). Although there is limited research available within nursing about what is nursing culture Suominen et al, (1997) noted that "nursing culture has its own distinctive characteristics: a common language, common rules and rituals, and common dress" (p. 187) whereas Asad (1986) defined family culture as "in it's broadest sense, culture has to do with deep and invisible structures in society which are transferred from one generation to another. The concept of culture in this regard, implies some kind of 'social tradition' through which people create collective history (cited in Suominen et al, p. 186). Of interest in regards to defining culture is the beliefs of Holland (1993) who argues that "nursing developed it's own 'special knowledge' in order to make a distinction between caregivers at home

and that given in hospital” (p. 1462) which is particularly relevant when considering the context of this research project and issues of nurses providing care at home for family members. Findings in relation to culture in nursing and family as identified in this study are recorded below.

Nursing culture: An acknowledgment of the cultural expectation within nursing that once you have trained as a nurse there is an obligation and a desire to care was evident. None of the nurse participants considered that once they finished their paid work for the day that their role as a nurse also finished. This was best highlighted by Polly, in her story, when she said, *“I think nursing is a way of life that you choose. It’s not just a job ... it’s not just a job that you do at work, unfortunately. You’ve got to say to yourself, now listen, I’m off work now, but you tend to do what you shouldn’t do, that is, be the caregiver all the time and forget about yourself. But I think it does become a way of life...”*. This can be supported by the fact that although two of the participants had left nursing to try different occupations and could identify the stresses of their jobs, all three remained in nursing after a period of between two to three decades following completing their initial training. As best described by Benner, Wrubel and Lazarus “Caring is embedded in personal, cultural meanings and commitments” (1981, p. 171). As previously noted in Chapter Two in the literature search the caregiving role is often dictated by societal and cultural expectations.

Family culture: Both Polly and Frances also described a culture of caring within their families that you looked after your own and described it as a natural thing to do. This is also highlighted by Marie’s decision to care for her father, even after taking into

account the effects of her father's alcoholism on the family life and after describing her upbringing as '*horrible*'. For Polly this was evident in her choosing to care for her ex-husband with the respect and dignity she felt all human beings deserved. Frances's comments that she assumed all families would provide care for family members who required it and it was the natural thing to do demonstrated that nurses often are not aware of their own expectations that it is their duty. As identified by Kersey in her research, "caregivers had a strong sense of moral duty and felt bound by their Christian beliefs and marriage vows" (1999, p.35).

### **'The silence of the nurses'**

In this research project it became evident that although all three participants were involved in multiple caregiving roles over varying lengths of time, none of the participants discussed their roles with either work colleagues or employers unless a crisis developed, or, as in Marie's case, when employer involvement could not be avoided.

Further to the participants' stories, when embarking on this research project I was taken aback by the number of work colleagues who had previously been involved or were still involved in caring for a relative without close work colleagues being aware, of this. I was only privy to this information when my own role as a researcher with this interest was disclosed. On reflection, I realise, in my own situation it was something I chose not to discuss with my employers or colleagues, unless they asked, or a crisis developed that required me to request time off work. When I question why this was, I felt it may be in relation to the need for privacy and personal space along with the fact that life as a nurse is busy and often stressful enough without staff taking personal stresses to work.

For me, in my own situation, the importance of respecting my brother's privacy also contributed to my silence in regard to my caregiving role. When listening to the women's stories I also wondered if the nurse caregivers felt that they would be seen to be not coping if they spoke of their roles and requested time off to fulfil these roles, although this was not identified by the women themselves. As identified by research findings, all three participants felt that their caregiving roles were personal and that it was not something they readily discussed with work colleagues or employers. Marie, Polly and Frances all spoke of work colleagues being busy and not wanting to burden them about personal issues. Marie stated *"you try not to take it to work really, don't you?"* Polly explained this as *"Well, you didn't take your home life to work did you?"* and Frances commented, *"I didn't come to work and tell them about it. You don't talk about it (caregiving role) unless people ask. I never spoke about it..."*

The reasons for this silence by nurses about their caregiving roles requires further research, but of interest in relation to this study are Polly's thoughts about the impact of primary nursing and nurses working more in isolation now, which in turn provides less time for social interaction. This can be supported by the findings of Ross et al, (1994), that the busyness of the nurse's working days and the casualisation of the workforce are also changes that have possibly impacted on the nursing workforce. Ross et al, (1994) identified that this isolation then creates a feeling of being unsupported in the work environment and that nurses felt more supported by spouses and children, than colleagues and employers.

The relevance of these findings is supported by Gottlieb et al, (1996) as previously documented, in relation to 'work-family conflict stress and job satisfaction among nurses'. Their findings stressed the importance of being supported by employers and colleagues and that the more responsive employers were to family caregivers' demands placed on them, the more satisfied the caregivers were with their jobs. As noted by Gottlieb et al, (1996) nurses were often so heavily taxed by their job responsibilities that opportunities to provide support to work colleagues were limited. All three research participants spoke of being busy at work and not wanting to bother colleagues with their own personal problems or responsibilities. Yet it was interesting that in the literature review in Chapter Two Angus (1994) felt that women found working alongside other women actually "*served to bolster and sustain them*" (p.30) and in turn the sense of satisfaction of providing support to other women was a powerful intrinsic reward for those women. Although the research participants did not disclose their caregiving roles in depth it was apparent that when colleagues and employers were aware to some extent of their roles, they felt they were supported at times, more so with colleagues than employers. For me, as the researcher, this raises questions in regards to if women who felt supported at work identified with this powerful intrinsic reward does this then promote strength of spirit to assist women in the caregiving they do outside of work, often in isolation, with little awareness by other family members of the impact of providing nursing care for family members on all aspects of one's life? This has major implications in the workplace, yet many nurses appear to choose not to acknowledge the fact that caring at home impacts on caring at work, a concept that would more than likely be debated by the research participants in this study, as it became evident that there is also a lack of insight by nurses into how home caring influences work caring



and performance. Davies, (1995) spoke of the findings of feminist academics of the need for women involved in family caring to overcome the silence about the work they do within the family, a principle that is important whether it is family caring or caring for a family member who is ill, elderly or with an enduring illness.

The research participants in this project had all worked full time as nurses and cared for family members who were ill, elderly or suffering from an enduring illness. None of the nurses chose to discuss their caregiving roles with their employers or colleagues unless a crisis developed or it was inevitable that disclosure was required. Consequently this lack of disclosure meant that employers were often not in the proactive situation of being able to provide support due to a lack of knowledge of caregiving circumstances.

Marie acknowledged that it was not until her caregiving role had impacted on her mental and physical state to the extent the amount of sick leave she was taking was questioned that her employers became involved. Marie also spoke of work colleagues covering for her when she was not functioning at the level required. Throughout Marie's caregiving experiences she gave examples of non-supportive employers, for example, when her father was dying and when she herself became unwell. However, one would question if the outcomes may have been different if she had approached her employers and discussed her situation earlier in her caregiving roles. For Marie, the personal toll on her health and the amount of sick leave she took as a consequence resulted in her having to meet with management to discuss the situation, which in turn had a negative impact on her self esteem, to the extent that she seriously contemplated

suicide. Nurses' privacy about their roles outside of work must be recognised as a barrier to feeling supported by both colleagues and employers.

Polly spoke of feeling supported by colleagues and employers, yet in contrast, within her stories it is highlighted that at times she was not supported, for example when the psychiatrist requested her input in decision making, although it placed her in the situation of facing a major ethical dilemma. Polly's comments about feeling at times a sense of working in isolation and the lack of social interaction as a result of primary nursing both conveyed a feeling of being unsupported. In complete contrast, Polly spoke of how supported she felt by her employers and colleagues when she was given time off to care for her estranged husband prior to his death. However, once again, in her caregiving roles Polly did not disclose her caregiving roles to employers and colleagues until it was unavoidable.

Over the thirteen years Frances cared for her parents she did not take any sick leave and did not discuss her caregiving roles with employers or colleagues. Due to living in a small town she felt her employers were more than likely aware of her role, but not the depth of the commitment it required on her behalf. Once again, due to Frances feeling it was a personal/private matter and not relevant to her work performance, she didn't see the need to disclose her role. For Frances her limited disclosure of her role and the fact that she did not take sick leave to perform this role resulted in a lack of opportunity for support from her employers and limited opportunity for support from close work colleagues, although on occasions when her parents were really unwell, she did receive acknowledgement by peers of her situation.

In my own situation, as previously mentioned, I seldom requested or used sick leave to help care for my brother unless it was an emergency or last resort. However, on the one occasion I did request time off to travel with my brother to the city where he was to have a skin graft I had to use my annual leave. For me this meant making a choice about the annual leave I was trying to accumulate so I could spend time with my children in the school holidays or letting my brother go alone for his operation to a city where he had no family and would have had no support or visitors. In the end I feel there was no choice, yet for me who had worked for the same health organisation for twenty odd years in which time I had used minimal sick leave there was a feeling of being 'let down' and unsupported, which resulted in the decision that I would never again ask for time off for caregiving for my brother, deciding instead I would use my annual leave or take leave without pay.

It is interesting that now I am in the position of managing staff this incident influences my decision making and my attempts to be a fair and supportive boss with an awareness of the stresses people may carry outside of work. With this awareness comes the recognition and acknowledgement of the ethics and values that are part of the nursing culture in that most nurses would not abuse or take advantage of leave granted for caregiving if required. I would advocate that a supportive work environment promotes returns in the form of workforce output, relationships and the powerful intrinsic rewards (as previously identified) that nurses gain from working alongside and feeling supported by work colleagues. It is interesting to note that Neal (1990) in his study of different occupations balancing work and family responsibilities (not necessarily caregiving for

ill or elderly family members) states that due to the “substantial amount of occupational stress they (nurses) experience, it is surprising that so little attention has been paid to the nature and antecedents of the conflict between their work role and their family role” (cited in Gottlieb, et al, 1996 p.101), and one would imagine this would be further exacerbated when caring for a family member who may be ill, elderly or with an enduring illness. If the situation of unsupportiveness in the work place is to change then nurses must take responsibility along with employers for this to happen. Nurses’ non-disclosure of their out of work nursing roles and the subsequent impact on all areas of their lives must be acknowledged so steps can be put in place to create change. As noted by Ross et al, (1994) “ the provision of care assumes a heightened importance in the lives of nurses who are mandated to care both within the context of their families and their professions (p.13). When examining the reasons why nurses choose not to disclose their caregiving roles outside of work, consideration must be given as to whether this is because nurses feel it is their duty and if there is an expectation they will fulfil the role, something they often keep to themselves. Gottlieb et al, (1996) also found in their overseas study that employees, regardless of gender, who appeared to have either personal problems or problems relating to family members that interfered with either productivity or staff relations at work, were often reprimanded and even dismissed. These research findings indicate that through informing employers of personal situations, gaining their support and providing an awareness of the impact of caregiving in all areas of the nurse’s life, this is a situation that can be changed.

### **‘Emotional Cloudiness’**

Brubaker (1983) suggested “... nurses and other service providers have observed that many caregivers are too involved in their difficult task to clearly see what their needs

are” (cited in Chinn, 1991, p. 177). Yet, as identified by Teutscher (2003), the situation is no different when nurses themselves are caregiving for ill or elderly family members, as objectivity is often lost when emotions are involved.

In this research project all three research participants identified with an ‘emotional cloudiness’ that created feelings of self-doubt and a questioning of one’s judgement and nursing skills. For Marie, when talking of her caregiving experience, she spoke of the self-doubt created by the misdiagnosis of her father’s illness during the interview she had organised with the doctor admitting him and the subsequent impact it had on her after a year of stressful caregiving for her father. It had major ramifications for her, both as a caregiver and on her health, which in turn impacted on her work performance, the consequence being her self esteem descending to the level that she contemplated committing suicide.

In Polly’s situation, when involved in caring for her brother, she spoke of a family member blaming her for his death. Polly described this as *“she thought that I had, that I didn’t know what I was doing, well she was probably right in a way. She probably was right”*.

Yet Polly is an experienced clinician of thirty odd years of nursing who is regarded by her colleagues as a caring nurse with sound clinical and assessment skills. She had been involved for many years in providing quality care for her brother and for the clients she worked with. Polly’s distress over this situation and the outcome can best be summed up by her statement *“... I thought I help other people, but I can’t help my own”*.

Frances described in her caregiving experience, when looking after her father, how it was the GP who had to contact her and suggest that, due to her father's failing physical and mental health, a psycho-geriatric assessment should be done. Although Frances had worked in the psychiatric field for many years she spoke of the emotional involvement preventing her from seeing things objectively. While being aware her father was deteriorating the family continued to carry on with the increasing stresses and workload. Frances described this as *"you don't want to see it ... and you don't want to make the decision"*. When Frances did co-ordinate a family meeting to discuss caring options some family members felt that she had made the choice and the decision that a psycho-geriatric assessment needed to be done and were against it happening. This lack of objectivity can be supported by Tetuscher's (2003) findings that:

Carer and family may need to take steps back at any stage to reassess, re-identify, re-plan, implement differently and re-evaluate, thus enabling both compassion and reason to work in what are often very fluid situations. Using an ethic of care approach to the nursing situation acknowledges the depth of the relationships involved, while retaining sufficient structure to prevent a purely emotional response to ethical issues. (p. 15)

Over the years in my role as a nurse family caregiver I can recall many times when I myself have felt a sense of my emotional responses rather than common rational decisions being made. The ability to separate the two is possibly not a reality and, therefore, the importance of nurses acknowledging and talking about their family caregiving roles must be encouraged if nurses are to educate other nurses and change this pattern. As previously noted by Tetuscher (2003) caring for a family member can result in care being compromised, a loss of objectivity, interference in family

relationships and alter future life experiences of the patient, the person providing care and family members.

Loss of objectivity or emotional cloudiness by the nurse family caregiver needs to be taken into account, particularly by other health professionals who may be involved in care delivery, when decision making is required which creates ethical dilemmas for the person providing care. Within this research two particular scenarios highlight how this emotional cloudiness impacted on the research participants. In Polly's situation when the psychiatrist encouraged her to attend the appointment with her brother and then ask her to be involved in the decision making this demonstrated a lack of insight into the position it placed Polly in and the possible outcomes and consequent effect it would have on her for the rest of her life. In Frances's situation she did not recognise that, for her father, his health was deteriorating to the stage that the GP had to step in and say what needed to take place. However, in turn this resulted in ethical dilemmas for Frances around organising an assessment in a psychiatric hospital and her family members' reactions and assumptions that she had made the decision.

In my own experience I can remember the feeling of being what I considered 'unethical' in my dealings with my brother with one of the ethical dilemmas I faced in regards to his treatment options. For seventeen years he had refused to have a Computerised Tomography (CAT) scan of his brain, stating he did not wish to know whether the remaining tumour, that was not able to be removed, was growing or stagnant – a decision accepted by our family members as his choice. However, when he was badly burnt having an epileptic seizure and then continued to have frequent seizures

that resulted in the healing skin being damaged and further admissions to hospital, I talked him into having the scan with him signing the consent with my prompting. Shortly after he was taken for his scan with me accompanying him. For me the mixed feelings of anxiety about the outcome, feelings that I had coerced my brother and excitement that it would be a positive outcome that could result in some closure are vivid in my recall, along with the anxiety provoking days my brother and family members spent awaiting the result. Yet, in hindsight, I am surprised that, although it was documented in my brother's notes about his decision declining to have a CAT scan (a decision not understood by many health professional) no-one questioned why he changed his mind or what input I had. To me it was evident that the doctors involved in his treatment were relieved that he finally agreed to have the scan and they would be able to complete their medical diagnosis and decide on treatment planning. For me, I felt the fact that I was a nurse who was known at the hospital and worked for the same health organisation was significant in that the responsibility and decision making in relation to the ethical dilemmas it created sat with me, the nurse family member, and for the health professionals involved in his care the focus of treatment centered on the medical outcomes and not the consequences of the results for my brother. These issues require further discussion particularly about what input nurse family caregivers should have in major decision making about care planning and the need for other family members and health professionals to be informed and aware of the loss of objectivity that is an unavoidable outcome of the nurse family caregiver experience.



## **The ‘natural’ role of the nurse through the nurse’s eyes - incorporating Responsibility / Advocating / Knowing**

Twigg and Atkin, (1994) described that, “being responsible is the primary element in caregiving and [argue] that it represents the core features that underline all caregiving” (p. 9). All research participants identified with feelings of being responsible, but to varying degrees. As previously mentioned, Marie spoke of the difference when caring for her dying father to caring for her chronically ill mother over a longer period of time. During her father’s illness family members were more available and supportive, whereas when her mother appeared to have numerous crises in relation to her physical health, Marie felt she carried most of the responsibility. Two particular situations identified scenarios that the literature demonstrates are familiar in family caregiving. Marie spoke of her brother being able to choose not to get involved stating, *“He just kept his nose out. He was quite good at saying no’*. Although Marie felt as if she wanted out of the caregiving role, and had insight into how it was affecting her own health, she didn’t feel she had permission to say no to family and family members requiring care due to illness. In her role caregiving for her mother Marie ended up shifting away to enable her to decrease her responsibility and the dependence she felt her mother had on her for input in all aspects of her life. As previously noted in the literature review in Chapter Two, the National Health Committee (1998), found that the responsibility for family caregiving most often became the role of family members who lived near to the person ‘being cared for’. Reflecting on my own situation I can relate to this concept. Although I have always been available to have input into my brother’s care I have chosen to live some distance away which has enabled me to be both readily accessible and not readily accessible. This decision was probably made subconsciously originally,

but over the years there has been a growing awareness of why I continue to chose to live some distance away from my brother, which in turn can complicate and make the caregiving role more difficult at times when input is required.

The other situation highlighted within Marie's caregiving experience was that which arose when her younger sister returned from overseas to assist with the caregiving. Marie spoke of her sister taking over and being a "*control freak*" and described feeling relieved when she left to go home. As identified by Ward (1993), women caregivers are often reluctant to relinquish the role and in Marie's case she had been organising and providing care for her mother over a long period of time and in a different way from her sister. Boland and Sims, (1996) suggested, "as caregivers become proficient in performing tasks of care, they become less willing to share this care with others" (p. 58). It is interesting to note that Boland and Sims also found in their 1996 study that "...the women participants gave permission to other family members for not being involved in caregiving or in not taking on roles previously filled by the caregivers. There was little 'giving up' or 'giving away' of responsibilities" (1996, p. 55). There was no literature located in relation to nurses and the reluctance to relinquish the caregiving role for family members who may require illness care, but it would be interesting to research whether this is even more difficult for the nurse who may be drawn to care.

Stanley (1993b) described her feelings about her caregiving role for her mother over a long period of time

Why me, why should I have to shoulder this enormous responsibility for another person? ... The resistance is harder to express... I feel involved...in various

parts of my emotions, where I can no longer respond as me... At times I also felt constrained by my responsibility to this other persona to express emotions I did not exactly feel (p. 210).

This was one of the few articles located that spoke of the negative feelings related to this experience. Similar sentiments were expressed by the nurse whose case study Teutscher (2003) presented in her article on caregiving for elderly parents. She described how the daughter caregiver found it almost impossible to admit to her parents how difficult she had found the caregiving work without feeling she had failed them.

Polly, in her caregiving roles, felt varying degrees of responsibility. With her father she was able to be involved in his caregiving without major responsibility, as she was in her late teens and her mother was still alive and was the main caregiver. In relation to caring for Robbie Polly saw this as the natural thing to do and was not overwhelmed by the role. However, in complete contrast, the responsibility Polly felt in relation to being involved in her brother's caring, and the subsequent impact of this responsibility upon his death, was overwhelming. On reflection, Polly could identify that some of the responsibility she felt for the decisions made were not actually hers, although this was complicated by some family members' reaction to her brother's death and their 'blaming' of Polly.

For Frances, throughout the caregiving roles for both her parents she stated, *"I never felt totally responsible, because there were five others. The co-ordination was fine and I never felt I couldn't hand it over to someone when I got tired"*. This may possibly relate to the fact that all Frances's family members lived locally, they had family meetings to

talk over care needs and had all been involved in the caregiving for both parents over a long period of time. All three research participants were seen by family members as the most appropriate person to advocate and liaise for family members requiring care. The research participants themselves all described feeling that this was a role they felt they should take on, as more often than not they had knowledge of the way the health services worked and what support services could be accessed. However, within the role many ethical dilemmas arose and in all participants' cases these dilemmas resulted in feelings of self-doubt and a questioning of one's judgement which resulted in an emotional cloudiness. For Marie, it was her role in liaising with the specialist when her father was admitted to hospital seriously ill, only to be told he had a different diagnosis. This episode, as previously highlighted, had a huge impact on Marie and her health. For Polly, she advocated for her estranged husband, Robbie, when he was informed of his diagnosis in an inappropriate way. The trauma and grief that she felt in relation to her liaising and being involved in her brother Shorty's assessment by a psychiatrist and his subsequent death from his illness made her question, not only her judgement, but also her role in caregiving. Frances described willingly taking on the advocacy liaison role as this being the most sensible thing to do, but felt that after co-ordinating a family meeting to organise a psychiatric-geriatric assessment for her father, as suggested by his GP, that some family members felt it was a decision she had made *independently*. All three participants chose to take on this role without coercion and all saw it as their role because they were the nurse in the family and had knowledge of the services available. In my own situation I to have taken on this role, a role that I considered to be naturally mine. This is possibly due to the acknowledgement that when you have knowledge of the services available, the people who need to be contacted and what processes you

need to follow it not only empowers the family member, but it is accompanied by an assertiveness in dealing with health professionals, which for those who are not health professionals, can be very disempowering and at times, overwhelming.

### **Multiple Caregiving Roles**

It is interesting to note that at the onset of this research project the aim was to obtain three female nurses' stories of their caregiving role for a family member who was ill, elderly or with an enduring illness. Yet it soon became obvious that all three research participants had been involved in more than one caregiving role, thus this research project included the stories of seven caregiving roles. A situation not unlike the role of the registered nurse who is often required to be the provider of care, counsellor, educator, technician, advocate and family caregiver and a possible reason why nurses are often able to cope with providing care not only at work, but for family members along with multiple other roles.

In both Marie's and Frances's stories they had helped, or been involved in helping, one parent care for another parent until the time of their death. In both cases, within twelve months of the deceased parent's death, the other parent required input or caring in relation to their health needs and, in hindsight, both identified that there was really never a break between the death of one parent to taking on the caring for the other parent. This would suggest that perhaps the role the caregiver fulfils creates a form of dependence for other family members that makes it difficult to maintain one's independence as the family has adjusted to the changes that result from the need for carer input. Other issues that may need consideration or contribute to this dependence are the impact of the loss of a partner, loneliness, and the effects on the living partner's

own health after being involved in providing care over a long period of time. This also raises issues in regards to the effects on the caregivers' health and the difficulty that is experienced in returning to the pre-illness caregiving relationship with other family members. These are issues that are worthy of exploration as a separate research project.

For Polly, from a young age she had been involved in caregiving for relatives and saw it as a natural thing to do. Within her story she described three very different caregiving experiences which impacted on her in markedly different ways. This raises questions about whether nurses are drawn to care, or is it because of the family culture we are born into - to care for one's own, or to feelings of obligation and that nursing is not a job you do only at work in work hours? Gottlieb et al, (1996) identified that "... *it would also be valuable if future investigations explored the kinds of personal coping strategies that nurses use to manage their dual role. Such information would yield new insights about how women cope with the chronic stress that attends fulfilling multiple social roles*" (p. 113).

## **Conclusion**

Throughout this chapter the main themes or common threads identified in the three research participants' narratives have been outlined. Culture, both family and nursing; non-disclosure – the silence of the nurses; emotional cloudiness, incorporating loss of objectivity, self-doubt and self-blame, ethical dilemmas and support; and the 'natural role of the nurse' looking at issues of advocacy, liaison and responsibility have been discussed. The impact of multiple caregiving roles has also been detailed. Although these common themes identified similar findings, the outcomes or responses in each situation was dependent on the family culture, how the family communicated and

worked together and what each nurse participant defined as their role. Through the telling of their stories each participant was able to reflect on how their caregiving experiences were unique to them, and the positive and negative aspects of those experiences. While acknowledging the uniqueness of their own experience, all participants were keen to discuss the outcome of research findings and how the experience had been for other research participants in their caregiving roles, for as already identified, nurses may be good at telling stories in their work, but not when it is about sharing their own personal stresses or burdens. As noted by Reason and Hawkins, “by bringing these stories alongside each other it is possible to ‘sense’ the underlying essence which they share” (1998, p. 89). It is hoped that this small research project will help nurses to see that they are not alone in fulfilling the family caregiving role for members who are ill, elderly or with an enduring illness, and how the impact of these roles can be reduced through disclosure, awareness, valuing themselves and their judgement. In Chapter Seven research outcomes, implication for nursing practice, future research and whether aims of this study have been met will be discussed.

# **Chapter Seven**

## **Discussions and Conclusions**

### **Introduction**

This research project was based on the question ‘What does it mean for a female nurse to be a caregiver to a family member who is ill, elderly or with an enduring illness and requires care?’ To assist in answering this question two further subsidiary aims were developed. The first subsidiary aim was to explore if a family nursing role is acquired by choice, obligation, or through perceived or real expectations of the family, whilst the second subsidiary aim was to explore how the family nursing role may impact on participants’ ongoing relationships with their family, their health, and their commitment to work and the implications of this for workforce development. Through the use of the limited literature available and the telling of three female nurses’ stories of their caregiving experiences for ill, elderly or family members with an enduring illness I have attempted to address these questions. In this chapter I will discuss the outcomes, implications for nursing and future research. As Parker (1990) noted “the more stories that surface, the greater the opportunity for nurses to join together and to analyse their collective meaning” (p.35).

### **Research Outcomes**

As detailed in the previous chapter, core themes from each woman’s narrative have been identified, along with the themes that appeared common to all three stories. These stories were a brief account of how each research participant experienced their caregiving roles and, no doubt, would have elicited richer data if successive interviews



had taken place. However, due to the inherent research design of this project, participants engaged in only two story-telling sessions each, with follow-up contacts as necessary, to clarify issues that arose.

Throughout the process of recruitment for research participants one of the most striking findings was the number of nurses who were performing a caregiving role for an ill family member outside of their work. This was supported by the fact that although I had agreed to work with three research participants in recording their caregiving experiences, during the time I was working with them I was approached by five other nurses requesting to take part in this study.

The literature revealed that, overwhelmingly, women fulfil the unpaid caregiving role within families (Angus, 1994; Boland & Sims, 1996; Bowers, 1987; Davies, 1995; Gottlieb, 1996; Marshall, et al, 1990; Tetuscher, 2003; Ward, 1993). It is supported within the research findings and participants' stories that there is a social, cultural and familial expectation that this is the role of the female, a habitual gender bias. Even when males in the family shared the caregiving role the female carer did more, for longer. In both Marie's and Frances's stories they spoke of their brothers helping, but Marie recognised that when her brother felt stressed by the situation he chose to disengage, while not requiring permission from other family members to do so. For the female caregivers within the context of this study, the option of disengaging, even when feeling stressed, was not considered. Frances spoke of feeling that the responsibility of caregiving was shared equally within her family, but family members still relied on her in times of crisis when decisions had to be made. Her brothers performed more social

types of caregiving while the female family members fulfilled the physical, social and emotional aspects of the caregiving role. This study suggests that the culture of being a nurse ensures that nurses continue to perform the caregiving role for ill, elderly or family members with an enduring illness, even when it is impacting on their own health, work and family life.

This study questions whether it is through our caring family culture that we are influenced in our decision to first become a nurse and that within each nurse does that culture promote an ethic of caring that in turn leaves no choice when it comes to caregiving for family members who are unwell? This is supported by Ross et al's, (1994) findings, that because nurses choose to care in their everyday work it makes it near impossible not to care for their own family members who are ill, elderly or with an enduring illness. However, as evident through the participants' stories, regardless of the stresses and traumas involved in fulfilling this role, it was something they wanted to do. So within this study when exploring whether the caregiving role is acquired by choice, obligation or through perceived or real expectations of the family, research findings have demonstrated through the limited literature available and the recording of the three women's stories that although there is an expectation by family members that the nurse in the family takes on this role, that it was a role all participants identified they wanted to do and considered was the natural thing to do. There was an acceptance that part of the nursing culture was that you didn't only nurse at work and regardless of what stresses were involved you kept on doing it. Within this role nurses were more often supported and assisted by family members, but in varying degrees, with the ultimate responsibility for all care belonging to the nurse family caregiver.

In addressing the second subsidiary aim of examining how this role impacted on the nurses' ongoing relationships with family members, their health, work commitments and implications for workforce development, several key outcomes were identified. The first key feature, as already documented, was the so-called 'silence of the nurses'. Nurses did not appear to discuss their caregiving role with colleagues or employers until disclosure was imminent, due to a crisis. Possible reasons for this, as identified by research participants, could be so as not to burden their busy colleagues with the stress of their role or possibly a desire to keep their personal lives private. Gottlieb et al, (1996) and Ross et al,(1994) have demonstrated in their studies the importance of informing employers of caregiving roles, due to the impact it has on work performance. All three participants identified that they felt that this was not necessary, unless time off work was required to enable them to fulfil their caregiving role. A lack of acknowledgment of the impact that caregiving had on every aspect of their lives was evident and it is interesting to note Gottlieb et al in their study questioned "is there something about the structure of nurses' work or about management practices, that generates more or greater conflict between work and family life than in other professions in which women are engaged?" (1996, p.14).

The second key feature identified was the lack of insight by nurse caregivers in relation to the loss of objectivity at times while fulfilling the caregiving role. Within this project a lack of objectivity was evident in all three research participants' stories. This can be supported by Benner and Wrubel (1989) and Tetuscher's (2003) findings of how caregiving can impact on those providing the care. This loss of objectivity when caring

for family members is unlikely to change due to the emotional connection with the family member being cared for, but an awareness by other family members and health professionals about how emotional connectedness can impact on decision making is vital if the nurse caregiver is to feel supported in their caregiving role. This issue is worthy of future investigation to help reduce the burden of care for nurse family caregivers. Further research in this area would also be useful when considering workforce implications and the long-term emotional impact caregiving roles and decision making can have on the nurse caregiver.

The third key feature is the impact on caregivers' health, work commitments and, in turn, workforce development resulting from the caregiving roles nurses perform outside of work. All three participants identified that family members left the advocacy/liaison role to the female nurse in the family and this was a role they all felt was 'naturally' theirs, due to their knowledge of available resources. Research findings demonstrated that, the outcomes at the cessation of that role, impacted on whether participants felt a sense of burden of care or a sense of well being or achievement in relation to the part they had played. Marie had a sense of doing her best to care for her father till he died. When caregiving for her mother the negative impact of chronic stress and excessive demands was highlighted with a resulting deterioration in her own health to the extent it was also impacting on her work to a serious degree. Polly, in her story, spoke of her caring experiences with both her father and estranged husband as positive experiences, and described caring for Robbie as a healing experience that would possibly influence her career pathway in nursing. Yet, in relation to her tragic experience of helping care for her brother, the traumatic effect will impact forevermore on her decision making,

self judgement and the degree of responsibility she undertakes in all the caring work she does. In Frances's situation she felt that on the death of her parents, the family all knew they had done their best for their parents and she felt at peace with the caregiving roles she had performed.

Highlighted within all three women's stories was the fact that often it was not until after the cessation of their caregiving (a period of twelve months or so) that they could reflect on the role they had played and how it had impacted on them as a nurse, physically; within their family relationships and, as previously mentioned, in their work. All participants reflected on how they actually managed to get through these stressful times and the physically and emotionally draining aspects of the role. I would question if nurses have an inbuilt resilience or survival instinct that is inherent within their occupations. This instinct in turn, spills over into their home environment enabling them to keep going and to cope, no matter what – a private burden of care. Within their caregiving roles all three women spoke of the effects and ethical dilemmas they faced that impacted on family relationships. It was evident through the women's stories (and as supported by Teutischer (2003)) that it is impossible to return to the pre-illness caregiving family relationship state once family care has been provided over a length of time. This then answers the question on how this role affects relationships within the family. Through this study it became obvious that when a crisis developed or a decision had to be made, regardless of the outcome or consequences on family relationships, the responsibility seem to fall on the nurse in the family, with little regard for the impact on their own wellbeing.

## **Implications for Nursing Practice / Future Research**

Within this study it has become evident that both nurse caregivers and employers need to consider the effects that caregiving for ill, elderly or family members with an enduring illness have on all aspects of the carer's life. Nurses spoke of varying degrees of support from colleagues and employers, yet non-disclosure of caregiving roles, unless a crisis developed, was evident. This phenomenon appears to be common among nurses caregiving for family members and it is difficult to enlist the support of colleagues or employers when they are unaware of these roles and the stresses involved. Future research could investigate this issue in more depth. Identifying the impact on work situations in regards to the amount of sick leave taken; reduction in work hours the nurse may have chosen to enable them to fulfil their caregiving roles for family members; declining of promotions; reluctance to be involved in workforce development or other committees due to time constraints and reluctance to take on further study outside of work all require consideration, particularly when nurses are not forthright in disclosing their reluctance to be involved in workplace development other than their clinical practice. It is hoped that this research project will make a contribution to the literature on nurses as caregivers to family members outside of the work environment and that the research findings may assist in future workforce planning, taking into account that the average age of female nurses in New Zealand is currently 43.7 years and, as previously identified, the age of women most likely to be part of the so called 'sandwich generation', that is, more likely to be involved in caring for elderly parents and growing children.

The importance of nurses recognising and trusting in their judgement, decision making and assessment skills, particularly when they are experienced clinicians, instead of living in the 'shadow' of the medical model, that is, doubting oneself instead of acknowledging that they were 'expert practitioners' (Benner, 1984) is highlighted within this research.

## **Conclusion**

This study aims to contribute to the limited amount of literature available about the caregiving roles nurses perform outside of work for family members who are ill, elderly or with an enduring illness. As the researcher it has enabled me to hear and record three women's stories of how the caregiving experience has been for them and the impact it has had on their health, work and family life. It is hoped that, in turn, this may encourage other nurses to tell their stories. For myself, as the researcher, the benefits of this research project, within my own clinical practice, has been highlighted by an awareness of the importance of story-telling, not only in reflecting and passing on information, but in working with clients in recording their life stories - a tool that is now recognised for its true value.

Belonging to a family with a sibling suffering with an enduring illness this study has enabled me to relate my own experiences (though only partially disclosed within this thesis) to the experiences of other nurses. This thesis has provided confirmation that many nurses carry an undisclosed burden of care and has highlighted some of the reasons why nurses choose to keep their personal lives private, although they work in a caring profession.

It is hoped through this study it will encourage more nurses to tell their stories because, as noted by Bennett, "To tell the story of the moments when we've suffered and then healed our essential wounds is to reveal a universal insight that extends far beyond the particulars" (1995, p. 114).





### **Appendix 1: Information / Participant Sheet.**

As a nurse in the family – expectations and choices when a family member is ill, elderly or has an enduring illness - the experience of up to four female nurses in caring for a family member.

#### **Researcher:**

I am a New Zealand Registered Comprehensive Nurse. I am currently working part-time as a clinical lecturer in mental health and for enrolled nursing students from Christchurch Polytechnic Institute of Technology. This research project is the thesis for a MA (Applied) that I am undertaking through Victoria University of Wellington.

#### **Purpose:**

The purpose of this study is to examine the stories of up to four women nurses (of European / Pakeha descent), who have been caregivers for a family member, and whether it is a role they have chosen to do, felt obligated to do or acquired by virtue of being a nurse. Narrative inquiry (storytelling) will be used and will involve analysing each story to identify common themes.

#### **Benefits:**

Participating in this study may be beneficial to you as a nurse. The knowledge gained from this study will be useful in examining the many roles nurses fulfil outside of work obligations and the expectations placed on them as a nurse. The roll on effects for the nursing profession is it will help address problems associated with nursing outside of work and will explore what it means to be 'a nurse'. The knowledge gained will be beneficial for all nurse and health workers.

#### **Procedures/ Risks:**

For this research project, the intention is to use audiotapes as the primary data collection method. This would involve up to two taped session of 60-90 minutes duration where research participant would tell their story / experience to the researcher.

The process of collecting and making meaning of the data will follow through various phases over a period of weeks. You will be asked to begin by telling your story of being a caregiver for a family member. Other data sources may be utilised as considered appropriate by the researcher. During the process participants and the researcher will re-read participants written stories to help understand issues that arise.

Audiotapes will be transcribed. Transcribed scripts will only be seen by the researcher and her supervisors. Participants will only be known by their pseudonyms. All audiotapes and other data collected will be kept for ten years following the completion of research, and then the researcher will destroy it.

A copy of the final report, which may contain anonymous quotations, will be available to you at the end of the study if you wish. A copy of the research project will be held at the Victoria University Library and also in the Graduate School of Nursing and Midwifery, Victoria University.



You may find that reflecting and analysing your experience/s surfaces unresolved issues for you. I will endeavour to be sensitive to your needs. However, you may find that you need further help and I will assist you to find the appropriate service for your needs. This would be at your initiation.

*Costs/ Reimbursement*

There will be no financial cost to you, and you will not be paid for your participation. Any travel expenses encountered, as part of the project will be reimbursed to you.

**Voluntary Participation / Confidentiality**

Your participation in this research is completely voluntary, and you may withdraw at any time. If you wish to withdraw, any information provided will be returned to you.

If you have further questions, or would like to receive further information, please contact me at home on  
or via e-mail on: or my supervisor, Dr Rose McEldowney,  
Senior Lecturer, Graduate School of Nursing and Midwifery, Victoria University of Wellington on Ph:  
(04) 463 6551 or via e-mail on: [Rose.McEldowney@vuw.ac.nz](mailto:Rose.McEldowney@vuw.ac.nz)

Nola Rochford



**Appendix No. 2**

**Graduate School of Nursing and Midwifery Victoria University of Wellington.**

**Research Project: 'As a Nurse in the Family – expectations and choices  
when a family member is sick, elderly or has an enduring illness'**

**Consent to Participate**

I ..... agree to participate in the research project identified on the information sheet. I understand pseudonyms will be used to ensure that individual and family members are not identified. I am aware I may withdraw from the research at any time. I understand all material audiotaped during the two interviews will be transcribed by a typist who will be asked to sign a confidentiality form. Transcribed recordings of sessions will be returned to me for critique and adjustments before data is used in research. I will be offered a copy of audiotaped interviews. I understand all material will be kept locked when not in use and all audiotaped interviews will be deleted on completion of research. Transcripts will be kept in storage for up to ten years. A summary report of research findings will be available on completion of thesis.

I am aware ethical approval has been obtained from the West Coast Regional Ethics Committee for this study. Research project supervision will be given by the Graduate School of Nursing and Midwifery Victoria University of Wellington.

Participant Signature \_\_\_\_\_

Date: \_\_\_\_\_

Researcher's Signature \_\_\_\_\_

Date: \_\_\_\_\_



**Appendix No. 3**

Graduate School of Nursing and Midwifery Victoria University of Wellington.

Research Project: 'As a nurse in the family – expectations and choices when a family member is sick, elderly or has an enduring illness'

**Transcriber Confidentiality Form**

I agree to ensure all material transcribed or typed in relation to the above mentioned research proposal will remain confidential and when not in use will be kept locked away and will be the responsibility of the investigator.

Transcriber/ Typist Signature:

Date:

Researcher's Signature

Date



*Appendix 4: Interview Prompts / Guidelines for initial interview*

1. How many siblings are there in your family?
2. Are both your parents alive?
3. Where does the family member who requires assistance live distance wise from you?
4. How many hours per day / per week of care time would you estimate is required of you for family member?
5. How many hours per week do you currently work?
6. What type of nursing are you currently employed in?
7. Do you think your family caregiving has prevented you from holding different nursing positions or accepting promotions?
8. What age were you when you started your nursing training?
9. Why did you decide to become a nurse?
10. Do you have a partner and /or any dependent children living with you?
11. Could you provide a brief history of the circumstances relating to your role of becoming involved in caregiving for a family member?
12. How do you see your role within the family and the nursing care you provide has changed over time?

15<sup>th</sup> October 2003

Nola Rochford

Dear Nola

Thank you for your letter received on 8<sup>th</sup> October 2003 asking for permission to place flyers  
at aiming at seeking participants for your  
research project.

I have no objections with your request proceeding and I wish you all the best with your  
project.

Yours sincerely

A handwritten signature in black ink, appearing to be 'A. L. Lark', written in a cursive style.

**CHIEF EXECUTIVE**



*Appendix No.6: Ethics Application: References:*

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## CAN YOU HELP?.....

I am currently completing a thesis for a Master of Arts in Nursing (Applied) through the Graduate School of Nursing and Midwifery at Victoria University of Wellington.

The purpose of my thesis is to examine the stories of four women nurses, of European / Pakeha descent, who have been caregivers for a family member who is sick, elderly or have an enduring illness.

The focus will be on whether this is a role:

- they have chosen to do;
- felt obligated to do; or
- acquired by virtue of being a nurse.

Four volunteers are required to participate in the project. Participation is voluntary, and you may withdraw at any time.

This project has been approved by the

### WHO AM I?

*My name is Nola Rochford.*

*I am a New Zealand Registered Comprehensive Nurse. At present I work as a Clinical Lecturer in Mental Health, and with enrolled nursing students for*

*My supervisor for this project is: Dr Rose McEldowney, Senior Lecturer, Graduate School of Nursing and Midwifery, Victoria University of Wellington, phone (04) 463 6551.*

### WHAT DO PARTICIPANTS NEED TO DO?

Most information used in the project will be gathered through participants sharing their stories. These will be audio taped over two sessions.

Transcribed stories will be reviewed by the participant and the researcher. Participants will be known by pseudonyms and their identity will remain confidential.

There will be no financial cost to you, and you will not be paid for your participation.

A copy of the final report will be available to you at the end of the project.

### IF YOU ARE INTERESTED IN FINDING OUT MORE.....

You can contact me

- by telephone at home or
- via e-mail at :

I am happy to answer any questions you have, or to discuss this project with you.

All information and queries will be treated in the strictest confidence.





Appendix No. 8

**Graduate School of Nursing and Midwifery Victoria University of Wellington**

**Research project: 'As a nurse in the Family – expectations and choices when a family member is ill elderly or has an enduring illness'**

Consent to Participate

I.....Lynden Guerin..... give permission for aspects of my illness to be discussed by my sister as part of her research project. I am aware I may withdraw my permission at any time and that on completion of the research project a copy of the thesis will be available for me to read.

Signature Lynden Guerin 28.9.2004

Researcher's Signature N. M. Rochford 28.09.2004

25 November 2003

Nola Rochford

Dear Nola

**WC 03/11/012      An exploratory descriptive study of what it means for a female nurse to be a caregiver to a family member who is sick, elderly or with an enduring illness.**

The Committee appreciates the time and effort you took to speak to your Masters student research proposal at our meeting on 19 November 2003. Thank you for your amendments, received 25<sup>th</sup> November 2003.

We are pleased to inform you that this study has received ethical approval until 30<sup>th</sup> May 2004.

Documents approved:

Participant Information Sheet V#2, 25/11/03

Consent Form V#2, 25/11/03

Transcriber Confidentiality Form V#2, 25/11/03

Appendix 4: Interview prompts / Guidelines for initial interview V#2, 25/11/03

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider, within whose facility the research may be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

A final report is required by 30<sup>th</sup> May 2004. A blank form should come off our database and will be duly forwarded to you for completion and return to the Committee.

The Committee wishes you well with your research.

Yours sincerely

*B.A. Beckford*  
Barbara Beckford

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