Being in the middle: registered nurses’ experiences of parent hospitalisation

Thesis submitted for the degree of Doctor of Philosophy

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Dedication

In loving memory of my parents Alexandra and John.
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There are many people who made the completion of this research possible – my heartfelt thanks to you all.

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To my husband Paul and my son Kieran who have always encouraged and supported me and my work; and my special appreciation to Kieran for assisting me in the production of the final document.
Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

.............................................

(Signature)

Helen Ledwidge
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ABSTRACT

Registered nurses (RNs) have a dual identity: professionally they are health practitioners and privately they are family members. This qualitative study described and interpreted the experiences of RN sons and daughters in their role as a relative of their hospitalised parent. RNs’ experiences of parent hospitalisation revealed the boundaries of these two identities within the hospitalisation context, the circumstances under which the boundaries became blurred or disappeared (which caused identity conflict and role confusion) and the impact of this on participants. The experience of parent hospitalisation was described by 15 daughters and 16 sons (age 44) registered with the NSW Nurses and Midwives Board in Australia using a mailed semi-structured questionnaire and in-depth interviews.

The phenomenon of being in the middle reflected the plight of participants who were navigating the boundaries between their family role and their RN role within the hospitalisation context. Being in the middle encompassed three categories: disclosure of RN status to nursing and medical staff; RN on standby (being expertly vigilant); and RN in action (imperative to intervene). Two sub-categories regarding disclosure were identified: the first sub-category was preferring to remain undisclosed (which was participants’ preferred option because disclosure was unnecessary or because they preferred to be treated as a lay relative rather than experience the disadvantages of disclosure). Despite this preference, their status was usually disclosed and/or was detected, and/or was revealed by others. The other sub-category was disclosing to activate RN power and credibility (which occurred if participants wanted to be treated as a peer/colleague or if they wanted to get action for their parent). Participants enacted being in the middle (disclosed or undisclosed) through two categories of behaviours: RN on standby (being expertly vigilant) behaviours; and RN in action (imperative to intervene) behaviours – which supplemented RN on standby behaviours when necessary. RN on standby (being expertly vigilant) encompassed four themes: leading and staying strong at any cost; expertly observing, detecting and protecting; being adept at hospital language; and keeping it real. RN in action (imperative to intervene) encompassed two themes: filling in the gaps and fixing. Daughters intervened by filling gaps in personal care themselves whereas sons assertively advised staff to fill gaps unless requested by staff to assist. There were positive consequences for the family and mostly negative consequences for participants of being in the middle.

RNs as family members with health expertise can serve as a knowledgeable resource for hospital staff to maximise the quality of care for the parent-patient. Nursing and medical staff can facilitate this outcome by working in close partnership with RN-relatives and providing expertise-appropriate information. Recommendations for RN sons and daughters include sharing critical decision-making with family members and finding avenues of emotional release during the stressful episodes of parent hospitalisation.
Activities of daily living: basic endeavours such as bathing or using the toilet (Levine, Reinhard, Feinberg, Albert & Hart, 2003).

Addisonian crisis: or "adrenal crisis" is a constellation of symptoms that indicate severe adrenal insufficiency. Untreated, an Addisonian crisis can be fatal. It is a medical emergency usually requiring hospitalisation.

Comorbidity: when a person has two or more health problems at the same time.

Decerebrate posture: an abnormal body posture that involves the arms and legs being held straight out, the toes being pointed downward, and the head and neck being arched backwards. The muscles are tightened and held rigidly. This type of posturing usually means there has been severe damage to the brain. http://www.nlm.nih.gov/medlineplus/ency/article/003299.htm

Directive behaviours: decision-making behaviours described by Jacelon (2006) involving three levels of participation in decision-making: caregiver acts in place of the relative without consultation; caregiver acts as advisor to the relative (who then decides whether to accept or decline the advice); and not acting (where the caregiver does not participate in decision-making).

Double-duty caregiver: women who care for individuals in both their professional and their personal lives (Ward-Griffin, 2004). For example an unpaid female RN caregiver of relatives in the home who is also concurrently working as a paid RN.

Formal caregiver: a paid health professional.

Gross domestic product (GDP): a statistic commonly used to indicate national wealth. It is the total market value of goods and services produced within a given period after deducting the cost of goods and services used up in the process of production but before deducting allowances for the consumption of fixed capital (AIHW, 2008).

Heterogeneity: the degree to which the individuals within a group are dissimilar (i.e. characterised by high variability) (Polit & Beck, 2004).

Hospital (acute): an institution (publicly or privately funded) which provides health care services mainly to admitted patients with acute or temporary ailments. The average length of stay is relatively short.

Identity: the essential characteristics that identify a person.

Instrumental activities of daily living: activities such as shopping and transportation (Levine et al., 2003).
**Lay caregiver**: a family member or significant other who is not qualified as a health professional and provides informal care or assistance to an individual because of that individual’s age, illness or disability (AIHW, 2008).

**Non-Hodgkin lymphoma (NHL)**: a range of cancers of the lymphatic system (lymph glands and the channels they are linked to) that are not of the Hodgkin variety.

**Primary caregiver**: the person with the main responsibility for caregiving (Schofield et al., 1998) who provides “the most ongoing assistance with core activities of self-care, mobility and communication” (AIHW, 2008, p. 450).

**Nursing homes**: (also referred to as residential aged care facilities): establishments which provide long-term care involving regular basic nursing care to chronically ill, frail, disabled or convalescing people, or senile inpatients (AIHW, 2008).

**Position power**: authority and influence bestowed by a position or office on whoever is filling or occupying it. [http://www.businessdictionary.com/definition/position-power.html](http://www.businessdictionary.com/definition/position-power.html)

**Registered Nurse**: a qualified nurse who is eligible to be included on the register of the NSW Nurses’ and Midwives’ Board.

**Role**: the usual or expected function of a person or the part the person plays in an action or event.
ABBREVIATIONS

ADL: activities of daily living.
AIHW: Australian Institute of Health and Welfare.
CCU: Coronary Care Unit.
CNS: Clinical Nurse Specialist.
EN: Enrolled Nurse.
ER: Emergency Room
GP: General Practitioner.
HCPs: health care professionals.
IADL: instrumental activities of daily living.
ICU: Intensive Care Unit.
IV: Intravenous
JMO: Junior Medical Officer.
NUM: Nurse Unit Manager/Nurse in charge of a hospital ward or unit.
NSW, NRB: New South Wales Nurses' Registration Board (now known as the Nurses' and Midwives' Board of New South Wales).
RN: Registered Nurse.
UK: United Kingdom
CHAPTER ONE

1.1 INTRODUCTION TO THE RESEARCH PROBLEM

The impetus for this research came from my personal experiences when my parents were hospitalised. It was during those experiences that I was struck by the discomfort that resulted in bringing my registered nurse (RN) knowledge and experience to the role of being the RN-daughter of a parent in hospital.

The extent of my discomfort with this situation varied according to the nature of my experiences and was noticeably increased whenever my parent was critically ill on admission to hospital or became so during the hospitalisation. I felt intimidated (disempowered) by being a RN and also because I was a senior academic which included ten years as dean of a university health faculty. For these reasons and in trying to keep my private life separate from my professional life, it was not my normal practice to disclose my RN status to hospital staff. Consequently in most cases it was not apparent that staff knew of my status, and I was conscious of wanting to avoid having my parents admitted to hospitals where I had worked and was well known. I was once recognised by a staff member who was a nursing graduate of the university at which I worked, and who then evidently passed this information on to the other ward staff. On another occasion it was obvious that my mother’s doctor had mentioned my status to ICU medical staff who then gave me very detailed and technical information about my mother’s condition.

The discomfort I experienced was at times due to my frustration and disappointment with the medical and nursing care and on a couple of occasions because of staff members’ unwillingness to freely share information with me about my mother’s condition. Added to those reasons for my discomfort was the knowledge that my parents (World War II refugees) were acutely uncomfortable with and opposed to the notion of complaining or being critical of any of the care given by the staff whose altruistic job it is to help sick people recover.
My father whose command of the English language was poor, was hospitalised 13 years ago at the age of 89 for a relatively minor surgical procedure, but had a fall the first night and suffered a fractured femur whilst trying to climb over bedrails to access the toilet. Whilst recovering from the surgery, he developed septicaemia and died in hospital six weeks later. During my father’s hospitalisation my mother who was a healthy active 78 year old at the time, visited on a daily basis, and as next of kin had the official role of primary caregiver. Nevertheless, she involved me closely in my father’s hospitalisation, and although she spoke English quite well she always involved me in communicating with the hospital staff and decoding ‘hospital speak’.

The nature of my experiences of having a parent in hospital was significantly different for my mother’s numerous hospitalisations than it had been for my father’s. My mother’s hospitalisations began a couple of years after my father died when she was diagnosed with a rare syndrome which led to episodes of Addisonian crises and necessitated emergency hospitalisation for treatment. My mother’s hospitalisations which also included surgery for a fractured femur took place within a three year period at three different hospitals and occurred on an almost monthly basis during her final year. She had lived a very healthy lifestyle and as an avid reader of health related literature she had developed strong beliefs about some aspects of traditional medicine. Despite her personal views, she was appreciative and accepting of the treatment and care she received. She was a very gentle and undemanding person and never complained. She was barely capable of communicating during her final two week hospitalisation and she died in hospital about seven years ago from pneumonia and septicaemia at the age of 83. My relationship with my mother was extremely close, and being the only available child, I was the next of kin and played an active role in her hospitalisations. I was involved in every hospital admission and spent many vigilant hours by her bedside during each of her hospitalisations.

I do not believe that the term ‘informal caregiver’ is appropriate to use when referring to RN-relatives of a hospitalised person. If this caregiver label is used when referring to me as a RN-relative, it implies to me that as a RN-relative I would expect and be
expected to give care within much wider parameters (namely the full range of nursing care) to my hospitalised parent despite my illegitimate (non-employee) status within the hospital. I acknowledge that RN-relatives care about their family member (as do lay relatives) and often also provide aspects of care for them but that professional boundaries are in place which differentiate the paid hospital RN’s role from my unpaid RN-daughter’s role. As a RN-daughter with a hospitalised mother I felt I had consigned my mother to the care of the hospital, and therefore I did not have preconceived expectations that I would behave as if I was in a legitimate paid RN role. I had entrusted my parent to the care of the hospital and its staff and I was acutely sensitised by my sense of appropriate professional behaviour which required me to remain in my off-duty nurse mode. Caring about involves feelings of affection and love, caring for is about tending to physical, mental and emotional needs (Ungerson, 1990). A hospital’s designated purpose is to care for their patients. I was not there to give nursing care. I was there because I was caring about my parent (Grant et al., 2004). I did not intervene until my trust was betrayed and I detected deficits in my mother’s care which were life threatening. It was as though I could only be in the role of the daughter if the hospital’s nursing and medical staff could be relied on to adequately perform their roles, and I stepped into the role of the nurse to address their shortcomings when urgent action was necessary (Kitson, 2003).

As a result of my experiences I wondered what other RNs had experienced in relation to their parents’ hospitalisations, and whether they too preferred not to disclose their RN status to nursing and medical staff.

1.2 AIM OF THE RESEARCH

Comprehensive research regarding RNs’ experiences of parent hospitalisation has not been conducted. In view of the lack of research on this topic it was appropriate to conduct this study using a qualitative research methods approach which would allow an open exploration of the topic with minimal imposition of preconceived ideas. A
constructivist paradigm was used. The purpose of this qualitative study was to describe and interpret registered nurses’ experiences as relatives during their parent’s hospitalisation.

The research question for this study was:

- What are RN-sons’ and RN-daughters’ experiences of having a parent/s in hospital?

My experiences as a RN-daughter provided me with valuable insights regarding the topic. Clearly my attitudes and preferences influenced my choice of topic and conceptualisation of the research question, and influenced the design and content of the questionnaire and the way in which I approached and conducted the in-depth interviews.

I have been conscious of the bias that I may bring to an open-minded exploration of the research question. I have endeavoured to minimise bias as much as is possible in such a situation by asking the interviewed participants to tell me of their experiences without attempting to redirect them during this process.

1.3 SIGNIFICANCE

The aim of improving the outcomes of hospital care so that older people can be successfully returned to live in the community requires that the negative impacts of hospitalisation on older people are minimised thereby also containing the costs of health care. Australia spent 9% of its gross domestic product (GDP) on health in 2005-2006 and the largest component of expenditure (39%) was on hospital services. According to Australian Institute of Health and Welfare (AIHW, 2008) data, the fastest growing portion of Australia’s population is 65 years of age and older (13% as at June 2006) and they consume a disproportionately high percentage (35%) of public and private hospital resources (AIHW, 2008). This trend is expected to continue for the next 20 years which will impact on the hospital system because older people usually have comorbidities, are more likely to suffer increasing disability with age, are hospitalised more frequently, stay longer and occupy more hospital bed days than any other age group.
Hospitalisation also puts older patients at greater risk of comorbidities and reduced functional status and they are more likely than younger people to enter residential aged care facilities or die than to return to their usual residence (AIHW, 2008).

RN-relatives have health expertise and can therefore serve as a knowledgeable resource for health care professionals (HCPs) and family members to maximise the quality of care for the parent and improve health outcomes. Nursing and medical staff can facilitate this outcome by working in close partnership with RN relatives and providing them with ongoing expertise-appropriate information about their hospitalised relative.

The value and benefits of this research lie in its contribution to raising awareness and developing an understanding of the unique needs of RN-sons and daughters when their parents are hospitalised. This knowledge may be helpful to other RN-sons and daughters, parents of RNs, and HCPs, by providing insight into what it is like being a RN-relative of a hospitalised parent. Such insights may influence the behaviours and communication strategies of all stakeholders and improve relationships between HCPs, RN-relatives and hospitalised parents, and thereby improve their health care outcomes and the experience and the aftermath of hospitalisation for all concerned.

RNs’ experiences represent an informed insider’s perspective: RNs are adept at detecting deficiencies in hospital processes and care. Northcott (2000) has argued that lay patients and their lay relatives have few points of reference from which to judge the quality of health care, whereas RNs as health care professionals are able to use their professional knowledge and experiences as a reference point, and thereby make insightful comments which could raise the standard of care for all patients. Presumably these insights could also lead to improvements in the caregiving experiences of lay family members of hospitalised relatives. Information and training could also be provided to families concerning strategies to improve the effectiveness of family participation when a relative is to be hospitalised, particularly in cases of elderly and chronically ill relatives who have an increased likelihood of repeated hospitalisation.
1.4 OVERVIEW OF THE THESIS

In this chapter, I have provided a brief background to the research problem and its significance, confirmed that a gap in knowledge currently exists concerning RN sons and daughters’ experiences of a parent’s hospitalisation, and stated the research question.

A review and critique of selected aspects of the caregiving literature (mainly from the perspective of family caregivers) and its relevance to this qualitative study is presented in Chapter Two which situates this research within the context of existing knowledge and highlights the gap in knowledge that this study is designed to fill.

In Chapter Three, the design and conduct of the study are described. The adoption of a qualitative methodological approach is discussed and the methods of data collection and data analysis are described including processes to ensure the study’s validity. Measures taken to protect the interests of the participants are included.

The findings are reported in Chapters Four, Five and Six.

Chapter Four provides an overview of the phenomenon of being in the middle and a summary in tabular form of all categories, sub-categories and themes which emerged from the data regarding the phenomenon. Being in the middle was the overriding concept identified in my study, reflecting the plight of participants who were navigating the boundaries between their family role and their RN role within the context of their parent’s hospitalisation. Participants’ stated perceptions of being in the middle are also included. A profile of participants and of their parents is presented. The profile of parents and their hospitalisations included: the age and marital status of the hospitalised parents, their medical condition, the recency and duration of their hospitalisations, whether there were multiple hospitalisations and if so over what period they occurred.

Chapter Five provides the findings in relation to the category of disclosure of RN status to nursing and medical staff as part of the phenomenon of being in the middle. The category of disclosure of RN status encompassed two subcategories (and their respective
accompanying themes): preferring to remain undisclosed (with two themes: disclosure unnecessary and rather be treated as a lay son/daughter); and disclosing to activate RN power and credibility (with two themes: to be treated as a peer/colleague and to get action).

Chapter Six contains the findings in relation to the final two categories of the phenomenon of being in the middle: RN on standby (being expertly vigilant) and RN in action (imperative to intervene). RN on standby (being expertly vigilant) encompassed four themes: leading and staying strong at any cost; expertly observing, detecting and protecting; being adept at hospital language; and keeping it real. RN in action (imperative to intervene) encompassed two themes: filling in the gaps and fixing.

Chapter Seven returns to the research question and it contains a summary and discussion of the main findings linked to relevant literature, notes the limitations of the study, and concludes with recommendations for practice, education and future research. Chapter Seven is followed by a list of references.

Appendix A contains abridged versions of each participant’s story using pseudonyms.

Appendix B contains the Questionnaire, Information Sheet inviting RNs to participate in the study, the Consent for Interview form, and University Human Research Ethics Committee letter of approval to conduct the research.

Appendix C contains three tables relating to the parents’ profile; the extent of each participant’s role in relation to their parent’s hospitalisation (noting siblings and place of work); and participants’ preferences and outcomes regarding disclosure of their RN status to hospital staff.
CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

In the first chapter, ‘RNs’ experiences of parent hospitalisation’ was identified as the topic of this research project, the topic’s significance to me as the researcher was described and its wider significance established. The principal purpose of the initial literature search was to see whether the topic had already been addressed. I discovered that little is known about parent hospitalisation from a RN son’s or daughter’s perspective, and consequently I used qualitative research methods to obtain information from RNs to gain an understanding of the phenomenon.

The general aim of the literature review was initially to develop the research question in order to shape the direction of the study, to situate my topic within a context of existing knowledge, and then to inform my discussion of the interpretation of the data. This involved undertaking a critical review of the relevant literature related to the topic which has been synthesised in an integrated way to facilitate the emergence of possible perspectives about RNs’ experiences of parent hospitalisation.

2.1.1 Parameters of the literature review: Lay and RN family-caregiving

The aim of this research was to provide an understanding of the nature of RNs’ experiences of parent hospitalisation. As stated, literature directly on the topic was scant (notably research literature) and as a result the literature review encompasses knowledge concerning closely allied topic areas and allows wide scope in relation to time frame so that there is sufficient information to contextualise the study (Bloomberg & Volpe, 2008). In addition to their role as son or daughter, the participants had the RN role within their repertoire; therefore an added aim of the literature search was to
provide an understanding of the contribution of this dual role to participants’ experience of parent hospitalisation.

To date, limited aspects of RNs’ experiences with hospitalised relatives have been described within a RN’s personal account (Rufano, 1985) along with one brief UK report of RNs’ concerns about the poor quality of care their hospitalised relatives had received, and their views and experiences of lodging complaints about care (Northcott, 2000). Due to the paucity of in-depth comprehensive studies of RNs’ experiences of parent hospitalisation, studies which featured RNs caring for non-hospitalised relatives within home settings have been included (Baird, 1988; Mills & Aubeeluck, 2006; Ward-Griffin, 2004) as well as four RNs’ brief personal accounts of their experiences of having a relative with a terminal illness (Harris, 1999; Nicholson, 1995; Perovic, 1999; Stoner, 1998). The modest number of studies which featured RN participants (almost exclusively comprised of female RNs) has been supplemented by a selection of the literature concerning the experiences of lay relatives. I have annotated these where possible with information regarding their applicability to RN-relatives.

Literature regarding lay relatives (particularly sons and daughters) has been included because there may be commonalities in their experiences and those of RN-sons and daughters. Alternatively they may serve as a contrast to the caregiving experiences of RN-offspring, thereby revealing any unique impact that a RN-specific layer has on parental caregiving experiences.

The caregiving literature is extensive and it is not my intention to present an exhaustive review of its full range. For the purposes of this research key elements have been selected for their illustrative relevance. Lay sons’ and daughters’ experience of hospitalised parents is a relatively under-researched area when compared with experiences of non-hospitalised parents and of parents residing in nursing homes (also known as residential aged care facilities). Consequently the literature review includes aspects of lay caregiving in the home, in hospital settings and in residential aged care facilities and is presented below according to the following six categories:
• Lay caregiving of a family member: offspring and spousal differences
• Lay caregiving of parents in the home and siblings’ filial responsibility
• Lay caregiving of hospitalised parents and other relatives
• Lay caregiving of relatives within residential aged care facilities
• RNs’ home based caregiving of family members
• RNs’ experiences of hospitalised relatives

2.2 LAY CAREGIVING OF A FAMILY MEMBER: OFFSPRING AND SPOUSAL DIFFERENCES

Research concerning caregiving of family members by lay relatives has often involved assorted family members as participants in proportions which tend to approximate those of caregivers in the general population. These caregiving participants were mostly female, and were usually spouses and adult offspring (including in-laws in some cases) and sometimes included a much smaller proportion of assorted other relatives and friends (Higgins, Joyce, Parker, FitzGerald & McMillan, 2007; Li, Stewart, Imle, Archbold & Felver, 2000; Lindhardt, Bolmsjö & Hallberg, 2006).

Heterogeneity in samples of caregiving participants can add strength to the findings because general concepts which are central to the phenomenon apply to the whole group in spite of its variations (Sandelowski, 1995). However, differences in relation to content and emphasis between spouses and offspring have been reported in their experiences of being a relative to a hospitalised elderly person in areas such as emotional support (spouses provide more), relationship changes (wives become nurse-like and offspring become parent-like) and preferences about personal care (parents prefer to receive personal care from spouses over offspring) (Lemieux, 1996; Qureshi, 1990; Levine et al., 2003; Li, 1998; Lindhardt et al., 2006; Ward-Griffin, 2004).

In the nursing home sector differences have also been reported: in vulnerability to experiencing demoralisation among offspring and spouses (spouses are more vulnerable); in experiencing guilt and worry about nursing home placement of a
confused relative (relatives other than spouses feel less guilt and worry) (Grau, Teresi & Chandler, 1993); in the extent to which family members support them (spouses receive less support); and in the extent of difficulty relatives present to staff because of their expectations of staff (staff find meeting the expectations of spouses to be particularly difficult) (Schmidt, 1990).

The above findings indicate a need to examine the experiences of sons and daughters separately from spouses to account for the possible influence of child-parent structures and associated role boundaries and to prevent spousal differences from obscuring the characteristics of sons’ and daughters’ experiences.

2.2.1 Relationship changes: role reversal

The term ‘role reversal’ has been used by some researchers to describe an inversion in the roles of the parent and their offspring when they carry out caregiver responsibilities, suggesting that the adult child takes on the parental role, and the increasingly dependent parent adopts a child-like role (Lindhardt et al., 2006; Miller, Shoemaker, Willyard, & Addison, 2008; Willyard, Miller, Shoemaker & Addison, 2008).

Miller et al. (2008) interviewed the caregivers of elderly parents (nine daughters and two sons) and found that they linked their identity to the concept of role reversal by drawing on the labels of parent and child, and Abel (1989) found that sons and daughters dispelled the illusion that parents are omnipotent when they exerted unaccustomed authority over them (which the parents did not welcome). Some researchers report that the relationship between caregiving offspring and their parents is qualitatively different and not a clear cut case of role-reversal in that the offspring try to preserve elements of their parents’ identity and dignity (Abel; Bowers, 1987) and the adult son/daughter can still experience a child’s need for the parent’s acceptance (Abel; Lindhardt et al., 2006).

It appears that the perception and acceptance of role-reversal is only displayed by the caregiving offspring while the parent resents and sometimes resists the offspring’s authoritative behaviour. Fischer (1985) found that offspring explicitly declared that a
role reversal had occurred during a medical crisis when they became even more protective and assumed that they could now make better decisions than their parent. The parents however did not accept that a shift in responsibilities had occurred and this frustrated the offspring. A compromise was reached when parents traded decision-making for the care they needed from their offspring.

In light of the above, the term ‘role reversal’ is confusing if used to describe the relationship between offspring and their dependent parents as it only applies to the offspring’s role perceptions and obscures the reality of the parent’s opposing perceptions.

In some studies it was reported that the nature of role reversal differed for a spouse (Lindhardt et al., 2006; Ward-Griffin and McKeever, 2000) in that some wives caring for an elderly husband in the home took on the role of a nurse. Lindhardt et al. (p. 139) described the role changes for wives and adult offspring (described as “parent to my mother”) as an unpleasant experience although necessary and inevitable. These findings further support the need to examine the experiences of spouses and adult offspring separately.

2.3 LAY CAREGIVING OF PARENTS IN THE HOME AND SIBLINGS’ FILIAL RESPONSIBILITY

Research concerning caregiving of parents by their adult offspring has tended to focus on caregiving within home settings (Abel, 1989; Bowers, 1987; Mui, 1995; Read & Wuest, 2007). Abel’s (1990) extensive critique of the literature regarding informal care for the disabled elderly during the 1980s concluded that the two major foci were the tasks of caregivers and the stress they experienced, and that structured approaches and quantitative methods were almost always used. She suggested that it was not helpful to focus on tasks as it did not extend our understanding of the experience of caregivers, and recommended that both qualitative and quantitative methods are needed, as well as
an injection of theoretical insights from a wide range of disciplines to advance our understanding.

Mancini and Blieszner (1989) conducted an exhaustive review of research themes citing over 100 studies regarding ageing parents and adult offspring spanning over 20 years (which contained an overlap of only six articles with Abel’s 1990 review) and echoed Abel’s recommendation, that more research using qualitative methods was needed to further our understanding of intergenerational relations. They also suggested that some research questions such as conflict between parents and offspring were in need of research whereas some questions had been answered several times over: for example, we have known since the 1960s that older parents are not alienated from their children – they are usually in frequent contact and they generally provide support and practical assistance to each other.

Since the time of these reviews by Abel (1990) Mancini and Blieszner (1989) the focus of research has moved closer toward the experience of caregiving using qualitative methods to capture the essence of the experience directly from the caregivers in an unfettered form. A selection of relevant research (using qualitative methods) concerning lay sons’ and daughters’ experiences of caregiving elderly parents in home settings is presented below. Further to the findings of Grau et al. (1993) regarding the impact of cognitive status on the caregiver (mentioned in section 2.2) the research is presented in two categories: cognitively impaired parents and cognitively intact parents. This is in order to detect differences due to the cognitive status of the parent. This is followed by a review of the research regarding lay siblings’ filial responsibility.

2.3.1 Lay caregiving of cognitively impaired parents in home settings
Bowers (1987) conducted interviews with 27 parents and 33 offspring, and generated a theory of intergenerational caregiving which conceptualised caregiving by purpose rather than by task. This represented a significant departure from the work of her contemporaries whose research had focused on instrumental care (the observable tasks
of caregiving which generally used data not drawn from caregivers themselves). Bowers’ research using grounded theory methodology was based on adult caregivers (31 females and two males) and their (mildly) cognitively impaired ageing parents who were living in the community. She identified five categories of caregiving: “anticipatory” (of the parent’s needs) “preventive”, “supervisory”, “instrumental” (hands-on care) and “protective” caregiving (Bowers, p. 25).

The primary caregivers in Bowers’ (1987) study considered instrumental care of least importance, and protective care of their cognitively declining relative’s identity and self-image (to preserve their self-image as competent and independent) as their most important caregiving function. This contrasted sharply with the views of health professionals (and less involved relatives) who more often considered preventive and instrumental care of greater importance than protective care. Bowers reported that a consequence of these differences was for her participants to remove themselves from the health care system (and sometimes from the family system) as one way to maintain control in order to preserve the parent’s self-image.

Most of Bowers’ (1987) caregiving functions can be performed by RN-offspring at an expert level (such as anticipatory, preventive, supervisory, and instrumental caregiving) although they may feel discomfort and reluctance to perform instrumental tasks of a personal nature for their parent as do lay offspring (Lemieux, 1996; Ward-Griffin, 2004). Perhaps offspring are engaging in protective care by avoiding situations in which they are required to assist their parent with tasks such as toileting and bathing because those actions would impinge upon the parent’s dignity, parental identity and self-image.

Various lay caregiving behaviours which were described by Bowers (1987) within the protective caregiving category are the antithesis of RN behaviour and these differences may create internal conflicts if applied to a RN operating in the role of a relative of a hospitalised parent. One of Bowers’ protective strategies involved neutralising the significance of a situation by attributing its cause to something perceived as less distressing to the parent’s self-image than its real cause. Unlike Bowers’ participants,
RNs are more likely to risk insulting the patient’s self-image than risk physical harm to the patient. They are also unlikely to deny their patient medical attention in order to preserve their self-image, however, when the RN is in the role of relative with a cognitively impaired parent their behaviour may alter and display similarities to lay offspring.

Abel (1989) interviewed 40 daughters caring for frail elderly parents who were mostly cognitively impaired and found that traditional support networks were not always helpful. She found that out of consideration for others or to avoid disparagement or friction (because sibling rivalries were often re-ignited) the primary caregiver tended not to involve friends (who sometimes trivialised their caregiving role) or other relatives in caregiving unless absolutely necessary and did whatever was possible to preserve a dignified image of the parent to others (Abel; Bowers, 1987).

Some aspects of Abel’s (1989) and Bowers’ (1987) findings are applicable to my research, however because of their expertise, RN-caregivers may differ in the types of support they require and the likelihood that they will look to lay siblings and others for assistance. RNs have high expectations of themselves in relation to their relative’s health care (Ward-Griffin, 2004) and family expectations of a RN-caregiver are higher than of non-RN siblings (Baird, 1988). These expectations may result in different attitudes toward RN-offspring by family and friends and present different challenges to those described by Abel. Similarly, the special circumstances of a cognitively impaired parent who is being cared for within the home and the caregiver’s ability to easily exclude others whose views are not in agreement with theirs may be responsible for Bowers’ findings regarding the predominance and overriding importance of protective care. These findings may not apply to RN-caregivers of parents who are hospitalised and not cognitively impaired.
2.3.2 Lay caregiving of cognitively intact parents in home settings

Some studies involving caregiving of cognitively intact parents have been conducted by interviewing adult siblings. Studies have involved parents of varying morbidity such as parents at risk of being institutionalised (Mui, 1995) and dying parents (Read & Wuest, 2007) and parents of differing levels of dependency ranging from totally independent to totally dependent where the extent of assistance from offspring ranged from an average of seven hours per week to several hours per day (Ingersoll-Dayton, Neal, Ha & Hammer, 2003; Matthews & Rosner, 1988; Miller et al., 2008; Willyard et al., 2008). These studies usually reported caregiving by a solitary (usually female) primary caregiver and identified the extent, types and sources of strain for caregivers and indicated that the degree of the parent’s dependency and morbidity influenced the extent and type of care required. Unlike caregivers of cognitively impaired parents reported by Abel (1989) and Bowers (1987) there was not an obvious priority given to preserving the parent’s identity and self-image.

Read and Wuest’s (2007) research involved 12 daughters caring for dying parents in the home and (because they were terminally ill) presents possible parallels for RN-offspring with hospitalised parents who have a life-threatening illness. The daughters experienced emotional turmoil: due to a sense of hopelessness and helplessness about the outcome, a belief the parent was suffering, a lack of information and experience concerning death and dying, and a sense of isolation; relational turmoil: due to the demands placed upon them by family members; and societal turmoil: due to dedicating vast amounts of time to the dying parent at the expense of their work, mothering and spousal roles – sometimes with enduring consequences. They managed their turmoil by keeping vigil, navigating systems of care, facing loss and finally coming to terms with their parent’s death. In the aftermath of their parent’s death, the daughters needed to attend to their physical, emotional, spiritual and social needs.

The sources and management of turmoil reported by Read and Wuest (2007) may differ for RNs because of their nursing expertise and familiarity with hospital systems. Their
RN expertise is also likely to affect the ways in which they exercise vigilance and strive for control. Read and Wuest’s research was exclusively concerned with daughters, and it is therefore possible that sons have different experiences and coping strategies, as gender differences have been reported by other researchers in relation to burden and morale. Mui’s (1995) study of frail elderly parents who were at risk of institutionalisation, reported that caregiving offspring experienced significant strain and gender differences: daughters were found to experience greater emotional strain than sons, and the source of strain for daughters was related to parent relationship factors and interference with work, whereas sons were more affected by parental behaviour and a lack of informal helpers.

2.3.3 Lay siblings’ filial responsibility

The likelihood of a particular sibling taking on the role of primary caregiver was found to be influenced by family structure (such as the importance of gender and being the eldest child) extra-familial ties (such as geographical proximity and competing commitments related to employment, spouses and children) and a sibling’s competence and suitability for the role of caregiver (Matthews, 2002; Matthews & Rosner, 1988; Stoller, 1983; Willyard et al., 2008). These factors also affected the extent of caregiving provided by siblings.

Matthews and Rosner (1988) found that in families of more than two offspring, at least two were usually involved (usually sisters) in routine core care. Most of the care was likely to be given by the eldest, by those with supportive spouses, and those with suitability for the role based on personality and capability. Willyard et al. (2008) interviewed two sons and 23 daughters and also found that sisters usually assisted a primary caregiver. They explored the ways in which siblings negotiate the division of tasks for elderly parents and found that there was little negotiation of caregiving tasks. As expected, daughters usually took on the primary role, and often did so believing it to be an individual activity for which they were especially suited, and because it reflected their values about family life.
It was clear in most studies that one sibling took responsibility for most of the caregiving of the parent, and that redressing inequity among siblings was seldom successfully tackled (Ingersoll-Dayton et al., 2003). Ingersoll-Dayton et al. used focus groups involving 23 daughters and 17 sons to research the applications of equity theory to redress inequities in siblings’ caregiving relationships: the underlying assumption was that inequity in caregiving caused distress to siblings and motivated siblings to achieve equity to alleviate distress. Inequities were redressed by requesting behavioural changes from siblings or by reconceptualising the situation to achieve psychological equity: using gendered expectations, proximity, other family responsibilities, employment status, and by making excuses based on the personality of siblings in their calculations of equity. In some cases unsuccessful attempts to redress inequities resulted in increased distress and the conflict among siblings escalated. The psychological factors identified in Ingersoll-Dayton et al.’s study were also identified as legitimate reasons for inequity in caregiving by Matthews and Rosner (1988).

Research has tended to focus on data provided by primary caregivers, but this can bias the results by eclipsing the contributions of other family members. This was Matthews’ and Rosner’s (1988) argument for researching the family unit as the primary caregiver. Their comprehensive study which focussed on shared filial responsibility included 151 siblings (which included 25 brothers). They interviewed fifty pairs of sisters to discover how siblings organised to meet the needs of their elderly parents (at least one parent was over 75 years old). Their study provided insights into the interactions of siblings and the kind of teamwork which can occur in caring for elderly parents. A limitation inherent in Matthews’ and Rosner’s research design was that they interviewed pairs of sisters who were amicable enough to volunteer to talk about one another. The convivial nature of their relationship may have led to the adoption of a joint caregiving approach. Despite this limitation, key factors affecting the type and extent of caregiving were identified.

Matthews and Rosner (1988) found that except in cases of long-standing animosity, siblings were able to work together to meet their parents’ needs. Conflicts among
members were reported in half the families, but this was usually kept within limits to preserve the working relationship. The most influential competing tie was described as loyalty to the spouse. Adult offspring with supportive spouses were likely to be routinely involved in caregiving, whereas openly antagonistic spouses made every filial activity a conflict-laden choice and there was not only a sense of “juggling priorities but of deciding which act of treason was easier” (Matthews & Rosner, p. 193). Stoller (1983) also reported that the competing demands of married offspring resulted in less time devoted to caregiving.

The influence of factors identified by Matthews and Rosner (1988) such as birth order, status within the family and the impact of the caregiver’s responsibilities on their own spouse and children are likely to also be pertinent to RN-offspring. The issue of competence is also a relevant one for RN-relatives as a nursing qualification may signify to other family members that the RN-relative is the most appropriate one to take charge when a parent is hospitalised and may override efforts to achieve equity. As reported in Willyard et al.’s study (2008) siblings may not take on caregiving tasks because they do not want to ‘step on the toes’ of the family’s most competent caregiver. When considering the sharing of caregiving tasks among siblings, continuity of care is also an important deciding factor. For example it is important that the caregiver knows the parent’s medical history when accompanying them to medical appointments, and lay siblings recognise that a RN-sibling is more effective in representing the parent and interpreting medical information for the parent (Matthews, 2002).

This idea of being in charge may be an important factor affecting the likelihood of sibling assistance being offered to RN-caregivers. By virtue of a RN-offspring’s nursing expertise, their siblings may defer to their knowledge and skill by leaving the leadership role to the RN sibling. Similarly, RNs are likely to be called upon to accompany a parent when seeking medical attention. Unlike Matthews’ and Rosner’s (1988) findings, an offspring’s RN expertise may negate or alter the tendency for their non-RN siblings to participate in their parent’s care. However, in families with more than one
RN-sibling the influence of gender and the adoption of Matthews’ and Rosner’s styles of participation may apply.

The differing levels of parents’ dependency evident in these community based studies, due to cognitive or other disabilities, affected the type and the extent of family caregiving (Stoller, 1983). Personal circumstances and attributes such as an offspring’s competence for the task of caregiving also increased the likelihood of a sibling being the primary caregiver (Matthews, 2002; Matthews & Rosner, 1988; Miller et al., 2008; Willyard et al., 2008). RN sons and daughters represent highly competent caregivers and therefore the findings of these studies are of significance to the present study.

2.4 LAY CAREGIVING OF HOSPITALISED PARENTS AND OTHER RELATIVES

This section focuses on studies of lay family caregiving of hospitalised adult relatives. These studies involved relatives of varying ages and levels of acuity (Carr & Fogarty, 1999; Thorne & Robinson, 1988). Research participants were usually mixed (typically comprising a majority of spouses and adult offspring) and their experiences were reported for the group of caregiving relatives as a whole (Ästedt-Kurki, Lehti, Paunonen & Paavilainen, 1999; Ästedt-Kurki, Paunonen & Lehti, 1997; Higgins et al., 2007).

2.4.1 Caregiving: motivation, preferences and types of care provided

Lay caregiving of a hospitalised relative may involve providing emotional support, assisting with activities of daily living and with instrumental activities of daily living (Li, 1998) and providing decision-making input (Jacelon, 2006). Conflicts have been reported to arise when relatives in the dual role of health practitioner and family member (“double-agents”) act as surrogate decision-makers on behalf of their relative, and make decisions which are not in their relative’s best interests or that are contrary to their relative’s wishes (Issa, 2002, p. 946). This is consistent with Fischer’s (1985) findings that parents can resent and resist moves by their offspring to take over decision-
making when their parent is ill (reported in section 2.2.1). Similar tensions and conflicts may occur if RN-offspring act as decision-makers on behalf of their parents.

The literature regarding relatives’ motivations and preferences in caregiving behaviour towards a cognitively intact hospitalised family member is inconclusive. Some research finds that family members do usually perform a wide range of caregiving tasks for hospitalised relatives which in many cases have been described as nursing tasks (Åstedt-Kurki et al., 1997; Åstedt-Kurki et al., 1999; Hall, 1989, 1990; Li, 1998; Lindhardt et al., 2006). In some instances relatives engaged in such activities to ensure an elderly hospitalised relative’s safety or as a substitute for shortfalls in the care provided by hospital staff (Lindhardt et al., 2006). Hall (1989, 1990) reported that adult sons and daughters continued to provide care to their cognitively intact parents despite their parents being consigned to the care of the hospital, and that caregivers experienced profound stress and strain as a result of providing assistance (in the form of psychological support, personal care, bureaucratic mediation services and maintaining their parent’s links to their community network). At times the care provided by family members has been extensive (Åstedt-Kurki et al., 1997; Åstedt-Kurki et al. 1999) even when the patients were neither cognitively impaired nor terminally ill (Li, 1998; Li et al., 2000). In contrast Laitinen’s (1993, 1994) research found that caregivers visited often but mostly gave emotional and social support and only gave limited and infrequent assistance in activities of daily living. Similarly, in a study concerning relatives of elderly mentally ill patients (following long term hospitalisation) Sharp (1990) also reported that relatives provided negligible direct care and did not wish to increase their involvement despite encouragement by nursing staff.

Despite evidence that caregivers do provide assistance to varying degrees and in various ways, it is not clear whether caregivers prefer to provide such assistance or whether they do so mainly out of perceived necessity (Åstedt-Kurki et al., 1997; Åstedt-Kurki et al., 1999; Hall, 1989, 1990; Laitinen, 1993, 1994; Li, 1998; Lindhardt et al., 2006). Comprehensive research concerning hospitalised relatives’ preferences regarding the type and extent of assistance they prefer their family members to provide within the
hospital setting is lacking and is currently limited to sporadic findings within broader
based research (Li, 1998).

2.4.2 Prominent themes of caregiving in a hospital setting

Five prominent themes were identified in the literature concerning caregiving of a
hospitalised relative (although the labels used to identify them varied):

- The need to be vigilant which encompassed the need to be physically present for
  the relative (Åstedt-Kurki et al., 1997; Carr & Clarke, 1997; Carr & Fogarty,
  1999; Jacelon; 2006; Lemieux, 1996; Li, 1998; Li et al., 2000; Lindhardt et al.,
  2006; Thorne & Robinson, 1988; Walters, 1995).

- The need to be well informed by health care professionals (Åstedt-Kurki et al. ,
  1997; Carr & Fogarty, 1999; Higgins et al., 2007; Lemieux, 1996; Lindhardt et
  al., 2006; Thorne & Robinson, 1988).

- The presence of emotional upheaval in the caregiver (Åstedt-Kurki et al., 1999;

- The resultant major changes in the caregiver’s lifestyle, role and daily rhythm
  (Åstedt-Kurki et al., 1997; Åstedt-Kurki et al., 1999; Carr & Fogarty, 1999;

- The need for the caregiver to be resilient (Carr & Fogarty, 1999; Lemieux, 1996;
  Li, 1998; Li et al., 2000).

Some of the studies listed above involved only cognitively intact patients and
participants who were all sons and daughters (Hall, 1989, 1990; Lemieux, 1996) or
mostly sons and daughters (Jacelon, 2006; Lindhardt et al., 2006) or included some sons
and daughters (Higgins et al., 2007) or did not specifically mention whether adult
offspring were included among the participants (Thorne & Robinson, 1988).
Other studies involved cognitively impaired patients. The study by Carr and Fogarty (1999) involved mostly cognitively impaired relatives admitted to neurological and rehabilitation wards who had limited or no ability to communicate; and the participants were a mixed group of unspecified family members who defined themselves as family and spent between six and 24 hours per day at their relative’s bedside. Family members (including sons and daughters) of relatives admitted to neurological wards were also the focus of research by Åstedt-Kurki et al. in 1997 and Åstedt-Kurki et al. in 1999. No specific information was provided regarding patients’ cognitive status in Walters’ (1995) study which involved critically ill relatives in an intensive care unit.

Despite the differing cognitive abilities of the hospitalised relatives and the heterogeneity of participants, some common themes were identified as listed above, indicating that some concepts are not affected by the cognitive status of the sick relative or the variability within the participant group. Studies highlighting these common themes are presented below.

2.4.2.1 The need to be vigilant by being physically present for the relative

Vigilance has been defined as close protective involvement of family members with hospitalised relatives (Carr & Clarke, 1997; Carr & Fogarty, 1999). Vigilance was demonstrated by the need to be physically present for the relative and was identified by participants as a very important function in several studies. It was often at least partly motivated by a lack of confidence in the staff and the system of care (Carr & Fogarty; Higgins et al., 2007; Jacelon, 2006; Lemieux, 1996; Lindhardt et al., 2006; Thorne and Robinson, 1988).

Being present included the need to stand guard to protect the patient, monitoring, seeking involvement in their care, observing for changes, coming to see them and staying with them to demonstrate caring, love and concern for their well-being and to offer emotional support; being there in case they were needed and to pursue involvement with HCPs which included goal directed activity (Åstedt-Kurki et al., 1997; Åstedt-Kurki et al., 1999; Carr & Fogarty, 1999; Higgins et al., 2007; Jacelon,
This caregiving function of “being there” for the hospitalised relative was identified by Higgins et al. (2007, p. 214) and others (Li, 1998, p. 75; Li et al., 2000, p. 8) and was included in Carr and Fogarty’s (1999, p. 435) category of “commitment to care” which entailed needing to protect the patient, wanting to be involved in care and watching for changes in the patient. Jacelon (2006, p. 244) described supportive care given by relatives “to keep the older adult going” by visiting and sitting with their hospitalised relative to demonstrate concern and love for them. Lemieux (1996, p. 67) reported that offspring thought it essential to be there for their parent to offer emotional support (especially if receiving bad news) and they were actively “pursuing involvement” with HCPs and being vigilant in “monitoring” their parent’s condition and care particularly because they had lost confidence in the system due to medical errors and because their warning pleas had been ignored. Mahoney (2003) reported caregivers of relatives with Alzheimer’s disease felt they had to be there to fill in the perceived gaps in staff members’ care of their relative. Thorne and Robinson’s (1988, p. 298) experienced caregivers who had progressed through the stages of “naïve trusting” and “disenchantment” to the stage of “guarded alliance” in their relationships with HCPs, remained vigilant in their advocacy of their chronically ill relative which entailed goal directed activity.

Lindhardt et al. (2006, p. 142) described relatives’ experiences about the encounter with the professional system as “standing guard” to ensure the safety and care of the elderly relative. They described relatives’ fears (“if you relax you fail”) because they lacked confidence in HCPs. Family members visited often and felt they had a responsibility to stand guard and advocate for the hospitalised relative to get sufficient care and they acted as watchdog and case manager by performing checks to avoid errors occurring.

RNs’ credibility as health care professionals and their expertise in monitoring care and detecting changes in the patient’s condition may influence their behaviour and their
interactions with HCPs which may result in different actions and outcomes to those of the lay caregivers described above.

2.4.2.2 The need to be well informed by health care professionals

The need to be kept well informed by health care professionals about their relative’s condition and treatment emerged in some studies as being of utmost importance (Åstedt-Kurki et al., 1997; Åstedt-Kurki et al., 1999; Carr & Fogarty, 1999; Higgins et al., 2007; Lemieux, 1996; Lindhardt et al., 2006; Thorne & Robinson, 1988).

Carr and Fogarty’s (1999, p. 436) “dynamic nexus” category was characterised in part by communication with HCPs which the majority of their participants found to be inadequate. The importance of receiving sufficient accurate and timely information on an ongoing basis about their relative’s condition and treatment in order to guide their involvement and plan for the future was a strongly recurring theme in several studies (Higgins et al., 2007; Lemieux, 1996; Lindhardt et al., 2006; Thorne & Robinson, 1988). Higgins et al. (p. 213) referred to this concept as “being informed”. The various other labels and descriptions given to this concept were: spending enormous energy in “relentlessly seeking information” from professionals who did not communicate effectively (Lemieux, p. 63) and participants’ feelings of “powerlessness about not knowing what to do and when it ends”, meaning they experienced frustration because they were not able to get a clear diagnosis and prognosis for their elderly relative, and they had no guidance about what to do to help their relative recover (Lindhardt et al., p. 142). In Thorne and Robinson’s (p. 297) “disenchantment” phase of participants’ relationships with HCPs, they were often angry fearful and frustrated due to difficulties acquiring information, which made it impossible for relatives to have effective involvement in their chronically ill relative’s care.

An analogy can be drawn between the evolving relationship between relatives and health providers described by Thorne and Robinson (1988) and the evolved state of a RN’s relationship with health providers. RNs are not naïve caregivers and are therefore not likely to resemble inexperienced lay caregivers who may naively trust all health
practitioners equally and without question. RN-relatives can presumably skip the “naive trusting” stage as they can easily detect errors and omissions in care, and if they become disenchanted with the parent’s care, the RN-relative is likely to be aware of appropriate processes to address any detected short-comings. The stage of “guarded alliance” which represented Thorne and Robinson’s (p. 298) evolved final stage for lay relatives’ relationships with HCPs may represent the entry level baseline for RN-relatives due to their familiarity with the hospital system and their expert nursing knowledge.

2.4.2.3 The caregiver’s emotional upheaval

The “emotional upheaval” theme described by Carr and Fogarty (1999, p. 435) within the phenomenon of vigilance was also featured in studies by Hall (1989, 1990) Lemieux (1996) and Lindhardt et al. (2006). The theme of “emotional upheaval” was to do with the feelings to be managed by the relative as a result of their family member’s illness and reflected the uncertainty of their situation, life and death decisions and feelings of loss for the future and loss of normalcy in their life (Carr & Fogarty). The emotional impact on the caregiver was often described as an accompaniment to the relative’s illness and hospitalisation. Hall’s (1989, 1990) participants (27 adult offspring) reported being emotionally exhausted by caregiving and all participants in Lindhardt et al.’s (p. 139) study expressed emotional strain, grief, worry and a feeling of guilt (“always back of my mind”). Relatives were emotional yet had to act rationally. The need for “expressing emotions” was stressed as was the critical importance of having family and friends to support them so that they did not feel alone (Carr & Fogarty; Hall, 1989, 1990; Lemieux, p. 68; Lindhardt et al.).

Baird’s (1988) finding that family members have higher expectations of RN offspring than of their non-RN siblings when added to the high expectations RNs have of themselves (Ward-Griffin, 2004) may result in significant added pressure to perform and achieve good health outcomes for the parent which may result in significant added emotional upheaval for RN-relatives.
2.4.2.4 Major changes in the caregiver’s lifestyle, role and daily rhythm

Major changes in the caregiver’s lifestyle, role and daily rhythm were reported by Carr and Fogarty (1999) Lemieux (1996) Hall (1989, 1990) and Lindhardt et al. (2006). Carr and Fogarty (p. 436) described the “transition” aspect of vigilance in terms of the major impacts that their relative’s illness and hospitalisation had on their life (such as transitions in lifestyle, role and daily rhythm). Examples included driving to visit, constantly describing over and over to relatives and friends what was happening; taking extended leave from work; and dealing with other family crises and emergencies which continue to arise whilst they are still dealing with the more important issue of their hospitalised relative. Lemieux (p. 76,79) also described caregiving in terms of “feeling imprisoned” and putting one’s “life on hold” because of the ambiguity of what lay ahead. Hall’s (1989, p. 74; 1990) participants described feeling “tied down”, and Lindhardt et al. reported role changes within the family when the elderly relative became dependent on a family member for assistance, and described a role-reversal for offspring and a nurse-like role for the spouse (as was described in section 2.2.1). 

RN-relatives may also experience major changes to their day to day life, to work and family responsibilities as a result of their parent’s hospitalisation. Due to their RN expertise, and their family’s expectations, their role as a family member may take on a more explicit pervasive and overriding nursing element.

2.4.2.5 The need for the caregiver to be resilient

The final prominent theme identified in the literature concerning caregiving of a hospitalised relative was resilience. Caregivers needed to take care of themselves and be resilient as an important coping strategy to enable them to perform their caregiving tasks effectively in order to support their relative throughout the crisis (Carr & Fogarty, 1999; Lemieux, 1996). Carr and Fogarty (p. 436) described the “resilience” aspect of vigilance as the need for participants to care for themselves in order to be able to last the distance, and this was also the case in Lemieux’s (p. 69) study in which “attention to self” was described as a coping strategy for participants. Attention to self was also a key
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element in Li’s (1998, p. 107; Li et al., 2000, p. 14) doctoral research regarding family participation in the hospitalised care of elders (participants were 4 wives, a husband and a son) where “taking care of self” was identified as one of three content domains (the other two areas were family members “providing care to the patient” and “working together with the health care team”).

RNs have experience in supporting patients during hospitalisation. They may not feel the need to take extra measures to care for themselves when exercising a caregiving function for their relative.

2.4.2.6 Summary

In summary, relatives’ experiences of a family member’s hospitalisation revealed five prominent common elements across a number of studies: the need to be vigilant which encompassed the need to be physically present for the relative; the need to be well informed by HCPs; the presence of emotional upheaval in the caregiver; the resultant major changes in the caregiver’s lifestyle, role and daily rhythm and lastly, the need for the caregiver to be resilient. The extent to which RN-relatives’ experiences differ from those of lay relatives in relation to these aspects will be explored within this study.

2.5 LAY CAREGIVING OF RELATIVES WITHIN RESIDENTIAL AGED CARE FACILITIES

Much of the abundant literature regarding family caregivers of nursing home residents has tended to focus on the placement aspect and the guilt and burden experienced by the primary caregiver. Often these feelings did not abate (and sometimes increased) following placement of their relative because participants continued to play a significant caregiving role (Bauer & Nay, 2003). Spouses and adult offspring comprised the majority of family caregivers within the selected studies reviewed. These studies focused on the experiences of family members following placement in exercising their caregiving role (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2006;
Fleming, 1998; Kellett, 2007; Nay, 1997; Russell & Foreman, 2002; Schwartz & Vogel, 1990); their satisfaction with and perceptions of care given to the resident (Berglund, 2006; Bowers, 1988; Ejaz et al., 2002); and their interactions and partnerships with staff (Bauer & Nay, 2003; Hertzberg & Ekman, 2000; Kellett, 2000; Nolan, 2001; Vinton & Mazza, 1994; Westin, Öhrn & Danielson, 2009).

Relatives were reported to differ in the extent to which they participated in providing direct care to the resident-relative and in whether they preferred to perform less or more direct care. This is despite the finding that most relatives often provided assistance to relative-residents with activities such as feeding, personal care/hygiene and toileting. Some participants stated that they did not wish their helping behaviour to be interpreted as criticism of the care that staff provided, however there was insufficient evidence to decide whether the relatives were filling in the gaps due to unsatisfactory care provided by staff. Residents however did not want their offspring to assist them with activities of daily living and preferred such assistance to be provided by staff. Offspring also preferred to leave some tasks to staff such as toileting assistance (Russell & Foreman, 2002). In some cases relatives’ efforts to engage in caring activities were thwarted by staff and this made relatives feel useless and stressed when they observed that the care given by staff was substandard (Kellett, 2000).

The experiences of family caregivers included the presence of emotional upheaval (feelings of guilt, sadness); resultant major changes in their lifestyle, role and daily rhythm; and the need to maintain the mental health and well-being of the caregiver. Grau et al. (1993) reported similar gender differences to Mui (1995) in that sons were generally less vulnerable than daughters to becoming demoralised, but were more prone to demoralisation if they perceived their parent to be confused.

Common findings in studies of lay family caregivers’ needs in relation to their elderly relative residing in a nursing home are summarised below to draw parallels and contrasts with lay and RN family caregivers’ experiences in community and hospital settings. Two categories were found to apply to findings across several studies:
• The need to be included in the life of the resident-relative within the world of the nursing home and to be treated like a partner in their care.
• The need to be vigilant which encompassed the need to be physically present for the resident-relative.

2.5.1 The need to be included in the life of the resident-relative within the world of the nursing home and to be treated like a partner in their care

This category included having family caregivers’ presence and contributions welcomed and acknowledged by the staff and feeling central to the care (Kellett, 2000, 2007; Nay, 1997; Westin et al., 2009) and having their extensive knowledge of the resident as an individual valued, drawn upon and applied to individualise the resident’s care (Mahoney, 2003) and to preserve their dignity and self-image (Bowers, 1988). It also included being kept fully informed about the resident (Nay, 1997). This differed from family members’ expectations within a hospital setting as the aim within the aged care facility was to become integrated into the resident’s new home context and the people within it.

2.5.2 The need to be vigilant which encompassed the need to be physically present for the resident-relative

This category is similar to ‘being there for the relative’ (described in section 2.4.2.1) and includes: looking out for the resident by overseeing (Bern-Klug & Forbes-Thompson, 2008) and monitoring care, filling in the gaps in care (Davies & Nolan, 2006; Mahoney, 2003) and providing love and affection and the special elements of care (Fleming, 1998) including their link to other relatives and life outside the nursing home. Needing to be able to trust staff and depend on them to provide timely good quality care for the resident (Mahoney, 2003) in a respectful, unhurried and compassionate manner were important elements (Bern-Klug & Forbes-Thompson, 2008; Nay, 1997; Russell & Foreman, 2002).
2.6 RNS’ CAREGIVING OF FAMILY MEMBERS IN HOME SETTINGS

The literature regarding caregiving of family members by RNs in home settings is limited. Four female RNs’ brief personal accounts of having a relative dying of cancer have been published. Stoner (1998) had a brother with lung cancer, Nicholson’s (1995) husband had liver cancer, Perovic (1999) nursed a father-in-law at home with gastric cancer, and Harris’ (1999) father had colon cancer. In addition to these one or two page articles, three research projects using qualitative methods have been published whose focus was restricted to particular aspects of caregiving rather than RNs’ caregiving experience as a whole. In two of these studies all the RN participants were female (Baird, 1988; and Ward-Griffin, 2004) and one male and four female RNs participated in the third study (Mills & Aubeeluck, 2006). The cognitive status of the participants’ sick relatives was not stated although two of the eight exemplars quoted by Ward-Griffin did mention the relative had been diagnosed with Alzheimer’s disease or another type of dementia.

The studies by Mills and Aubeeluck (2006) and Ward-Griffin (2004) focused on the impact of RNs’ dual role as “double-duty caregivers” (Ward-Griffin, p. 100). That is, the RNs were working concurrently as paid health professionals and also performed unpaid caregiving for a family member in a home setting. Mills and Aubeeluck (2006) researched RNs’ information needs, availability of support systems, and the impact on their quality of life of providing unpaid caregiving to unspecified relatives with a life-threatening illness whilst concurrently working full-time within the UK National Health Service. Ward-Griffin researched 15 female RNs’ unpaid caregiving of elderly relatives (ten parents, two parents-in-law, a spouse, a sister and a grandparent) whilst concurrently working either full-time or part-time as community nurses. Baird’s (1988) research focused on relationship consequences for 27 RN-daughters (mostly married and working full-time) who were cancer nurses and had a parent dying of cancer (who did not live with the daughter).
Ward-Griffin’s (2004) was the only study to report the extent of caregiving provided by RN-relatives (at least one hour per week). All three studies were focused on caregiving within the community, although two studies (Mills & Aubeeluck, 2006; Ward-Griffin) did not exclude sporadic episodes which occurred within a hospital setting.

2.6.1 Prominent elements of RNs’ caring for relatives in home settings

Three prominent elements were identified in the literature concerning RNs caring for a relative within the community.

- Role confusion, identity conflict and other major changes in the caregiver’s lifestyle, role and daily rhythm as a result of the relative’s illness (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Stoner, 1998; Ward-Griffin, 2004).

- The presence of emotional upheaval in the caregiver (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Perovic, 1999; Stoner, 1998; Ward-Griffin, 2004).

- “Being there for family members” and “a never-ending vigil” (Stoner, 1998, p. 16) and providing direct nursing care (Baird, 1988; Harris, 1999; Nicholson, 1995; Perovic, 1999; Stoner, 1998; Ward-Griffin, 2004).

In addition to the above, the need to be well informed by health care professionals was reported by participants in one study in which researching RNs’ information needs was within the stated aims of the project (Mills & Aubeeluck, 2006). In this study RNs’ expertise was a disadvantage in that HCPs did not provide full explanations and family members expected the RN-relative to have all the answers. The absence of this element within the other studies of RNs may be a consequence of the differing foci of those studies or may indicate that RNs’ information needs were satisfied.
2.6.1.1  Identity conflict, role confusion and major changes in lifestyle

Issues of identity conflict with accompanying role confusion were a feature of all six accounts/studies (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Stoner, 1998; Ward-Griffin, 2004). Some RN-relatives felt they had no choice about taking on the caregiving role for their relative due to their obvious expertise for the role and because they were female (Ward-Griffin).

Harris (1999, p. 49) described her situation as “balancing precariously between loving daughter and diligent nurse”, and Baird (1988) also referred to the need to balance the role of nurse and daughter, adding that the role balances may vary with the course of the disease and with the expectations of others. Stoner (1998, p. 16) said she coped with her brother’s terminal illness by distancing herself and “being a nurse and not a sister”.

Nicholson (1995, p. 50) “agonized over her dual role as wife and nurse” and found the dual role to be insupportable. She was confused between being her husband’s competent nurse or his loving wife and stated she “couldn’t be both because the nurse had to be detached and professional and the wife acted on emotional impulses” (p. 50). The community nurses ignored Nicholson (p. 50) when she was in tears: they seemed to be “uncomfortable in the presence of a colleague”. She was obviously in need of support yet did not receive any, and reported she was appalled by the callous and insensitive way she was treated by HCPs generally.

Frustration was expressed by one RN because of an inability to separate the two identities of nurse and family member. She felt she could neither be just the nurse nor just the daughter, but was unable to fulfill the roles of either when attempting to be both (Mills & Aubeeluck, 2006).

One newly graduated RN-daughter, whose father had undergone major surgery, admitted that she could not help herself from assessing him post-operatively but that she was being there as a daughter and hoped that everyone else would do their job properly so that she could continue just being the daughter (Ward-Griffin, 2004).
Dealing with the difficult issue of personal and professional boundaries was described. Some participants were privy to information and some felt ethically compromised by their easy access to information (Mills & Aubeeluck, 2006). On the other hand, participants felt pressured by their family’s expectations to “have all the answers” (Baird, 1988, p. 14; Mills & Aubeeluck, p. 162). Some participants who had accessed insider information were then faced with the dilemma of whether to share it with the family particularly if it was bad news (Baird; Mills & Aubeeluck) and although they wanted information they did not want to influence treatment decisions (Mills & Aubeeluck) presumably because of the repercussions if a poor outcome resulted (Stoner, 1998). Conveying or interpreting bad news caused conflict in that “the nurse could not deny the truth in the situation but the daughter wanted to” (Baird, p. 14).

When the situation called for the participant’s clinical expertise it became extremely awkward if they needed to confront the parent concerning their incorrect practices, or if their RN expertise led them to carry out necessary but unpalatable actions. Participants felt conflicted in situations where the parent’s condition worsened and they needed to exercise professional judgment and when they were expected to assume too much responsibility for their parent’s care (Ward-Griffin, 2004).

Baird (1988) acknowledged that having a RN as a family member was an important resource but two thirds of her participants had experienced identity conflict within the family as a result. Three common sources of conflict related to the level of responsibility participants felt because their family’s expectations were not met: regarding family expectations of the actions of HCPs; or when the level of care by HCPs was less than expected; or because participants perceived that their parent had higher expectations of the RN-daughter than for their lay siblings (Baird). Ward-Griffin (2004) also noted that participants had high expectations of themselves and that HCPs and others also had unrealistically onerous expectations of them due to their RN status even in situations where they lacked the necessary knowledge and skills (Mills & Aubeeluck, 2006). Half of Baird’s participants also reported they had unrealistically high expectations of themselves.
Some participants found it especially difficult and uncomfortable to be both nurse and daughter when HCPs talked to them as a nurse which did not allow them to have the emotions of a daughter or when HCPs expected them to be daughter and nurse simultaneously by enlisting their assistance with embarrassing aspects of the parent’s personal care (Ward-Griffin, 2004).

Caregiving duties significantly restricted the lifestyle of some participants due to their family caregiving role (Mills & Aubeeluck, 2006). Most participants in Baird’s (1988) study also identified an impact on their personal life and/or their professional life such as changing work commitments and dropping out of courses; and they frequently found it difficult or impossible to care for patients with the same diagnosis as their parent (Baird; Nicholson, 1995).

Ward-Griffin’s (2004) study focused on double-duty caregiving. The premise of this study was that the role of HCPs was to care for clients, and for family members to care about their sick relative, and because emotional attachment interfered with professional judgement it was inadvisable for RNs to care about clients or to care for family members. She found that in some cases it is possible (and sometimes preferable) for RNs to care for and care about a client, and to care about and care for a relative, thereby demonstrating that the boundaries between caring for and caring about are sometimes permeable and sometimes cease to exist. Some RNs used strategies to manage their family caregiving responsibilities by setting limits on the care they provided, coordinating delegating and supervising others to provide the care, or by performing all the caregiving themselves without assistance from HCPs or family members.

Ward-Griffin (2004) concluded that the dynamics of care are quite complex when the RN-relative gives care to family members. Factors which influenced the mix of ‘caring for’ and ‘caring about’ for individual RNs were not investigated, however, it was recognised that the expectation that the RN-relative provide competent nursing care
while functioning in the role of family caregiver frequently placed them in a no-win situation, adversely impacting on their health and leaving them with feelings of helplessness and guilt because of their perceived inadequacies.

2.6.1.2 Emotional upheaval

Participants often had feelings of inadequacy (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Perovic, 1999; Ward-Griffin, 2004). As a health professional Harris (p. 49) felt helpless when confronted with her father’s poor prognosis, and when her father died she could not bring herself to assist the hospice nurses prepare the body because at that stage, she was fully in her role as daughter. Stoner (1998) had to distance herself from her feelings in order to cope and worried that her suggestions for alternative treatments may have been incorrect and would lead to self-blaming and blame by others. Mills and Aubeeluck reported participants often spoke of their thoughts jumping ahead to anticipate the next stage of the illness and they were often unable to express feelings for fear of being perceived as pessimistic and unsupportive of their loved one and family members.

Baird (1988) reported that participants were unable to handle the dying and death of their parent and felt frustration and anger and had unresolved grief and guilt. Many felt guilty that they had not been more helpful (Baird; Mills and Aubeeluck, 2006; Perovic, 1999; Ward-Griffin, 2004) and could not alter the experience or outcome of their parent’s illness (Baird). Perovic admitted that she was dismayed at being overwhelmed so quickly because her father-in-law came to rely on her totally, so she resorted to staying late at work to rejuvenate herself. In Baird’s research, the majority of daughters noted changes in family communication patterns since the cancer diagnosis: some positive (closer and more open communication with parent and family, and members increased dependence on one another); but some negative (siblings withdrawn and some siblings resented the nurse-daughter’s privileged position, family more reserved about feelings and sick parent withdrawn).
Nicholson’s (1995) emotional upheaval (as described in the previous section) was also evident. It was clear that she felt guilty about needing emotional support when she wondered whether it was fair of her to expect nurses and doctors to look after her as well as her dying husband. Ward-Griffin (2004) described the emotional state of participants who were stressed and worried about a critically ill family member; about their feelings of accountability and guilt in case they missed a critical sign or symptom especially if their parent’s health deteriorated under their care; about being emotionally exhausted by caregiving for a parent on discharge post-surgery; or as described in the section above: feelings of guilt and helplessness due to their perceived inadequacy. Similarly, Mills and Aubeeluck (2006) noted participants experienced distress when HCPs and family members had unrealistic expectations of them. They experienced emotional upheaval in trying to meet their family’s expectations and many expressed feelings of inadequacy and guilt.

RN-relatives also felt disempowered when faced with needing to complain about aspects of the care. They were emotionally conflicted because they did not want to seem critical of their colleagues, yet they wanted the deficits addressed. This left them feeling emotionally exhausted and feeling responsible for the unsatisfactory outcome that ensued following their overly gentle and hence ineffectual efforts for care problems to be rectified by staff. Participants felt the need to take time off work because of the physical and emotional impact but felt this was not possible due to staff shortages (Mills & Aubeeluck, 2006).

2.6.1.3 Being present and providing direct nursing care

Harris (1999, p. 49) stayed with her dying father as much as she could and referred to the importance of the “gift of time” whilst also reflecting her perceived inadequacy by stating “it never seemed long enough”. Her feelings of inadequacy were further revealed when her father’s skin started to break down despite her diligent efforts. Perovic (1999) admitted that she was not able to give 100 percent of herself every day but she was there for her father-in-law as much as she could cope with, and did her best.
Nicholson (1995) nursed her dying husband giving injections, suppositories, trouble-shooting by continually calling on HCPs when palliative treatments were ineffective and eventually summoning up the courage to ask for a syringe driver to be provided.

Baird (1988) found that the daughters (who did not reside with the parent) had previously acted as a source of information or as an advisor and this increased following the parent’s cancer diagnosis as did decision-making on behalf of their parent (particularly in relation to the management of medications and side effects). They also provided direct care and served as an intermediary in coordinating care.

Stoner (1998, p. 16) wrote of the importance of “just being there” for family members and described her role as a “never-ending vigil” when her brother was dying. Ward-Griffin (2004) also described participants being there and performing nursing care for their parent/relative such as giving mouth care, re-positioning and changing bed linen.

2.6.1.4 Summary

RN-relatives reported the problems of identity conflict and role confusion and major changes in their lifestyle, role and daily rhythm as a result of their relative’s illness (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Stoner, 1998; Ward-Griffin, 2004). They also experienced emotional upheaval (Baird; Harris; Mills & Aubeeluck; Nicholson; Perovic, 1999; Stoner; Ward-Griffin). They recognised the importance of giving up time to be there for their relative (Perovic; Stoner) and to provide direct nursing care as needed (Baird; Harris; Nicholson; Stoner; Ward-Griffin). Their need for information from HCPs was mentioned in the study by Mills and Aubeeluck and their experiences made it difficult to continue caring for patients with similar diagnoses (Baird; Nicholson). These findings are similar to those identified within the literature concerning lay caregivers’ experiences whose relatives are hospitalised, however the type and extent of RN-relatives’ needs differed from those of lay caregivers. They were under extra pressure to perform due to the higher expectations placed on them by family members (and the high expectations they had of
themselves) and this intensified the resultant emotional upheaval with feelings of inadequacy and guilt, and detrimentally affected their health. In addition, the problems they faced in relation to an inability to separate professional and personal role boundaries were unique.

2.6.1.5 Conclusion

Community settings differ significantly from institutional settings. The studies in section 2.6 above were all concerned with caregiving within community settings by RN-relatives. Whilst there are likely to be some similarities in RNs’ caregiving experiences across settings, there will also be differences. Factors which may affect the nature of RNs’ experiences of their parent’s illness within a hospital setting, include the setting’s formal nature, the availability of immediate medical attention, and the presence of nursing staff around the clock which may minimise the likelihood and need for intervention by the RN-relative. Under these circumstances the RN-relative’s skills may be considered superfluous and somewhat constrained by their professionalism and professional courtesy towards hospital staff.

RN-relatives caring for a family member within the community operate under fewer constraints than RN-relatives who are operating under the constraints imposed by the regulations and structures of a hospital, and the power of a RN-relative on the home turf of professional caregivers is relatively compromised when compared to the power of a RN-relative caring for a family member on their home turf within the community (Lindhardt et al., 2006; Surpin & Hanley, 2004).

2.7 RNs’ EXPERIENCES OF HOSPITALISED RELATIVES

One personal account of a RN’s husband’s emergency hospitalisation (Rufano, 1985) has been published, in addition to a brief report by Northcott (2000) of his conversations with four nurses about their experience of hospitalised relatives (parents, a child and a partner). Northcott’s article focused mainly on the poor quality of the care that was
provided and he also mentioned RNs’ experiences of lodging complaints, and their reluctance to complain. Whilst these very brief one or two page articles do not explore RNs’ experiences of parent hospitalisation in an in-depth comprehensive manner, they serve as useful indicators of a limited set of aspects of RNs’ experiences in relation to hospitalised parents and other relatives.

Northcott (2000) makes the point that unlike lay relatives RNs are able to use their professional knowledge as a reference point in evaluating care. The RNs were in fact horrified by the standards of care. Patients were often left to care for themselves, and staff were too busy and ignored patient comfort and hygiene in favour of technical tasks. Delays with receiving analgesia were a commonly reported concern. Communication was poor between staff and patients and information about care and treatment was often only available on request. Some of the RN carers complained (with little success) and they expressed feelings of vulnerability and fears that complaints might lead to sanctions and reprisals. The main focus of the article was on the quality of nursing care their relative experienced as detected through the trained eyes of a RN rather than on the comprehensive nature of the RN’s experience as the relative of a hospitalised parent, child or partner.

Rufano (1985) a North American psychiatric nurse described her experience of dropping her husband off at the ER thinking he had a bad case of the flu. Rufano disclosed her RN status to medical and nursing staff and experienced identity conflict and role confusion: she felt pressure to act like a professional. She wanted to be there for her husband but waited patiently instead and did not make a scene when the hospital staff denied her access and did not provide her with information about her husband’s critical condition. He unexpectedly lapsed into a coma and died the next day. Rufano suffered emotional upheaval because she was treated in an uncaring callous manner and not given support or understanding by the staff. She has been haunted by the way her husband died and the painful memory that he died without her by his side to comfort him. Rufano wanted information about her husband’s condition and his final hours, but this was not provided until she threatened legal action. When she did meet with staff it
was not fruitful: the nurses recalled very little about her husband but said he had been uncooperative.

Nurses constitute anomalous visiting relatives since they confound two roles which are generally held to be separate: their professional role and the role of relative. There is scope for role confusion in relation to their other roles: nurses perform their professional roles and perform roles in their private life as family members such as sons and daughters, husbands and wives, mothers and fathers. The role of nurse as family member of a hospitalised relative provides an example of an anomalous role because the role of relative and the role of health practitioner (nurse) are generally separate but are sometimes confused or merged. Placing these anomalous relatives in a hospital setting where they interact with hospital staff and family members regarding the health of a hospitalised relative, impacts on the performance of their role as a son or daughter with potential for role stress, strain and the merging of their family role with their professional role (Hardy & Conway, 1988).

2.7.1 Conclusion

The two brief articles mentioned above provide glimpses of the prominent themes identified in the literature concerning RN-relatives’ experiences in home settings and lay caregiver’s experiences in hospital and residential aged care settings. Elements of identity conflict and role confusion, emotional upheaval and the strong desire to be there for the relative surfaced, in addition to the importance of meeting the RN-relatives’ needs for information regarding their hospitalised relative.

2.8 RNS’ EXPERIENCES OF PARENT HOSPITALISATION: GAP IN KNOWLEDGE

In considering previous research (as described in section 2.7) it is evident that a gap in current knowledge exists concerning RNs’ experiences of parent hospitalisation. It is also noted that male RN-relatives have seldom been included within qualitative studies
of family caregiving of hospitalised family members, and their inclusion in research is needed (Ward-Griffin, 2004). An examination of the research concerning lay and RN family caregivers has resulted in an identification of aspects of interest in relation to my research. These aspects are summarised below.

2.8.1 Lay caregiving: hospital, home, and nursing home settings

- There is uncertainty regarding whether relatives want to participate extensively in the direct care of a cognitively intact hospitalised relative (Laitinen, 1993, 1994) or a hospitalised elderly mentally ill relative (Sharp, 1990) or for a relative residing in a nursing home (Russell & Foreman, 2002). Nursing home residents reportedly prefer to be given care by staff rather than by family members (Russell & Foreman, 2002).

- Lay caregivers of hospitalised relatives sometimes engage in activities aimed at securing their elderly relative’s safety, and if they are not satisfied with the performance of staff they also perform activities which are usually performed by hospital staff (Lindhardt et al., 2006). Lay family caregivers of nursing home residents often perform care for their relative to fill in perceived gaps in addition to providing special care tailored to their relatives’ individual needs (Bern-Klug & Forbes-Thompson, 2008; Davis & Nolan, 2006; Kellett, 2000; Mahoney, 2003).

- Health care professionals acting as “double-agents” can trigger conflicts within the family and with health care providers by acting as surrogate decision-makers of cognitively intact relatives (Fischer, 1985; Issa, 2002, p. 946).

- Differences in relation to content and emphasis between spouses and offspring have been reported in their experiences of being a relative to an elderly hospitalised person. This indicates a need to examine the experiences of sons and daughters separately from spouses to prevent spousal differences from obscuring the features of sons’ and daughters’ experiences, and also to take
account of the possible influence of child-parent structures and associated role boundaries (Li, 1998; Lindhardt et al., 2006; Qureshi, 1990).

- The caregiving priorities of relatives of cognitively impaired parents who are living within the community identified by Bowers (1987) may differ from the caregiving priorities of relatives of cognitively intact parents who are hospitalised, however some aspects of protective care may be operating and could explain RN-offspring’s reluctance to assist their parent with personal care.

- The sibling most competent for the caregiving role is most likely to be the primary caregiver for their parent (such as a health care professional). Other factors such as being the eldest child, being female, having fewer competing commitments, and being geographically available are also factors which increase the likelihood (Matthews, 2002; Matthews & Rosner, 1988; Willyard et al., 2008).

- The most prominent themes across the literature for caregivers of hospitalised relatives described participants’ need to be vigilant which encompassed the need to be physically present for the relative; the need to be well informed by health care professionals; the need to manage their feelings due to the presence of emotional upheaval; the resultant major changes evident in the caregiver’s lifestyle, role and daily rhythm as a result of the relative’s illness and hospitalisation; and the need for the caregiver to look after themselves to be resilient. (Åstedt-Kurki et al., 1997; Carr & Clarke, 1997; Carr & Fogarty, 1999; Hall, 1989, 1990; Higgins et al., 2007; Jacelon; 2006; Lemieux, 1996; Li, 1998; Li et al., 2000; Lindhardt et al., 2006; Thorne & Robinson, 1988; Walters, 1995).

2.8.2 RN-relatives’ caregiving: home and hospital contexts

- A prominent theme within the literature regarding RNs caring for relatives within home and hospital settings involved participants’ problems of identity
conflict and role confusion (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Stoner, 1998; Ward-Griffin, 2004).

- RNs experienced emotional upheaval which was intensified because they were under extra pressure (self-induced and due to family expectations) to perform at an expert level which led to feelings of inadequacy and guilt (Baird, 1988; Harris, 1999; Perovic, 1999).

- The importance of being there for their relative was often stressed (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Perovic, 1999; Stoner, 1998; Ward-Griffin, 2004);

- The need for information from HCPs was mentioned (Mills & Aubeeluck, 2006).

- RNs’ experiences of family caregiving within home contexts may differ from RNs’ experiences within a hospital setting because of the differing structural constraints which affect their power to intervene in care (Lindhardt et al., 2006; Surpin & Hanley, 2004).

2.9 CONCLUSION

This chapter has presented a review and critique of selected aspects of the caregiving literature (mainly from the perspective of family caregivers) and its relevance to this qualitative study. This situates the research question: ‘What are RN-sons’ and RN-daughters’ experiences of parent hospitalisation?’ within the context of existing knowledge and highlights the gap in knowledge that this study is designed to fill.

In Chapter Three the design and conduct of the study are described. The adoption of a qualitative methodological approach is discussed and the methods of data collection and data analysis are described including processes to ensure the study’s validity. Measures taken to protect the interests of the participants are included.
CHAPTER THREE

METHOD

3.1 INTRODUCTION

This chapter provides a description of the research methods together with the rationale of their suitability for this research project and a statement of the ethical considerations. The basis for selection of the interpretivist paradigm using qualitative methods involving interviews and open-ended questions within a mailed questionnaire is explained. An overview of the research design is provided, followed by a discussion of the strengths and limitations of the methods used. The research design is described in two stages (the mailed questionnaire followed by the interview stage) and includes the sampling of RN participants. The process of data analysis is described and information is provided about the strategies used to ensure rigor and trustworthiness of the data. The chapter concludes with an identification of the limitations of the method including a discussion of the influence of my role as the researcher.

3.1.1 Overview and rationale

The paucity of literature regarding the experiences of RNs with a parent in hospital has influenced the choice of methodology adopted. The dominant research approach chosen was therefore within the interpretivist paradigm, using qualitative methods as RNs’ experiences of parent hospitalisation have not been comprehensively researched to date. The aim of qualitative research is to understand, describe and explain social phenomena from an insider’s perspective focusing on individual meaning. This is done using an inductive style by analysing (directly or indirectly) the experiences of people, and discovering the way that they construct their world in order to gain rich insights regarding the phenomenon under study together with its complexities (Creswell, 2009). This approach is particularly relevant in this study as very little information about parent
hospitalisation is available and therefore a structured approach with pre-determined closed questions would not illicit the necessary depth and breadth of information about the phenomenon from the participant’s perspective.

Typically the instruments and procedures for qualitative studies differ from quantitative studies; however the nature of the problem to be studied best determines the tools and processes used to collect data, in order to achieve the objective of obtaining convincing answers to the topic under investigation (Flick, 2007a; Thomas, 2003). In relation to instruments for qualitative research, Creswell and Plano-Clark (2007) cited surveys as an example of a traditional quantitative source of data being used effectively in various types of qualitative research projects. They explained that the open versus closed-ended nature of the data better differentiates qualitative from quantitative research, thus indicating their support for greater flexibility in the selection of data collection methods for qualitative research.

Demographic and contextual data were obtained from participants, which complemented and contextualised the qualitative data about their experiences of parent hospitalisation. The dominant method was qualitative, asking participants to describe their experience predominantly using an unstructured open-ended questioning approach within interviews and asking participants to respond within the questionnaire to similar open-ended questions about their experience.

It was advantageous to use a blended approach (interview and questionnaire) to obtain open-ended qualitative data and some closed-ended quantitative data as this approach facilitated access to the participants and provided participants with a choice regarding the avenue for communicating their responses (Creswell, 2009). Individuals have different communication abilities and preferences that can influence how effectively they can communicate their experiences to others. In recognition of these individual differences, and in aiming to maximise the likelihood that registered nurses of varying backgrounds and circumstances would participate in the research, it was decided to offer
participants both a written and oral avenue through which to communicate their experiences.

Access to participants was readily and cost effectively achieved via a mailed questionnaire which was mailed by the New South Wales Nurses’ Registration Board (NSW, NRB) (now known as the Nurses’ and Midwives’ Board of New South Wales) to a large sample of RNs in order to locate RNs who had experienced the hospitalisation of a parent. Prospective registered nurse participants were offered three ways in which to share their experiences (as detailed in the Information Sheet, Appendix B). They were invited to complete a semi-structured mailed questionnaire, or to share their experiences via an in-depth interview, or to do both. Participants who chose to participate in an interview had the option of either a face-to-face interview, or a telephone interview. Interviews were audio-taped and then transcribed verbatim.

The constructivist paradigm underpinned this qualitative study. Essentially, the philosophical basis of this paradigm fuses ontology (the nature of reality) and epistemology (the relationship between the researcher and what can be known) which results in realities being constructed through interaction between the researcher and participants (Lincoln & Guba, 1985). Individuals’ various socially and experientially derived mental constructions are thereby interpreted and distilled into a more informed construction. Interpretive phenomenological analysis (IPA) (Smith, 2004) which is aligned with a constructivist paradigm provided a means by which to learn from the insights of research participants. This involved coupling the participant’s ‘lived experience’ with a subjective and reflective process of interpretation, in which the researcher explicitly entered into the research process.

The inductive nature of IPA assists the researcher to develop an insider’s perspective regarding the research topic. This perspective is then documented in the form of an interpretive commentary, using verbatim examples to illustrate and support it. In addition to taking the insider’s perspective, the researcher also offers an interpretive account of what it means for these participants to have their particular concerns within
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their particular context. There is therefore a balance between the phenomenological (emic) insider’s perspective, and the perspective of an interpretative (etic) outsider to illuminate the experiences in a way that answers the particular research question (Reid, Flowers & Larkin, 2005).

The outcome of IPA’s analytical and evaluative processes is a set of themes (which represent commonalities across participants’ accounts, and also accommodate variations within the data set) which are organised into an overall structure.

The chosen methodology and methods optimised the information that participants were willing to provide and its interpretation by using the following seven strategies:

- The blended qualitative/quantitative approaches used to gather information increased the likelihood of obtaining rich data and comprehensive answers to the research topic;
- the flexibility of the time period encompassed by this study provided RNs the opportunity to freely describe their experiences of contemporary and past events;
- the ways of collecting information (via telephone or face-to-face interviews and mailed questionnaires) accommodated the different communication preferences of participants;
- my relationship to the participants of the study viewed from my insider’s perspective as a RN researcher who had personally experienced parent hospitalisation assisted in developing rapport with participants;
- the convenience sampling strategy described above which was used to access participants for the study influenced (and probably increased) the number and possibly the variety of RNs participating in the study;
- the way of organising collected information was according to typology. That is, a system of categories into which phenomena can be placed, and the way in which categories are related to each other (Thomas, 2003).
3.2 ETHICAL CONSIDERATIONS

The UWS Human Research Ethics Committee reviewed the ethics application for this research project and granted approval for the research to be conducted (Appendix B). The research was supported by University of Western Sydney student research funding.

3.2.1 Integrity, respect for persons, beneficence and justice

The research was conducted according to recognised research and ethical principles. There were no elements of deception, and information about the project and its expected benefits was provided to prospective participants within the information pack mailed to all participants (Appendix B). My contact details (and those of my Principal Supervisor) were provided on the Information Sheet to enable participants to contact me (or my supervisor) at any stage of the project to respond to queries. Individuals’ rights were respected by confirming there was no obligation to participate in the project, and that participants could withdraw from the research at any time without question or adverse consequences. Participants were also assured that the information they provided would be kept confidential and stored securely. Only de-identified results have been reported within the thesis.

3.2.2 Consent

Prospective participants were mailed an invitation-to-participate package which included an Information Sheet, Consent Form (2 copies), a questionnaire, reply-paid envelope and Results Notification Slip. Participants were asked to indicate their consent to an (audio-taped) interview by signing the Consent Form. A copy of the consent form (labelled ‘Consent Form – Participant’s Copy’) was supplied for the participant’s records. The return of the questionnaire indicated a participant’s consent to participate.

The taping of telephone conversations is legally permitted for the purposes of research as specified within The Commonwealth of Australia Telecommunications Act 1997 (2010) which provides safeguards for individuals and the community in relation to
telecommunications activities. Audio-taping a telephone conversation is an activity that requires consent from the person being interviewed and authorisation for the interviewer to use the recorded information. The Act clarifies that a person may disclose information to another person for the purposes connected with research and that the person given authority to use the information must do so for that purpose that is, to record telephone conversations as part of a research study. All interview participants had consented to audio-taping of the interview, and the research was authorised by the University on the basis of ethics committee approval for the research.

3.2.3 Research merit and safety

The research was conducted under the expert guidance of a supervisory panel. The research is justifiable. The value and benefits of the project lie in its potential contribution to knowledge that could lead to improvements in care and support of hospitalised patients and their families, in instances where they have RN family members. It is also possible that some of the issues faced by RN-relatives may provide insights and suggest strategies to improve the experience of non-RN relatives with a parent in hospital, and to improve the care and support provided to their parent.

The risk of possible psychological distress to participants was identified in the ethics application, and a means of providing assistance to any distressed participants specified. Care was taken to separate the researcher’s role from that of counsellor. The research protocol specified that if participants were affected in this way the interview would be terminated, and the participant supported by referral to a (registered psychologist) counsellor. A number of participants were emotionally affected during their interview; however, they all expressed the desire to proceed with the interview, and although referral to a counsellor was offered to them, they declined.

3.2.4 Ethical review and conduct of research

The results of the research have been recorded within the thesis and will be disseminated in relevant publications and conference presentations. A summary of the
findings will also be provided to those participants who expressed interest in this by returning the Results Notification Request Slip. The raw data will be stored for at least five years in a locked filing cabinet, and will only be accessible to me. The data has been de-identified for the purposes of confidentiality, using pseudonyms and number codes instead of participants’ real names.

3.2.5 Privacy: recruitment of participants
The NSW, NRB provided me with indirect access to registered nurses’ names and addresses by mailing out the initial ‘invitation to participate’ packages on my behalf to a sample of 500 registered nurses who met the inclusion criteria. Registered nurses’ names and contact details only became known to me if the registered nurses chose to provide me with those details for the purposes of notifying them about the findings of the research. This arm’s-length approach to the recruitment of participants ensured that registered nurses’ privacy was maintained.

3.3 RESEARCH DESIGN
This is a descriptive interpretive study using a questionnaire and interview as the research tools. The research design comprised two stages. The first stage involved mailing an ‘invitation to participate’ package to prospective participants. This package included the semi-structured questionnaire (Appendix B). The second stage of the research involved interviewing consenting registered nurses. The interviews took place six to nine months after the return of the completed mailed questionnaires and consent forms. The rationale for choosing to obtain information from participants using a questionnaire and/or an interview was briefly mentioned in section 3.1.1, and is discussed in more detail below. This is followed by a discussion of the advantages and disadvantages of interviews and questionnaires as data collection strategies in qualitative research. An overview of the two stages of the research is then provided, in addition to information about the sample participants, data collection, and data analysis.
3.3.1 Rationale for using questionnaire and interview methods

A semi-structured questionnaire was developed to facilitate access to multiple participants at arm’s length via convenient and cost-effective means. The NSW, NRB agreed to mail the information pack on my behalf to 500 RNs who met the eligibility criteria regarding age. This strategy of simultaneously mailing information packs to a large number of RNs (who met the inclusion criteria of being between the ages of 40 and 65 years) in the expectation that some would meet the criterion of having had a parent in hospital proved successful in quickly identifying a group of eligible, willing participants. The strategy of receiving RNs’ questionnaire responses prior to conducting any interviews was helpful as this broad range of information about RNs’ experiences of parent hospitalisation served as a basis for more in-depth exploration during the interviews.

The information pack contained an invitation to participate either by interview or questionnaire or both. It was anticipated that providing prospective participants with a choice of three response options (interview, questionnaire, or interview and questionnaire), would maximise the response rate, improve the diversity of participants, and thereby improve the quality of the data and the research. The number of participants was maximised as some RNs would not have participated in the study at all if only one avenue of participation was offered. One participant (Eliza) reported that the questionnaire was the preferred avenue to share her experiences as her father had recently died and she felt too fragile to participate in an interview. Another participant (Andrew) mentioned he preferred an interview as he did not want to write it all down.

An increased amount of data and a wider range of participants were achieved as a result of using two tools (rather than one) and offering participants two avenues (oral and written) of communication (rather than one). The combination of multiple empirical materials and methodological practices added “rigor, breadth, complexity, richness, and depth” to the inquiry (Denzin & Lincoln, 2005, p. 5). That is, by gathering data using two different tools, and by gathering data from the same participant on separate occasions using different means – as was the case for eleven participants who
participated via interview approximately nine months after completing the questionnaire (participants’ choices regarding interview and/or questionnaire completion are included in Table 4.3).

Those participants who chose to complete the questionnaire and participate in an interview provided me with an opportunity for follow up questions, and clarification of the information they had provided within their questionnaire. By offering RNs a choice of two avenues to communicate their experiences, the quality of the research data is optimised by tailoring the mode of communicating to their preferred mode of communicating.

Some participants preferred to submit information in writing. Perhaps this was because they communicate more effectively in writing, or they may have preferred the added distance, convenience and anonymity of responding in writing. At interview one participant (Oliver) mentioned he believed (rightly) that he had expressed himself more effectively in writing within the questionnaire. Alternatively some participants may be more effective oral communicators, and may prefer the more personal avenue that an interview provides.

The two opening questions of the questionnaire paralleled those used in the interviews. They were open-ended and unstructured to allow participants to freely report their experiences. This qualitative approach suited the research topic in that comprehensive research regarding this topic had not been conducted to date.

3.3.2 Interviews and questionnaires: strengths and limitations

Interviews have the advantage (over questionnaires) of providing greater flexibility and opportunity for clarification, and interviewees can more easily elaborate on their answers, and explain conditions that affect their views. The one-to-one communication can also build rapport and affect motivation (usually to improve it) for the task. Face-to-face contact is often the preferred mode of interviewers as it provides non-verbal cues which can aid in developing rapport with participants. Similarly, it may be the case that
some participants prefer the more personal atmosphere of a face-to-face interview (Kvale, 1996).

Interviews are time consuming and the quality and trustworthiness of the information provided can be detrimentally affected if the questions posed are found to be personally sensitive by the interviewee. Sometimes this limitation can be overcome through the added distance and anonymity that a telephone interview provides. The relatively impersonal telephone interview situation can provide greater psychological distance (Fenig, Levav, Kohn and Yelin, 1993) and may lead to more candid responses and less embarrassment when talking about very personal or sensitive issues. On the other hand, the social distance of a telephone conversation can also make rapport more difficult to achieve and reduce spontaneity and can result in less information sharing. The effectiveness of communication may also be impaired because non-verbal cues are absent and can make it difficult to assess the emotional state of the participant (Bobevski & McLennan, 1998). Similarly laughter can easily be misinterpreted during a telephone interview in the absence of non-verbal cues, and can lead to more guarded responses (Lavin & Maynard, 2001).

To counter this difficulty of assessing the participant’s emotional state during telephone interviews, I alerted interviewees to this problem at the commencement of the interview (asking them to tell me if and when they were finding the session upsetting). I also checked whether they were alright at the conclusion of the interview even if they sounded fine.

There were also significant advantages of telephone interviewing for me in the role of interviewer. Telephone interviews were less costly in terms of travel cost and time allocation. The convenience of simply arranging a mutually suitable time for the phone interview to take place and then just picking up the phone without the time and cost involved in travelling throughout NSW was clearly an advantage. Telephone interviewing was less intrusive in that the potentially distracting or intimidating physical presence of recording equipment was eliminated, and I was able to monitor the
recording equipment during the interview, refer to the questionnaire and take notes freely without fear of distracting the interviewee.

The telephone interviewee can also be at higher risk of being distracted by what’s happening in their environment (Midanik, Hines, Greenfield and Rogers, 1999). One of the participants being interviewed had a group of children playing in the background (it was during the school holidays) and another participant had a young baby who needed attention now and again.

Despite the possible limitations and disadvantages of telephone interviews, the primary consideration in my view was to abide by the preferred medium of the interviewee as I believe this optimised their level of comfort and this ‘freeing-up’ possibly increased the amount of information they divulged, and also improved the communication of their experiences to me.

Questionnaires and inventories gather factual information and information about opinions, attitudes and preferences, as was the case in this study where both types of information were obtained. The participants can remain anonymous, and this can lead to more candid responses. Completing the questionnaire in the absence of the researcher, and the opportunity to express oneself in writing can also be advantageous. The researcher’s presence may bias the participant’s responses, and in some cases, participants may express themselves more articulately in writing than orally (Creswell, 2009).

Filling out a questionnaire also provided a less emotionally charged avenue for those participants who were still very emotionally affected by their experience of parent hospitalisation. Questionnaires have the added advantage of collecting a large amount of data from people in distant locations and in a relatively short time. The limitations of questionnaires (in addition to those mentioned above) include a low return rate (6.2% in this case) or omitted responses (not found to be a problem in this study) to some questions (Thomas, 2003).
The questionnaire provided an easy and non-intimidating method of accessing suitable participants for the research. It could be argued that participants completing a questionnaire are less likely to respond in a way which they think would match the views of the researcher than if they were in the presence of the researcher-interviewer. It could also be argued that participants completing a questionnaire are not subjected to the influence-to-participate that the physical presence of the researcher may exert. This influence may bias a participant’s decision to participate, and may also influence a participant’s responses (Creswell, 2009).

The added advantage of using two means of collecting information from participants is that it serves to underpin knowledge by gaining additional information (Flick, 2004, chap. 4.6).

3.4 STAGE ONE: THE MAILED QUESTIONNAIRE

The focus of the research was on RNs’ experiences of having a parent in hospital, the context being the familiar hospital work environment but with the RN in the off-duty non-nursing role of a relative/next-of-kin/son or daughter/visitor. A registered nurse in this situation may keep to the parameters of their off-duty role or may become motivated in particular circumstances to try to use their RN status and skills to interact with hospital staff and to assist a parent who is hospitalised.

The research process commenced with a focus on my own experiences of having a parent in hospital. Those experiences, together with spontaneous comments to which I had been exposed from registered nurses about their experiences of parent hospitalisation, and aspects of related literature, determined the questions to be included in the pilot questionnaire for this research. These questions served as a starting point to surface as much information as possible from registered nurses about their experience of having a parent in hospital.
3.4.1 The questionnaire

The questionnaire was designed to provide participants with a relatively unstructured, open-ended opportunity to share their experience of having a parent in hospital. This aim is reflected in the two opening questions: “What was the experience like for you, of having a parent/s in hospital?” and “In what ways, if any, did you think that because you are a registered nurse the experience may have been different to that of a non-registered nurse?” Participants were encouraged to say as much as they wanted about these experiences.

In addition to these key opening questions, a few semi-structured questions were included about disclosure of their RN status to hospital staff. RNs were asked about their preference regarding disclosure of their RN status and whether there were circumstances under which their preference changed. RNs were also asked whether there were times when they had no choice concerning disclosure because staff already knew they were a RN.

The rest of the questionnaire was devoted to questions seeking demographic information (RN’s gender, age, years as a RN, highest educational qualification, and parent’s age) or helpful contextual information about the RN’s experiences (whether the RN worked at the same hospital, whether they played the most active role concerning the parent’s hospitalisation, and the type of contact they had with staff and the parent during the hospitalisation), and lastly, information to provide a context relating to the parent (the frequency and duration of the mother’s and/or father’s hospitalisation, and how recently they had been hospitalised).

Two optional questions were included which provided participants with an opportunity to add any information about their parent or themselves which they believed to be relevant background to assist me to gain a better understanding of their experiences.

The contextual questions described above were included as it was thought that the participant’s experiences would have been affected by these factors. For example, it is
clear that working at the same hospital where the parent is hospitalised denies the RN a choice regarding disclosure of their RN status, and that it may blur the nursing role boundaries for the RN-son/daughter. The experience of participants who did not play the most active role in their parent’s hospitalisation may also differ from those who did, and the question regarding the contact participants had with staff and the parent gives further indication of the type and extent of the participant’s interactions. The rationale for including the above-mentioned contextual questions within the questionnaire was to minimise the information gaps which are likely to occur due to the limitations of a mailed questionnaire when contrasted with the information which a participant would generally provide unprompted during an interview.

3.4.2 Piloting and the final version of the questionnaire

The questionnaire was piloted with a group of 30 registered nurses (university staff and students) who attended a ‘research in progress’ presentation. The pilot questionnaire was subsequently modified in response to RNs’ suggestions to improve its clarity and the comprehensiveness of its scope. This involved minor changes to the wording of the questions, deleting the question asking whether or not the parent lived with the RN and how far away they lived; adding a third possibility to the questions about disclosure of their RN status (that is, being recognised rather than choosing to disclose their status); and increasing the comprehensiveness of the question regarding the RN’s contact (with the parent and the staff) during the hospitalisation by asking whether this contact was face-to-face or by telephone. The piloted version of the questionnaire showing these modifications as tracked changes has been provided in Appendix B.

3.4.3 Sample of registered nurses invited to participate

A sample of 500 registered nurses (250 male RNs and 250 female RNs) who were within the 40 to 65 years age range (List A, NSW, NRB) were invited to participate as the views of both male and female registered nurses were of interest in this research. The rationale for restricting the sample to the 40-65 age bracket was that registered
nurses of this age were more likely to have ageing parents who had been hospitalised. No requirement was stipulated for the recency or duration of the parent’s hospitalisation, only that prospective participants must have had a parent in hospital.

The number of male and female registered nurses on the NSW, NRB’s register at that time between the ages of 40 and 65 years was 36,234 (91.5%) female registered nurses, and 3,345 (8.5%) male registered nurses. The sample of registered nurses invited to participate in the research therefore accounted for approximately 0.7% of the female registered nurses and approximately 7.5% of the male registered nurses on the NSW, NRB’s register (Kate Mertens, NSW Department of Health, personal communication, September 11, 2002). A summary of the participants is provided in Table 4.3.

3.4.4 Data collection - questionnaires
Five hundred ‘invitation to participate’ packages were addressed and mailed by the NSW, NRB (on my behalf) to 250 (50%) male RNs and 250 (50%) female RNs who were at that time on the Board’s (List A) register, and met the 40-65 years of age criterion. The package comprised the Information Sheet, two copies of the Consent Form for Interview, a reply-paid envelope, a Research Results Notification Slip and the questionnaire, (Appendix B). Registered nurses, who received the packages and decided to participate in the research project, mailed the completed questionnaire to me within three weeks of receiving the package.

3.4.5 Questionnaire sample of registered nurse participants
A total of 28 mailed questionnaires were completed and returned by RNs who met the inclusion criteria for the research project. Of these, 14 RNs (50%) were female and 14 RNs (50%) were male. The ‘Consent Form’ for interview was signed and returned by 14 RNs (11 of whom had also completed the questionnaire) who were subsequently interviewed. The response rate was low (6.2%) but this was expected as the invitation to participate was mailed to RNs without knowing whether they had experienced parent
hospitalisation in the hope of identifying RNs who did fit the eligibility criteria and were willing to participate.

3.4.6 Data analysis - questionnaires

The information contained in the questionnaires was transcribed and coded. The data was managed using NVivo software (QSR NVivo, 2002) to facilitate organisation of the data. Questionnaire data were analysed when the questionnaires were returned and served to inform the interview data collection. I engaged with the textual data in a systematic way. A general sense of the questionnaire data was obtained by reading and re-reading all the responses, making notes ongoing to record my thoughts about the data at this stage, and reflecting on the overall meanings emerging.

Detailed analysis involved coding the data into segments of text and using a term to label these categories. In some cases in vivo codes (using the words of the participant) were used (Berg, 2007; Creswell, 2009). For example when participants mentioned they had to be strong, that information was coded as “had to be strong”. Codes such as this were then compared across all participants, and similar codes were clustered together and given a name for that cluster. For example, “being brave” and “being strong” and “making sure I didn’t fall in a heap” were clustered under the label “being strong”. Extracts from the questionnaires were arranged according to the codes assigned to them, and the codes were refined through an examination of the data of each participant, and subsequently the participants’ interview data were included in this iterative process until the main categories of participants’ experiences of their parent’s hospitalisation (the phenomenon of being in the middle) were identified: disclosure, RN on standby and RN in action (together with their sub-categories and themes).

3.5 STAGE TWO: THE INTERVIEWS

Participants were offered the option of being interviewed to share their experiences in greater depth than in a questionnaire. The interview also provided participants with the
opportunity to interact with me, to establish rapport, or to simply exercise their preference for verbal communication. Three participants preferred to speak about their experiences rather than write about them, and some confided that there were issues and topics that they would tend not to write about. In addition, some registered nurses who had completed the questionnaire and participated in an interview believed (rightly) that they had expressed themselves more effectively in writing within the questionnaire. The information provided in writing by these participants was found to be more articulate, concise and better sequenced.

3.5.1 Interview sample of registered nurses

The qualitative nature of this project did not require large numbers of RNs to participate as there was no intention to generalise, and the sample comprised information-rich cases made possible through methods such as in-depth interviewing and the use of open-ended questions (Holloway, 2008).

The ‘Consent Form’ was returned by 14 RNs (50% male and 50% female) who subsequently participated in an interview. A questionnaire was also completed by 11 of these RNs (five male and six female) as given in Table 4.2. The experiences reported by six registered nurses concerned their father’s hospitalisation. The age of these fathers ranged from 62 years to 82 years, and three of the six fathers were in their sixties. Three registered nurses shared their experiences concerning their mother’s hospitalisation. The age of these mothers differed considerably. One was 87 years old and the other two were 49 and 65 years of age. Five registered nurses described their experiences concerning the hospitalisation of both parents. In all five cases, both parents were over 65 years at the time of their hospitalisation.

Sample sizes for qualitative research tend to range between four and 40 participants, but this depends to some extent on the diversity of the sample, such that a smaller sample size is sufficient for more homogeneous groups, and when the principal aim of the research is to identify the essence of a phenomenon as was the case for this research.
Holloway, 2008). The sample size achieved for this project was sufficient in that it was a somewhat homogeneous group of individuals who shared common traits, and because these cases were information-rich.

3.5.2 Data collection - interviews

Interviews were conducted in private at a mutually convenient time and location. Interviews were audio-taped using a mini-disc recorder. A telephone pickup lead was used to record the telephone interviews - the suction cup was secured to my telephone’s earpiece.

A flexible approach was taken with the interviews with minimal interruption by me to prevent bias and researcher expectation effects. Those registered nurses who had not completed the questionnaire were simply asked to tell me about their experiences and where appropriate, the questions contained within the questionnaire served as interview prompts to aid the flow, scope and depth of the interview. Most participants needed few prompts as the account of their experiences flowed easily. Participants were generally articulate and gave moving accounts of their experiences.

Registered nurses who were being interviewed and who had previously completed the questionnaire were invited to clarify, amplify, or provide new information. As the interviews progressed, important issues emerged which led to additional questions and probes being asked of participants.

The interviews provided the added advantage of incorporating a response-guided strategy which involves the researcher spontaneously generating follow-up questions that are logical progressions to the responses provided by the participant to the broad opening question (Thomas, 2003). Supplementary information was requested via a series of structured and semi-structured questions about the participant, their experience in relation to divulging their RN status to hospital staff, and information about their parent. This included some demographic information of a quantitative nature. RNs’
responses to these structured and semi-structured questions provided a context within which their experiences of parent hospitalisation could be better understood.

One of the participants (Cameron) mentioned during the interview that he had taped some of his observations at the time of his father’s hospitalisation, and as I expressed interest in this, he forwarded the tape to me as supplementary material for transcription. Another participant (Ryan) mentioned he had a RN-brother who played a major role in the parent’s hospitalisation and may want to speak with me. I therefore extended a verbal invitation via Ryan for his brother to contact me if he wished to participate in the research project, but the brother did not contact me. All RN participants consented to further contact by me if I required clarification, or to ask follow-up questions if any emerged during subsequent analysis of the data, but this did not prove necessary.

Participants were offered the option of a face-to-face or a telephone interview. Some participants mentioned there were advantages to telephone interviews. Telephone interviews were very convenient with minimal disruption to a participant’s daily routine and responsibilities, and some RNs mentioned they felt more comfortable talking about sensitive issues with the added anonymity a telephone interview provided (Falthzik, 1972).

Most participants (nine out of 14) opted for a telephone interview. Admittedly seven of these participants lived well outside the Sydney metropolitan area, and perhaps this at least partly influenced their choice despite my stated willingness to travel if they preferred a face-to-face interview. I did however detect on some occasions that a telephone interview was considered less intrusive by participants as it preserved their privacy.

It was interesting to note that similar numbers of males (three) and females (two) opted for a face-to-face interview and that the number of males and females opting for a telephone interview was also similar (four males and five females). On the basis of this information, there was no gender difference in this study regarding preference for face-to-face versus telephone interview.
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The duration of most interviews was approximately one hour. Three interviews lasted two to three hours to allow participants adequate time to recount their experiences. Thirteen of the 14 interviews were conducted within 18 days. This schedule proved to be physically exhausting, emotionally draining and intellectually demanding. The experience was especially emotionally draining for me as many emotionally charged events and issues related to my experience of having a parent in hospital came to mind whilst listening to the experiences of other registered nurses. Despite these challenges the experience was very engaging and compelling. The tight schedule provided me with intensive sustained exposure to the interviewing process allowing me to fine-tune my interviewing skills, and to immerse myself in the data which proved to be a particularly satisfying, insightful and productive experience.

3.5.3 Data analysis

Audiotapes were transcribed verbatim and coded using NVivo software (QSR NVivo, 2002) as a data management tool (Bazeley & Richards, 2000). Data analysis occurred ongoing with interview data collection. The questionnaire data analysis served to inform the interviews, and as the interviews progressed, the constant comparative method had an ongoing impact on the interviews and the analysis. The constant comparative method refers to the process of analysis which involves comparing different incidents and aspects within the data for similarities and differences (Corbin & Strauss, 2008). Following each interview, notes were made and reviewed, the audiotapes were played, and additional insights recorded.

A thorough approach to the analysis and interpretation was achieved by keeping the focus of the analysis strictly centred on the research question; describing the phenomenon of RNs’ experience of parent hospitalisation as it was experienced by participants; treating all elements of the information provided by participants with equivalent importance; scrutinising the data for different ways in which participants conceptualised the phenomenon; and using the variations between participants’
responses to test the fit of the analysis to the phenomenon (Minichiello, Sullivan, Greenwood & Axford, 2004).

As was the case with the questionnaire data, detailed analysis and coding of the interview transcripts was also undertaken. The codes were used to develop descriptions and identify themes of RNs' experiences of parent hospitalisation, how and in what circumstances these may differ, and how the key themes identified from participants’ accounts of their experiences related to one another. The analysis and coding was revisited on several occasions over the ensuing months, resulting in ongoing revisions and refinements.

As described in section 3.4.6 (data analysis of the questionnaires) data codes were initially chosen to reflect the participants’ own words (in-vivo codes) as these are taken directly from the language of the area of investigation which ensures close alignment between the analysis and the participants’ experiences as recounted to me (Bohm, 2004, chap. 5.13). As explained in section 3.4.6 early analysis identified key phrases within the data, and these units of analysis were then gradually grouped and organised into a system of categories, subcategories and themes and compared across all participants by reading and re-reading participants’ interviews and written accounts of their experiences many times. This inductive category formation is based on ongoing analytical summarising of the material (Mayring, 2004, chap. 5.12).

On the basis of the analysis described above and in section 3.4.6, the findings were then represented in tables and quotes, and interpreted by moving beyond description of events and people, to proposing meanings which included stating lessons learned, comparing the findings with aspects of past literature and theory, raising questions, and proposing ideas for changes to practice which are presented in Chapter Seven (Thomas, 2003; Holloway, 2008).

The codes and categories which emerged were revised and refined and negative cases considered in light of the whole. Data provided by participants that does not appear similar to the patterns found in participants’ narratives as a whole, are referred to as
‘negative cases’ (Flick, 2007b). Negative cases can add richness to interpretation, and although they are exceptions, they do not necessarily negate an analyst’s conceptualisation of the data as these cases “represent a dimensional extreme or variation on the conceptualisation of data” (Corbin & Strauss, 2008, p. 263). As an example of the value of negative cases in adding richness to interpretation, it was noted in the present study that only some participants engaged in filling in the gaps in their parent’s nursing care. On closer examination it was revealed that male participants seldom engaged in filling in the gaps (they sought to have the staff fill in the gaps instead) unless they were called on by a staff member to assist. It was also noted that one female participant (Olivia) whose father was dying and (was to have life support withdrawn within a few days) did not engage in filling in the gaps because Olivia had a relationship of mutual trust with the nursing staff, and did not believe it was appropriate to intervene in the care of her father despite witnessing some episodes of unsatisfactory nursing care.

The NVivo program (QSR NVivo, 2002) was useful in the initial phase of coding the questionnaire and interview data, and then the transcripts were examined as a whole to capture the essence of the overall phenomenon of participants’ experiences of parent hospitalisation (Denzin & Lincoln, 2005).

3.6 RIGOR AND TRUSTWORTHINESS OF THE DATA

Criteria for assessing the rigor and trustworthiness (or validity) of the data, together with some strategies for meeting these criteria are detailed below as applied to this research project. Trustworthiness refers to the extent that the findings are true to the aim of the study and whether they accurately reflect the purpose of the study (Holloway, 2008).

Trustworthiness was enhanced by my conscious efforts to take a critical stance throughout the research process and to heighten awareness of the bias that my part in the study can bring (Munhall, 2007). Notes were kept and provided developmental information about methodological decisions and the reasons they were made, and these
were also useful in assessing trustworthiness by considering the criteria of credibility, transferability, dependability, and confirmability (Guba and Lincoln, 1989). The term ‘reflexivity’ has often been used to refer to this process of self-questioning by the researcher, however, Silverman and Marvasti (2008, p. 510) point out that this is an incorrect use of the term which is derived from ethnomethodology and is used “to describe the self-organising character of all interaction so that any action provides for its own context”.

3.6.1 Credibility
Credibility refers to the degree of confidence in the ‘truth’ that the findings of a particular inquiry have for the subjects in which, and the context within which, the inquiry was carried out (Lincoln & Guba, 1985). It relates to the fit between the social reality of participants and the way I have reported their experiences (Holloway, 2008). The strategies employed to increase the likelihood of credible findings for this research were prolonged engagement and persistent repeated review of the data, and the use of both questionnaire and interview methods of data collection (Flick, 2004, chap. 4.6).

The aim of prolonged engagement is to openly subject the researcher to the multiple factors that contribute to the topic being researched. That is, to put aside preconceptions and guard against personal distortions which serve as barriers to achieving a credible interpretation of registered nurses’ experiences of parent hospitalisation. Prolonged engagement was achieved by carefully considering the data supplied in turn by the 31 registered nurses who participated in the research, and asking questions of the data provided by each successive participant regarding the emerging characteristics of their experiences in order to establish the scope of the phenomenon.

Similarly, persistent repeated review of the data was achieved by identifying the characteristics and factors most relevant to the experiences of registered nurses with a parent in hospital. This level of depth is achieved through an approach of healthy scepticism to challenge conclusions.
The validity or accuracy of the findings is strengthened by obtaining data from more than one source or method (Creswell, 2009; Hesse-Biber and Leavy, 2004). Two different methods to collect the data were used. Method one was a mailed questionnaire, and method two was the in-depth interview (telephone or face-to-face). The information contained within the mailed questionnaires was found to be consistent with the information provided in the interviews, thus adding to the richness of the data and providing confirmation of the legitimacy of the findings. The findings have been reported using detailed descriptions which provide further evidence to the reader of the accuracy of the links between the raw data and the insights and interpretations which emerged from the reporting of the data (Creswell, 2009). Extracts from the data provided by all 31 participants are included to some degree within the findings which are reported in Chapters Four, Five and Six.

In seeking to develop an understanding of the phenomenon that encompasses all instances of participants’ experiences of parent hospitalisation, the themes were refined throughout the analysis until they accounted for all participant cases.

3.6.2 Transferability
Transferability refers to the application of the findings to other contexts and settings (Holloway, 2008). The widest possible range of data was included to provide a wealth of detailed and colourful descriptions regarding registered nurses’ experiences of parent hospitalisation. This rich database can now be available for transferability judgements to be considered by others.

3.6.3 Dependability
Dependability relates to whether the data is consistent over time (Holloway, 2008). This involved undertaking an inquiry audit (that is, examining the process and the products of the inquiry) to ensure the phenomenon (that is, registered nurses’ experiences of parent hospitalisation) was fairly and accurately represented. This was also achieved through performing a fresh analysis of the data on repeated occasions over the period of the
study. This strategy increased the trustworthiness of the data analysis. The interview and questionnaire data were re-visited with fresh eyes following substantial periods of no analysis activity on three separate occasions during the period of the project. On each of these occasions, I chose to re-commence my coding and analysis without reference to previous coding categories and notes. This strategy further enhanced the rigor of the analysis.

3.6.4 Confirmability
Confirmability demonstrates that the researcher has represented the participants within context (Holloway, 2008). Confirmability has been achieved through attention to an audit or decision trail. This is the step-by-step record of the procedures undertaken and the decisions made in relation to the research. This includes describing the rationale and methods for the research as presented within this chapter, as well as presenting excerpts from the data such as quotes from the interviews (which are presented in Chapters Four, Five and Six).

3.7 LIMITATIONS OF THE METHOD
Limitations are identified below to provide balance to the weight of the research findings.

3.7.1 The researcher’s role
As the researcher and instrument in this research project, I operated from the perspective of a RN who has had many experiences of a parent in hospital, and I cannot divorce myself entirely from the influence of those experiences. The significance to the research of my role as a researcher and the inherent subjectivity this brings to the project is acknowledged. These are unavoidable limitations (Creswell, 2009).
In a general sense, it is accepted that an interviewer’s (and interviewee’s), status, race, culture and gender do influence what is said during an interview (Nunkoosing, 2005). In view of my experiences of parent hospitalisation, my awareness of possible bias was consciously heightened in an effort to minimise bias in conducting the research and analysing the findings. My relationship to the participants of the study was inevitably influenced by the choice of research question I sought to answer, the sources from which I gathered my information, my personal presence during the interviews, the techniques I used to collect the information, the way I classified and interpreted the data, and my personal relationships with the people and events being investigated (Creswell, 2007; Flick, 2007b; Thomas, 2003). At the same time, it is acknowledged that my first hand experiences of parent hospitalisation provided me with empathy and valuable insight regarding the research topic which had the considerable advantage of providing me with heightened sensitivity in relation to the phenomenon being studied.

My experiences whilst working as an academic for 23 years within higher education which included 10 years as Dean of Nursing and Health influenced and shaped my ideas, perceptions and behaviours throughout the project. My status within academia may have influenced participants’ responses or the willingness or some RNs to participate in the research. I believe that my education which includes qualifications in behavioural sciences, education, and research, together with my background and past experiences contributed in a positive way to the project by providing depth and breadth of relevant knowledge relating to this nursing research project. As a result, my relationship to the participants of the study viewed from my insider’s perspective as a RN researcher who had personally experienced parent hospitalisation facilitated the development of rapport with participants, and my insights added to my understanding of participants’ experiences, and minimised bias through strategies described above and in sections 3.5.2 and 3.6.1.
3.7.2 The questionnaire

The semi-structured nature of a questionnaire can shape and reduce the flexibility of participants’ responses in relation to their experience of parent hospitalisation (Flick, 2002). This possibility was minimised by asking two broad open-ended questions at the start of the questionnaire regarding their experiences, and encouraging participants to add extra pages to extend their responses, which was done by some participants. These early questions provided participants with the opportunity to respond in a free way unshaped by the bias of the researcher (‘What was the experience like for you of having a parent in hospital?’ and ‘In what ways, if any, did you think that because you are a registered nurse the experience may have been different to that of a non-registered nurse?’)

3.7.3 Lack of representativeness

Generalisability of the findings is not an automatic expectation of this type of qualitative research (Flick, 2002). The findings are specific to the individuals and situations described and may not have general applicability. However, the knowledge gained regarding RNs’ experiences of parent hospitalisation of the concepts identified may apply or provide insights into similar situations. The purpose of this qualitative study has been to explore the essence of the phenomenon of RNs’ experience of parent hospitalisation, and not necessarily to generalise from the modest number of cases presented here. The descriptions of life experiences which have been reported may be typical for parent hospitalisation taking into account the context and conditions under which they occurred, and this possible typicality may be tested if future studies of similar topics, populations and methods are examined (Holloway, 2008).

3.8 CONCLUSION

This chapter described the method, its suitability and its limitations for researching parent hospitalisation. The research design, sampling of participants and the ethical
considerations and safeguards were also detailed. The next three chapters (Chapters Four, Five and Six) provide the findings which emerged from the data analysis.
CHAPTER FOUR
FINDINGS (PART ONE): PARTICIPANT AND PARENT PROFILES & THE PHENOMENON OF BEING IN THE MIDDLE

4.1 INTRODUCTION
The research question of this study was: What are RN-sons’ and daughters’ experiences of their parent’s hospitalisation? In the previous chapter the design and conduct of the study were described. The adoption of a qualitative methodological approach was discussed and the methods of data collection and data analysis were described.

This chapter begins with an overview of the phenomenon of being in the middle by providing a summary in tabular form of all categories, sub-categories and themes which emerged from the data. This is followed by a profile of participants and their hospitalised parents. Participants’ age, gender, years of RN experience and educational qualifications form the basis of the profile of participants. The profile of parents and their hospitalisation comprises information about the age and marital status of the hospitalised mother and/or father; the medical reasons, recency and duration of their hospitalisation; whether there were multiple hospitalisations and if so over what period they occurred. The chapter concludes with a summary of the findings presented herein.

4.2 PHENOMENON OF BEING IN THE MIDDLE: OVERVIEW, CATEGORIES AND THEMES

The phenomenon of being in the middle captures the essence of participants’ experiences of parent hospitalisation which revealed the boundaries at the hospital interface of their two identities: a health professional and a family member of a hospitalised parent. Being in the middle reflected the situation of participants who were navigating the boundaries between their family role and their RN role attempting to reconcile the conflicting characteristics of these roles within the context of their parent’s hospitalisation. The phenomenon of being in the middle encompassed three categories:
disclosure of RN status; RN on standby (being expertly vigilant) and RN in action (imperative to intervene). These categories and their accompanying sub-categories and themes are summarised in Table 4.1 below.

Table 4.1

Phenomenon of Being in the Middle: Categories, Sub-categories and Themes

<table>
<thead>
<tr>
<th>Categories of Being in the Middle</th>
<th>Sub-categories</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure of RN status</td>
<td>• Preferring to remain undisclosed</td>
<td>i) Disclosure unnecessary</td>
</tr>
<tr>
<td></td>
<td>• Disclosing to activate RN power and credibility</td>
<td>ii) Rather be treated as a lay son/daughter</td>
</tr>
<tr>
<td>RN on standby (being expertly vigilant)</td>
<td></td>
<td>i) To be treated as a peer/colleague</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ii) To get action</td>
</tr>
<tr>
<td>RN in action (imperative to intervene)</td>
<td></td>
<td>i) Filling in the gaps</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ii) Fixing</td>
</tr>
</tbody>
</table>

An understanding of the phenomenon of being in the middle is built progressively by presenting the findings over three chapters (Chapters Four, Five and Six).
Participants’ stated perceptions of being in the middle are presented in this chapter as an introduction to the phenomenon of being in the middle and this provides a context for the findings in relation to the categories and themes of the phenomenon which are presented in Chapters Five and Six.

Findings for the category of disclosure of RN status are reported in Chapter Five, and the findings in relation to the final two categories RN on standby (being expertly vigilant) and RN in action (imperative to intervene) are reported in Chapter Six.

4.3 PROFILE OF RN PARTICIPANTS

Thirty-one registered nurses (16 sons and 15 daughters) participated in this study. An early source of data was obtained via mailed questionnaires. Most participants (28) completed the questionnaire, 11 of these participants also participated in an interview, and three additional participants opted to participate in an interview without completing the questionnaire, taking the total number of interviews to 14 (45% of participants). Equal numbers of sons (seven) and daughters (seven) were interviewed.

Interviews were held about nine months after the questionnaires were returned. The questionnaires were analysed ongoing, as were the interviews, and the interviewing process was informed by information that participants had supplied within the questionnaires. Upon completion of the interviews and their preliminary analysis it was evident that the information obtained from the questionnaires was consistent with that of the interviews. This was not surprising because most of the RNs interviewed (11 of the 14) had also completed a questionnaire. Consequently, the findings related to the 28 questionnaires and the 14 interviews are presented together within this and the next two chapters. Appendix A contains condensed versions of each participant’s story. Appendix B contains the questionnaire, the Information Sheet inviting RNs to participate in the study, the Consent for Interview form and Human Research Ethics approval documentation.
Chapter Four

Findings (Part One)

Of the 31 participants, eight wrote and/or spoke about their mother’s hospitalisation, 13 wrote and/or spoke about their father’s hospitalisation, and ten participants described experiences involving both parents (Table 4.2).

Table 4.2

Number of RNs Interviewed and/or Surveyed about their Parent’s Hospitalisation

<table>
<thead>
<tr>
<th>Interview/Response</th>
<th>RN Sons</th>
<th>RN Daughters</th>
<th>One Parent Father</th>
<th>One Parent Mother</th>
<th>Both Parents</th>
<th>Total</th>
<th>Total No. of Fathers</th>
<th>Total No. of Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews (Questionnaire also completed)</td>
<td>7 (5)</td>
<td>7 (6)</td>
<td>6</td>
<td>3</td>
<td>5</td>
<td>11 (10)</td>
<td>8 (6)</td>
<td></td>
</tr>
<tr>
<td>Questionnaire Responses (no interview)</td>
<td>9</td>
<td>8</td>
<td>7</td>
<td>5</td>
<td>5</td>
<td>12</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Participant/Parent Totals</td>
<td>16</td>
<td>15</td>
<td>13</td>
<td>8</td>
<td>10</td>
<td>23</td>
<td>18</td>
<td></td>
</tr>
</tbody>
</table>

Pseudonyms were allocated to the 31 participants, and their demographic data are detailed within Table 4.3 below, showing that the youngest RN was 41 the eldest 53 years and that their experience as registered nurses ranged from 10 to 26 years. Most participants had completed a bachelor degree or higher (25 out of 31). Four participants (Jack, Cameron, Max and Eliza) mentioned they were no longer working as nurses and had been out of nursing for five, 11, 13 and 20 years respectively.
Table 4.3

RN’s Type of participation (questionnaire and/or interview), age, gender, years of experience and highest qualification attained

<table>
<thead>
<tr>
<th>RN</th>
<th>Age</th>
<th>Gender</th>
<th>Years RN</th>
<th>Highest Qualification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Q</td>
<td>Adam</td>
<td>41</td>
<td>M</td>
</tr>
<tr>
<td>2</td>
<td>Q</td>
<td>Amelia</td>
<td>42</td>
<td>F</td>
</tr>
<tr>
<td>3</td>
<td>I</td>
<td>Andrew</td>
<td>41</td>
<td>M</td>
</tr>
<tr>
<td>4</td>
<td>Q+I</td>
<td>Ben</td>
<td>44</td>
<td>M</td>
</tr>
<tr>
<td>5</td>
<td>Q+I</td>
<td>Cameron</td>
<td>44</td>
<td>M</td>
</tr>
<tr>
<td>6</td>
<td>Q+I</td>
<td>Claire</td>
<td>42</td>
<td>F</td>
</tr>
<tr>
<td>7</td>
<td>Q</td>
<td>Daniel</td>
<td>50</td>
<td>M</td>
</tr>
<tr>
<td>8</td>
<td>Q</td>
<td>Eliza</td>
<td>42</td>
<td>F</td>
</tr>
<tr>
<td>9</td>
<td>I</td>
<td>Emma</td>
<td>41</td>
<td>F</td>
</tr>
<tr>
<td>10</td>
<td>Q</td>
<td>Eva</td>
<td>42</td>
<td>F</td>
</tr>
<tr>
<td>11</td>
<td>Q</td>
<td>Gail</td>
<td>53</td>
<td>F</td>
</tr>
<tr>
<td>12</td>
<td>Q</td>
<td>Harry</td>
<td>45</td>
<td>M</td>
</tr>
<tr>
<td>13</td>
<td>I</td>
<td>Jack</td>
<td>51</td>
<td>M</td>
</tr>
<tr>
<td>14</td>
<td>Q</td>
<td>James</td>
<td>43</td>
<td>M</td>
</tr>
<tr>
<td>15</td>
<td>Q</td>
<td>Jane</td>
<td>42</td>
<td>F</td>
</tr>
<tr>
<td>16</td>
<td>Q+I</td>
<td>Kate</td>
<td>42</td>
<td>F</td>
</tr>
<tr>
<td>17</td>
<td>Q+I</td>
<td>Lara</td>
<td>41</td>
<td>F</td>
</tr>
<tr>
<td>18</td>
<td>Q</td>
<td>Lucy</td>
<td>44</td>
<td>F</td>
</tr>
<tr>
<td>19</td>
<td>Q+I</td>
<td>Madeline</td>
<td>45</td>
<td>F</td>
</tr>
<tr>
<td>20</td>
<td>Q</td>
<td>Matthew</td>
<td>45</td>
<td>M</td>
</tr>
<tr>
<td>21</td>
<td>Q</td>
<td>Max</td>
<td>43</td>
<td>M</td>
</tr>
<tr>
<td>22</td>
<td>Q+I</td>
<td>Oliver</td>
<td>44</td>
<td>M</td>
</tr>
<tr>
<td>23</td>
<td>Q+I</td>
<td>Olivia</td>
<td>41</td>
<td>F</td>
</tr>
<tr>
<td>24</td>
<td>Q</td>
<td>Patrick</td>
<td>53</td>
<td>M</td>
</tr>
<tr>
<td>25</td>
<td>Q</td>
<td>Rachel</td>
<td>41</td>
<td>F</td>
</tr>
<tr>
<td>26</td>
<td>Q+I</td>
<td>Ryan</td>
<td>47</td>
<td>M</td>
</tr>
<tr>
<td>27</td>
<td>Q</td>
<td>Sam</td>
<td>47</td>
<td>M</td>
</tr>
<tr>
<td>28</td>
<td>Q</td>
<td>Sarah</td>
<td>42</td>
<td>F</td>
</tr>
<tr>
<td>29</td>
<td>Q+I</td>
<td>Sophie</td>
<td>45</td>
<td>F</td>
</tr>
<tr>
<td>30</td>
<td>Q+I</td>
<td>William</td>
<td>49</td>
<td>M</td>
</tr>
<tr>
<td>31</td>
<td>Q</td>
<td>Zac</td>
<td>45</td>
<td>M</td>
</tr>
</tbody>
</table>

4.4 PROFILE OF PARENTS AND THEIR HOSPITALISATION

The profile of parents includes their age, whether they had a spouse at the time of their hospitalisation, their medical condition and the number and duration of their hospitalisations (Appendix C, Table C1).
The 31 participants' experiences involved a total of 41 parents. The youngest parent was 45 years, the oldest 87 years, and the parent group comprised 56% fathers (n=23) and 44% mothers (n=18). The average age of the mothers was 64 years and average age of the fathers was 71 years. The mothers were a more age-diverse group which contained both the youngest and the oldest parent. The similar medians (69 years for the mothers and 72 years for the fathers) indicated the groups were otherwise quite similar with only a three year median age difference.

4.4.1 Parent’s marital status
The marital status of 31 of the 41 parents at the time they were hospitalised was reported by participants (Appendix C, Table C1). Five parents did not have a spouse (four were widowed and one was divorced) and the other 26 sick parents did have a spouse at the time of their hospitalisation.

4.4.2 Parent’s medical condition
Participants provided information about the reason for their parent’s hospitalisation for the majority of parent cases (85% n=35). Two thirds of these parents (66% n=23) were clearly critically or terminally ill, and of these seriously ill parents, about three quarters (74% n=17) died either during or following their hospitalisation. Deaths were mostly due to cancer, stroke, coronary artery disease and complications of coronary artery bypass surgery. All but two parents were conscious during their hospitalisations, and in the main, parents were not cognitively impaired. Two fathers lost consciousness and died in hospital: Oliver’s father became unconscious shortly after being hospitalised, and Olivia’s father had suffered a stroke and was unconscious throughout his hospitalisation (Appendix C, Table C1).

4.4.3. Multiple hospitalisations of parents and years they spanned
Most parents (78% n=32) had been hospitalised on more than one occasion. Significantly fewer fathers had multiple hospitalisations (65% n=15) than mothers (94% n=17): a little over a third of the fathers (35% n=8) had been hospitalised on only one
occasion and most of these fathers died (75% n=6). The multiple hospitalisations had occurred within a five year period for mothers and fathers as a combined group in 79% (n=25) of cases. The mothers’ group was more diverse with periods ranging from two weeks to 44 years (SD 11 years) whereas the fathers’ group ranged from two months to 20 years (SD 6 years). The median period over which hospitalisations of each group had occurred was three years.

4.4.4 Recency of parent’s hospitalisation

The parent’s hospitalisation which formed the principal focus of participants’ experience of parent hospitalisation had mostly occurred within the last 5 years (71% n=29) and this was more the case for mothers (78% n=14) than fathers (65% n=15).

4.4.5 Duration of parent’s hospitalisation/s

Overall, 44% (n=18) of parents’ hospitalisations were brief, 32% (n=13) long, and 24% (n=10) varied (that is, included some brief and some long hospitalisations). Fathers tended to have brief hospitalisations of days rather than weeks (48% n=11) compared to mothers (39% n=7) and mothers tended to have longer hospitalisations of weeks or months (39% n=7) compared to fathers (26% n=6).

4.5 THE PHENOMENON OF BEING IN THE MIDDLE

The phenomenon of being in the middle captures the gestalt of participants’ experiences regarding their parent’s hospitalisation which revealed the boundaries at the hospital interface of participants’ two identities. One identity was that of being a health professional: participants who disclosed their RN status to staff were thereby identifying themselves as a registered nurse, and in doing so were signaling to staff that being a RN was their identity. The other identity was that of being a family member: participants who did not disclose their RN status to staff, were thereby identifying themselves as a son or daughter and in doing so were signaling to staff that being a son or daughter was their identity. Undisclosed participants privately navigated the role boundaries of being
a RN and a family member, whereas disclosed participants managed the added impact and complexity of negotiating role boundaries in their interactions with staff who were aware of their RN status. Being in the middle reflected the situation of participants caught between their family role and their RN role whether they were in disclosed or undisclosed mode (within the context of their parent’s hospitalisation).

4.5.1 Participants’ perceptions of being in the middle

Being in the middle refers to the situation in which RN sons and daughters found themselves in the role of their parent’s relative when their parent was hospitalised and they were off-duty nurses. They felt they could neither be fully in the role of a son or daughter, nor could they legitimately be fully in the role of a RN in relation to their hospitalised parent. Both of these roles (RN and offspring) were in the participants’ repertoire and aspects of each identity surfaced as necessary depending on their needs and the needs of their parent.

In describing their experiences it was clear that participants could not entirely divest themselves of their RN identity. When they were off-duty in the role of the relative they were a RN on standby ready to spring into RN in action mode if necessary to come to the aid of their parent.

Participants responded to the vulnerability of their sick parent by being strong for the family through an activation of their RN persona, although they sometimes expressed a yearning to just be the son/daughter. They experienced the emotions of being the child of the parent but participants did not allow themselves to give in to these emotions. This tension between their identity as a rational dispassionate RN and their identity as the emotional child created confusion about their role. These findings are presented below in three sections:

- Identity conflict and role confusion
- Yearning to just be the offspring but wanting the power of a RN
- Being the dispassionate, rational RN versus the emotional child of the parent
4.5.1.1 Identity conflict and role confusion

Some participants described their experience of being in the dual role of RN and offspring by referring to the conflict between their identity as a nurse and their identity as a son/daughter which caused confusion in the way they functioned as the offspring of the hospitalised parent (that is, confusion in their role as a son/daughter).

Kate described her confusion between being a RN and an offspring and the lack of stable role boundaries when her father became ill and required hospitalisation.

These roles are not in a blender but you have this mixing, it's like TV channels and someone keeps flicking the remote; and you keep jumping into that role. That's the whole experience. You go click nurse, click daughter, click nurse, click daughter, and this can be ... ten times within a conversation. It's that click, click, click, flicking all over the place. Oh and by the way I am my mother's daughter; oh click over to that one. [Kate]

This confusion surfaced when Kate visited her father in ICU immediately following his surgery (coronary artery bypass graft). On the one hand, her RN identity equipped her to cope with seeing a helpless patient, but she fell apart when she saw her father, because as the child of a parent, her expectation had always been that her parent was the stronger one, and she could not cope with seeing her father so helpless.

I was confused between being a daughter and a nurse. The ICU nurse was great she said “look when you go in there, he's going to be tubed, his colour's going to be shot”; and all this. And I said look I'm a nurse, I understand this, just take me to him. I walked in and saw him and completely fell apart. ... because I'd never seen my own father so helpless ... you always have this image of a parent being something stronger than you. And I said I have to go now. I can't look at this. [Kate]

Kate found it helpful when her best friend, Margaret (who is a nurse) later accompanied her to the hospital. As a trusted friend, Margaret provided Kate with reassurance and a safety net by explicitly stating that she would be the nurse instead of Kate so that Kate could focus just on being the daughter. This strategy re-defined the role boundaries which then allowed Kate to relinquish the RN role (with a sigh of relief) and play the role of the daughter.
I had gone from one extreme, thinking as a nurse all the month before about the clinical procedures of resuscitating my father, to totally not coping with the whole thing. And then once I got over it, my best friend came in with me. And she said “ok Kate I’ll be the friend, who is a nurse and you be the daughter.” And I went ok. And she went through it with me. It’s a re-definition of boundaries. [Kate]

Olivia was conscious of the impact that being a RN could have on hospital staff. She told staff that she could only be the daughter. However, privately, she found comfort in moving into her nursing role which was devoid of daughter emotions and found that intellectualising (which involved thinking like a RN) helped her cope.

I was conscious of it and I explicitly said: I’m actually a daughter at the moment – that’s all I can be. Even though while I was saying that I was still ... I mean there’s some comfort in moving into your nursing role – when you’re a daughter it’s like you’re working with your body and your emotions. When you go into your nursing role we have a role that’s nursing, and we do something different with our emotions when we put on that persona. And I think that somehow intellectualising or at least being able to grasp onto something more concrete and intellectual kind of helped me. [Olivia]

4.5.1.2 Yearning to just be the offspring but wanting the power of a RN

Participants revealed a yearning to just be the son/daughter (although they gave the impression that they really did not expect it was an option, or even the better option) but they also wanted the power of a RN. They really wanted the best of both worlds. They carried with them RN expertise and familiarity with the hospital and health care system. What they lacked in relation to their RN identity was the legitimate position power to take action, and they lacked full access to medical records and hospital resources.

It was unusual for me in that I had no control over the situation nor the care of a loved one - my mother. [Amelia]

That’s exactly what it was like [I was stepping out of the role of the daughter, the family member]. Whereas I really just wanted to be the daughter, yet I wanted to retain my power. [Claire]

When Kate experienced confusion between being the daughter and being the nurse, she felt she did not have the choice of being the daughter because her family expected her to
be the strong one in the family, nevertheless she acknowledged that being in the role of the nurse empowered her to achieve a good outcome.

At the time ... with my father, I didn’t know who I was and I didn’t know what to be; because there was the role of being the daughter but I wasn’t allowed that role .. because I had to be the strong one and I was also imposed upon because I was a nurse; but also for my own benefit, I manipulated the situation to get what I want, to get a good outcome. I used to say to my husband sometimes it would be a bloody relief if I wasn’t a nurse and then I’d think no, because ... then I wouldn’t be able to get what I want. [Kate]

Sophie’s experience with her mother’s hospitalisation had been protracted and harrowing and she was very much in the role of the nurse constantly for her mother’s hospitalisation. Sophie was saddened by her father’s terminal diagnosis, however she was much relieved and grateful that his hospitalisation was brief as she could not have coped with another long hospitalisation. She was also happy that her father preferred her to just be the daughter and not be involved in overtly nursing behaviours for him, and because her parents had divorced when she was young she treasured the opportunity to spend time with him as a daughter.

[My father] preferred me to be just the daughter and not the nurse. I was very happy about that]. It was lovely. He was in a lot of pain but he was quite lucid. So we actually just talked and it was just beautiful to just talk about when I was little and that was really nice. That was very special. I’d just hold his hand and stroke his forehead and we’d chat and when he’d go to sleep because he was on morphine, I just thoroughly enjoyed just sitting beside him ... and do some sewing, and it was actually very peaceful. Whereas my mother was totally the opposite ... [Sophie]

Sophie’s father needed toileting assistance and he found it embarrassing on the odd occasion when his daughter assisted him (which was not surprising as it was an example of a child intruding on the corporeal privacy of their parent). He preferred to be assisted by the nursing staff. Sophie was very happy to just be the daughter and not get involved in his nursing care. In this instance the confirmation of child-parent boundaries provided a mechanism to override Sophie’s RN identity and allowed her to keep mostly within the identity boundaries of being just the daughter.
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On a couple of occasions I helped him to the bathroom but he was embarrassed ... he didn’t like to think that his daughter was having to help him go to the toilet and he’d say “no, no call the nurse.” So he preferred me to be just the daughter and not the nurse. I was very happy [about that]. [Sophie]

Sophie was not entirely in the role of daughter during her father’s hospitalisation. She engaged in nurse behaviour to support her father’s wife (not her mother) who was not coping. Due to the sudden onset of his illness and his rapid deterioration his wife could not understand what was happening and could not accept that Sophie’s father was dying or that his cancer was inoperable. Sophie and her father’s wife were at his bedside every day supporting him and observing his needs and treatment. It was very difficult for Sophie who kept trying to explain gently to his wife that he was beyond treatment. She looked to Sophie for that nursing knowledge and support and Sophie stayed with her for the period of her father’s hospitalisation.

[My father’s wife] certainly was having a very difficult time. So I stayed in Sydney with her... she definitely looked [to me] for that knowledge and that support ... because I understood what the processes were. I was able to explain things to her ... They simply couldn’t do anything. I did keep trying to reinforce that in a really gentle way ... the same as with my family. ... I knew that it wouldn’t be very long before he actually passed away. His wife totally believed that if he’d just had an operation ... give him chemotherapy ... he would get better and it was very difficult for me to explain that it was beyond that. That was just terrible because she kept begging them to treat him. You know “please, please treat him.” Even when the social worker was saying that it was coming to the end and to prepare ourselves she was still saying “but you haven’t given him any chemotherapy yet. How do you know that it’s at the end?” And that was really very difficult. ... within that month ... suddenly to just be so sick that he was going to die in such a short time ... it was too fast. She just could not comprehend it at all. I on the other hand was thankful because I couldn’t have coped with seeing him deteriorate like Mum. [Sophie]

4.5.1.3 Being the rational RN versus the emotional child of the parent

A defining characteristic of participants’ identity as a RN was the need to be strong by maintaining control over their emotions when providing care for hospitalised patients. This characteristic conflicted with the emotional investment inherent in caring about a hospitalised parent which was an integral part of their son/daughter identity.
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Andrew’s mother had died unexpectedly in hospital and it was his task to contact his four siblings (two sisters are RNs) to advise them. This was extremely stressful and draining, and he knew he had to be stoic and brave. He did not allow himself to cry partly because he felt as a RN he had to act professionally and partly because he had so much to deal with. Having to tell them, knowing he could not just say “you better come in something’s wrong [with Mum]”, he must tell them the facts and was trying to find the correct words to help his siblings cope with the bad news as quickly as possible. When it was all done, he surprised himself in the way he maintained a facade of composure and did a good job by acting in a professional way. “It was all hell with everyone crying and carrying on.” He thought he had done his duty and was now just going to be a son. He just wanted time on his own with his deceased mother to be just the son. But this was not possible as his siblings and members of their families were also present at the bedside.

I’d done my bit. I was just going to be a son. But one thing I really felt was I wished that everyone else ... were gone. I wished it was just me and her there. That’s all I wanted ... a little bit of time on my own ... after ... ringing all these people and having to tell them and it was just like god this is tiring I’ll have a bit of a sit down and just sit down with mum; but ... you couldn’t do it. [Andrew]

As the distraught daughter, Olivia sometimes found respite in her nursing role. Olivia’s father had suffered a cerebral bleed, lost consciousness and was dying. Her family kept her in touch with the sadness of the situation which was part of being a daughter and kept her in touch with reality as a family member. There were times when she switched from being the emotionally distraught daughter to being the RN negotiator. She found comfort in the safety of her nursing role when she negotiated with medical staff for her family and the RNs to be included in her father’s medical rounds.

It's that kind of flip flop – on the one hand there's this emotionally distraught daughter and on the other hand you negotiate the ward in a much more comfortable way. ... it's more intellectual ... I want to see that the world I espouse happens in the world I live. But there's also a bit of safety in it. A bit of taking back control over something that just one Friday morning – suddenly life went out of control – it changed forever – that was the end of it. Life went
Participants’ feelings and expectations in the role of offspring to the parent conflicted with aspects of their RN identity. Despite the reassurance of a familiar hospital environment, having a parent in hospital stirred familial emotions in participants, which conflicted and interfered with their normal RN reasoning processes.

The main issue was the conflict between being a health care professional and being a relative (son) of the person in hospital ... especially in the area of emotional detachment or separation issues interfering with good judgement. [Daniel]

Cameron held back at times not wanting to over-react because he questioned his own professional judgement and wondered whether he was accurately assessing the seriousness of his father’s condition, or whether he was being too emotional and therefore lacked objectivity.

In the early stages when it started and something serious was happening I didn’t want to panic and over-react [because this would risk upsetting my father who was already very stressed about his angiogram/surgery being brought forward to the following morning] and what I was trying to work out was, was it me being too emotional or was it really that serious ... [Cameron]

Cameron was angry with himself for getting emotional when the crisis occurred. Cameron’s father had previously advised his doctors that he valued his quality of life and did not wish to be resuscitated if he were to have a cardiac arrest. In spite of this advice, when he did arrest, Cameron was asked by the doctor (although it felt more like interrogation) whether he wanted his father resuscitated. Cameron felt he did not have the right to make this decision. He said that he was placed in an unfair position: frozen due to being torn between keeping him alive for the family and abiding by his father’s wishes, which he ultimately did.

I can be pretty detached in that sort of situation normally [his father was about to arrest and Cameron was asked whether he wanted him to be resuscitated] just do the rational thing, but I remember being ... almost angry with myself when I was getting so emotional about everything that was going on at the time ... Yes, that responsibility for ... like being detached and being head of my [family ... and not having the right to his own personal reactions] ... It’s funny,
a colleague at work at the time who was a nurse was asking about the whole process and she said something like: I'm sure it was pretty easy for you being a nurse ... I said no, it had nothing to do with it.  [Cameron]

Participants often mentioned feelings of helplessness, failure, anxiety and stress as well as an inability to express their emotions well. Gail described the impact of her dual identity: she experienced high anxiety as the helpless child of the parent, and yet her ability to display feelings was paralysed by the emotional detachment that was an integral part of being a RN, and as a result she felt she had failed her parent because she was unable to assist.

This was very anxiety provoking. All my intellect as a nurse practitioner became intertwined with the emotions of being a helpless child of the parent. If I had not been a registered nurse I would have been able to emotionally show my feelings better. I may not have analysed as much as I did. I may have been able to seek out counselling and to deal with my distress and disbelief at what was happening. I may not have felt so deeply unable to be of assistance. I may not have felt that I had failed my parent in some way. It was a very traumatic experience and all my coping skills were tested just to be able to deal with the experience.  [Gail]

At times, participants communicated with staff and their family using the communication style which typifies professional RN behaviour. They spoke about their parent dispassionately, adeptly using hospital language just as they would normally do if they were speaking about a patient to whom they were not related.

Sometimes it was painful talking about my father in the abstract. Like saying well the reason that ... they're not giving [my father] too much [hypnotic/sedative] is that they could slow his breathing down too much and I mean then you've got to say well that's straight out euthanasia; and it was hard to be objective. [Claire]

This RN style of communicating can give the impression that the RN-son/daughter is coping well and is in control of the situation, involuntarily disguising their struggle with role confusion and their parent’s hospitalisation. It can also be interpreted as unfeeling and distant in terms of the offspring’s relationship with the parent, particularly in the eyes of relatives. Gail mentioned that her siblings perceived her to be uncaring. This resulted because of her role confusion, which led to Gail behaving like a RN instead of showing emotion like a lay daughter.
My distress at the role confusion led to me appearing aloof to other siblings and therefore being criticised by them for not showing that I cared. [Gail]

Kate explained that acting like a nurse helped her to cope by keeping her emotions under control and detaching herself from the emotionally fraught situation of preparing for the possibility of resuscitating her father if he arrested. However, she found it painful to be interacting with her father devoid of filial emotions and felt deprived because she was not free to express those emotions.

At that stage I wasn’t thinking like his daughter I was thinking like a nurse. I started taking his watch off, and starting undoing his shirt, loosening, taking his belt off, and I was talking to him and reassuring but at the same time preparing for him to arrest and this is without actually any feeling whatsoever. Really hurt actually. This was just ... I’m numb. It’s detached and ... the only way I could cope with it was to be a nurse. and I starting talking like a nurse and [my parents are] looking at me and I thought don’t talk like a nurse, but I need to gain some control over the situation so I started talking like a nurse ... it’s worse than being the daughter ... that responsibility [that comes with being a nurse] and because you have a medical background in that sort of situation ... but no one understanding that I was on [an] equal playing field with everybody else in that situation and thinking how sad, to have to try and bring my father back to life and really feeling how, not grief, not distress ... it was like I stood outside of myself and thought, what an awful position to be in. [Kate]

Andrew, the youngest of five siblings, felt robbed of the comfort in just being the son like his two older non-RN brothers when his mother died after an unsuccessful resuscitation attempt just as he arrived at the hospital ward to visit her. He felt he had to stay strong for the family by maintaining the professional role of his RN identity. This put a lot of pressure on him to keep his emotions under control while he telephoned his siblings (which included two RN-sisters) to advise them that their mother had just died.

My experience ended very tragically because my mother died. They weren’t able to bring her back. When it’s your mum it’s really hard to keep composed. I think of that often and I would have liked to have fallen on the ground and cried and carried on but no I definitely felt that I had to maintain a role as it were and be professional. I regret not breaking down ... but I did put a lot of pressure on myself to maintain this control. ... I thought if I was a fitter or a welder or anything like that I would probably have acted differently. [Andrew]
Kate acknowledged the burden of constantly being in the role of the nurse and not having any respite for emotional release as the daughter.

That was the hardest thing because I was so busy being the nurse and there was no down time to sit there and look at the situation as a kid. [Kate]

Looking back on her experiences of parent hospitalisation, Sophie recognised that she could neither refuse to take on the nurse role, nor allow herself to feel the emotions as a daughter and now believes it would have helped her if she had allowed herself some emotional release, because after the deaths of both parents and her son in close succession she fell apart badly.

You have to put aside that you are a nurse and allow yourself to have those feelings ... as the child of the parent. Allow those things to actually be expressed. I don’t know that you can say “oh no, no I don’t ... want to take this burden on.” I think probably the only thing would be to allow myself to just acknowledge the grief and the pain a lot sooner than I did. [Sophie]

Andrew also recognised the importance of showing emotions during the crisis, and as a result of not expressing his emotions at the time of the crisis, he sought counselling in the aftermath of his mother’s death.

Try and be professional ... but don’t let that inside ... don’t be afraid to show your emotions ... you’re a human being as well ... and I regret not breaking down and carrying on like a blubering idiot but I did put a lot of pressure on myself to maintain this control ... well I cried heaps later on of course, but yeah, but don’t be afraid to let your emotions show ... Mum died in January and I went and saw this guy in February and March and then I saw someone [the following year too] because I was drinking a lot and that was why; because I was just not getting it together. [Andrew]

As a by-product of their professional RN-like behaviour due to their dual role and role confusion, participants were perceived to be unfeeling. This led both staff and family members to treat them like a RN, and this treatment made them outsiders to both camps. They were members of both camps but not exclusively in either camp. They were in the middle. Consequently, no one connected with them as a son or daughter and there was a lack of emotional and other support for many participants. Rachel described it as a lonely experience because no one connected with her as the daughter of a dying mother.
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The ward staff - nurses - appeared to not want to ‘act’ involved with me or the family situation. I worked at the hospital in which my mother was managed. So - in one word it was a LONELY [sic] experience. [Rachel]

Participants were conflicted: they yearned to be a son/daughter but they wanted the power of a RN. They kept their emotions as the child of the parent in check which resulted in being criticised by their family as uncaring, and being perceived to be coping by staff. Participants were consequently not well supported by staff or family, which, coupled with not allowing themselves any avenues of emotional release, caused them to succumb to emotional strain when the crisis of their parent’s hospitalisation was over.

As described above, being in the middle is about struggling with the dual identity of being a nurse and being the son or daughter of the hospitalised parent. Disclosure of RN status is an important aspect of being in the middle because disclosure/non-disclosure sends signals regarding a participant’s identity to hospital staff. In choosing not to disclose their RN status, participants were thereby identifying themselves as a son or daughter. The identity of ‘nurse’ is revealed to the hospital staff through disclosure. Once the participant’s RN status is revealed to staff, the impact of the participant’s dual identity becomes public and this dual identity affects the behaviour of staff towards the RN son/daughter.

The findings in relation to the category of disclosure of RN status as part of the phenomenon of being in the middle are presented in Chapter Five. The category of disclosure of RN status encompassed two subcategories: preferring to remain undisclosed and disclosing to activate RN power and credibility.

4.6 SUMMARY OF FINDINGS (PART ONE)

This chapter provided an overview in tabular form of categories, sub-categories and themes which emerged from data regarding the phenomenon of being in the middle. A profile of participants and their parents was also provided, and participants’ perceptions of being in the middle as a result of having a dual identity and role were presented. Being in the middle was the overriding concept identified in this study which reflected...
the situation of participants who were navigating the boundaries between their family role and their RN role within the context of their parent’s hospitalisation. Being in the middle was described as the situation of RN sons and daughters of a hospitalised parent who have a dual identity: an identity as a nurse and also an identity as an offspring of the patient. A summary of these findings is given below.

4.6.1 Participant and parent profile summary
The sample of participants was evenly divided between sons and daughters of similar age (average age was 44 years) and educational qualifications.

The parents were mostly in their sixties and seventies at the time of the hospitalisation on which participants’ experiences were based, they had been hospitalised on more than one occasion (particularly the mothers) which generally occurred within a five year period. Their hospitalisations were relatively recent (most had occurred within the last five years) and the duration of the hospitalisation tended to be longer for mothers than fathers. The parent’s medical diagnoses (not available for six of the 41 parents) were often cancer of various types (lung, breast, pancreas, liver, bowel, brain, lymphoma) or of cardiovascular origin (cardiac valve insufficiency, coronary artery disease, cerebrovascular accident) but did also include some hospitalisations for orthopaedic and other elective surgery, thoracic surgery and medical conditions such as diabetes and obstructive airways disease, and in one case mental illness. Two-thirds of the parents were critically or terminally ill, and three-quarters of these died either during or after their hospitalisation. Hospitalised parents were almost all conscious, and in the main they were not cognitively impaired. Most parents had a spouse at the time of their hospitalisation.

4.6.2 Participants’ perceptions of being in the middle summary
Participants experienced identity and role confusion and experienced emotional barriers which prevented them from showing emotion as the child of the parent as this conflicted with their identity as a rational dispassionate RN who was playing the leadership role in relation to their parent’s hospitalisation. Participants acknowledged the advantage and
power of being a RN which came at the cost of forfeiting an opportunity for emotional release as a son/daughter.

The next chapter (Chapter Five) adds to the above information regarding the participants and their parents by reporting the findings in the category of disclosure of RN status to nursing paramedical and medical staff.

Chapter Six contains the remaining findings in relation to the final two categories of the phenomenon of being in the middle: RN on standby (being expertly vigilant) and RN in action (imperative to intervene).
CHAPTER FIVE

FINDINGS (PART TWO) BEING IN THE MIDDLE: DISCLOSURE OF RN STATUS

5.1 INTRODUCTION
The previous chapter presented an overview of the phenomenon of being in the middle, reported participants’ perceptions of being in the middle and provided a summary of the categories, sub-categories and themes within this phenomenon. Three categories were identified: disclosure of RN status; RN on standby (being expertly vigilant) and RN in action (imperative to intervene) and the profiles of participants and their parents were included.

This chapter progresses an understanding of RNs’ experiences of parent hospitalisation by presenting the findings of the first category of the phenomenon of being in the middle: disclosure of RN status to nursing, paramedical and medical staff. The category of disclosure of RN status encompassed two subcategories: preferring to remain undisclosed and disclosing to activate RN power and credibility. The findings in relation to the category of disclosure of RN status as part of the phenomenon of being in the middle are presented in section 5.2 below.

5.2 DISCLOSURE OF RN STATUS
The category of disclosure concerns whether information about a RN’s professional nursing status is provided (or becomes known) to the hospital’s nursing, paramedical and medical staff. Participants’ disclosure of their professional status emerged as an important issue which influenced their experience of parent hospitalisation. Two sub-categories regarding disclosure have been described: preferring to remain undisclosed, and disclosing to activate RN power and credibility. An overview of the disclosure category, together with its sub-categories and themes is presented in tabular form below.
Table 5.1

Phenomenon of Being in the Middle: Disclosure Category, Sub-categories and Themes

<table>
<thead>
<tr>
<th>Categories of Being in the Middle</th>
<th>Sub-categories</th>
<th>Themes</th>
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<tbody>
<tr>
<td>Disclosure of RN status</td>
<td>• Preferring to remain undisclosed</td>
<td>i) Disclosure unnecessary</td>
</tr>
<tr>
<td></td>
<td>• Disclosing to activate RN power and credibility</td>
<td>ii) Rather be treated as a lay</td>
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<tr>
<td></td>
<td></td>
<td>son/daughter</td>
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<tr>
<td></td>
<td></td>
<td>i) To be treated as a peer/colleague</td>
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<tr>
<td></td>
<td></td>
<td>ii) To get action</td>
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When a parent is hospitalised, the RN son or daughter sometimes has a choice regarding whether to disclose their RN status when interacting with the hospital’s staff. The reasons given by participants for their preference to remain undisclosed and the circumstances which resulted in disclosing their RN status are detailed in the sections below.

5.2.1 Preferring to remain undisclosed

Almost all of the participants in this study (30 of the 31) stated or implied a preference to remain undisclosed. However, for 28 of the 30 participants, their preference of remaining undisclosed was not achieved or was not an option (Appendix C, Table C3). This was because most participants found they needed to disclose to be treated as a peer or colleague in order to obtain detailed information about their parent or to get action (n=19) and/or they were recognised by staff because they either worked at the same hospital or encountered past nursing colleagues (n=15) and/or a family member had
revealed the participant’s status to staff (n=10) and/or they were detected by staff due to participants’ expert knowledge, behaviour and use of medical terminology (n=6). Only two participants, Harry and Patrick, who preferred not to disclose their RN status, achieved this outcome – they both remained undisclosed and unrecognised during their parent’s hospitalisation. Matthew remained undisclosed and undetected and reported that there were not times when he chose not to disclose his RN status. Matthew did not elaborate his reasons in response to the question regarding disclosure (that is, that he did not opt for non-disclosure) however his responses implied that disclosure was not an issue for him one way or the other. The reasons given by participants for not wanting staff to know of their RN status are described within two themes: disclosure unnecessary and rather be treated as a lay son/daughter.

5.2.1.1 Disclosure unnecessary

Participants did not generally want or expect to take over the nursing of their parent. They expected the hospital staff to nurse their parent. They did not believe that disclosing their RN status would result in improved care for their parent, and they also recognised that they lacked legitimate power to interfere with the hospital staff’s care of their parent. Some participants did not consider it relevant and some mentioned it was not necessary or appropriate to disclose their RN status.

Staff were doing their job - not to my satisfaction but it was not my situation to control or interfere with. [Patrick]

Eva did not believe it necessary (or helpful in achieving better care for her father) to announce her RN status to staff, as she believed that staff could interpret such disclosure as a threat – that they are being monitored and will be taken to task if their work is not satisfactory. On the other hand her father would tell everyone that she was a RN and “knows everything about everything” and as it was Eva’s training hospital she was also known by friends who worked there.

*People know their job. What are you hoping to achieve by telling staff you’re an RN? That they’re going to look after your father better? Aren’t they already*
doing the best job they can? The implication in telling people you’re an RN is that they’d better watch out because you’re watching them. It’s just not necessary [Eva]

On a couple of occasions, when Emma’s father told staff of her RN status, she told him there was no need for them to know.

[Dad] did [tell staff] on two occasions and I actually said to him privately maybe that’s not a good idea. He just laughed and said “why don’t you want them to know?” I said: I just think: do they really need to know? [Emma]

Andrew does not like to disclose his RN status unless it becomes necessary as he thinks it sounds self-aggrandising and it can be poorly received by some staff who may become defensive. Andrew thought his RN-sister’s disclosure (that he and his mother were also RNs) to the cardiologist sounded a bit like that when they accompanied their mother to see him, however it was helpful and it did put them all at ease a little.

*I don’t say anything. Because I think if you say something to someone, I think you come across as big-noting yourself. And I think people kind of look at you and go oh, or people look at you and go big shit, I don’t care who you are.* [Andrew]

One of Andrew’s prior experiences of disclosing was that as soon as he did, the staff were taken aback. He perceived that they were then immediately self-conscious as though they wondered what possibly incriminatory things they had been saying in front of him as a RN-relative.

*I said I’m an RN – “oh you’re an RN” and they all turn around and look at me like I suddenly said I’m gay or something ... And they looked at me ... oh my god what have we been saying. And well you don’t have to be like that you can just be polite to start with.* [Andrew]

Andrew thinks that staff RNs need to have more self-confidence as this would facilitate a more comfortable and transparent relationship with RN-relatives. He suggests that tact is important when interacting with nursing staff and advised against performing nursing tasks or making a grandiose statement when disclosing as this would imply that the staff are less competent than the RN-relative and would result in them leaving the care to you.
If you’re going to say who you are and if a situation arises that you need to say who you are, you say it tactfully and not like you’re making a grandiose statement that you’re this, this and this ... and that you’re better than the person that looks after your relative. People can tend to do that and just completely ruin the relationship. And also respect other people’s feelings as well when you’re telling them things and don’t do their job for them otherwise they’ll just leave and you’ll have to end up doing it ... and be confident in your ability as well. That’s what I think from the perspective of being an RN looking after someone who used to have a medical background. You’ve been trained to do this, and be confident and be comfortable with what you’re doing with your job. [Andrew]

Emma found the nurses within the CCU were confident about their competence and were very comfortable with her RN status and her hospitalised father’s professional status as a retired medical doctor – “it was no big deal” which also indicated that staff RNs who are confident in their ability do not feel threatened by the presence of a RN-relative.

5.2.1.2 Rather be treated as a lay son/daughter

Participants believed that staff would treat them differently and that they would be disadvantaged by disclosing their RN status so they preferred to be treated as a lay son or daughter rather than as a RN. They believed that staff would have behavioural expectations and would make various assumptions about RN-relatives. They thought that if they disclosed their RN status it would have the following effects:

- Participants’ comments/actions may not be viewed objectively or could be misinterpreted as criticism
- Staff would become hesitant, uncomfortable, fearful and consider them a threat
- Staff would communicate less
- Staff would give their parent less care
- Participants might be called on to assist with aspects of their parent’s personal hygiene

Participants’ views concerning the implications of disclosing their RN status to staff are presented below according to the five effects listed above.
5.2.1.2.1 Actions could be misinterpreted as criticism and not viewed objectively

In Olivia’s case she did not have the option of keeping her RN status to herself. She was known to the nursing staff and had built up a trusting relationship with them, but she said that in different circumstances where she does not know the staff, she would definitely not disclose her RN status. She believes that doing so in such circumstances could damage the relationship between hospital staff and a RN-son/daughter because it would not be possible to control staff members’ misinterpretations of her actions.

I had no choice in my situation. ... but I wouldn’t [normally] tell them ... absolutely not ... because I think it’s not really about me going in there and saying I’m a nurse – I actually think it triggers other people’s stuff ... and what you can’t control is the response of other people. And you actually can’t control a misinterpretation of tucking up a bag off the end of the bed and someone thinking – oh she obviously thinks I’m a bad nurse because the bag’s down there – you can’t control those misinterpretations. [Olivia]

Harry felt strongly that any concerns voiced by him “would not have been taken objectively” if his RN status was known as he believed it would have been perceived as “stepping on [their] toes”; and Madeline finds that staff are more patient and forgiving with lay relatives (than with RN-relatives) because they do not have an understanding of the hospital system and the roles and responsibilities of staff,

I think you basically hold back because you are an RN ... nursing staff will resent you [if you] try to run what their job is. [Lay relatives] just don’t listen. They’re too stressed. And they obviously don’t understand what [the staff are] doing either. [Madeline]

Ben’s mother had informed him of the uncaring attitudes of certain nurses and he wanted the opportunity to observe the routine nursing care of his mother without disclosing his RN status as he believed that disclosing would have led to modified care in his presence.

To observe the general care of nursing staff especially when informed by my parent of ‘less than caring’ attitudes. [Ben]
5.2.1.2.2 Staff hesitant, uncomfortable, fearful and feel threatened

Participants also believed that staff were often uncomfortable or considered them a threat and acted differently toward RN-relatives. Madeline tends not to disclose her RN status as she finds that RNs are scared of her and Oliver mentioned that junior nurses were nervous or sometimes petrified when Oliver was present – fearing he might be watching them too closely. Sarah and Cameron also found that staff became uncomfortable.

Staff tend to act differently. Tends to make it uncomfortable for them [Sarah]

... often causes RNs to become uncomfortable. ... There was a real sense of injustice that [RNs] were disadvantaged by identifying themselves as a nurse. [Cameron]

James chooses not to disclose his RN status to staff because it has led to staff treating him differently. Specifically that medical staff treat him “with some disdain” and nursing staff tread warily, along the lines of “he knows it all”, and he would be considered a threat or they would suspect that he had a motive for disclosing. Although James did not intentionally disclose his status, he noted that it was easy for staff to work out when he asked questions using medical terminology.

Eliza and Emma noted that nursing staff were more helpful and friendly if they said nothing about their status and staff found out through other means. There were times when Eliza chose not to disclose her RN status because she found that if nurses knew she was a RN they tended to steer clear of her and her father. She finds this understandable to some extent, having witnessed some very pushy and overpowering nurses, and also that some RNs may feel overly scrutinised and consequently feel threatened.

It’s weird isn’t it? I found that if I said nothing to the nursing staff and they later found out I was an RN they were much more friendly and helpful than if you did say so. [Eliza]

Emma had told her father not to tell staff of her RN status as some staff may be hesitant or uncomfortable or more distant in relating to them.
...because I think it does make the other registered nurses uncomfortable. Sometimes you could tell that they looked at you and you thought ohhh. I think that registered nurses are a bit sort of hesitant. It’s like when you go in as a registered nurse [as a patient] and people know you're a registered nurse I think you either get under-cared for or you get over-cared for big time. I don’t think there’s a happy medium. [Emma]

5.2.1.2.3 Staff communicate less

Kate learned from her experience that it is better not to disclose her RN identity in some situations. She feared she would be treated differently or ignored if she disclosed, and that staff would not provide the same type and amount of information and explanations regarding care and treatment because they would assume her knowledge as a RN would make such communication unnecessary.

I told people I was a nurse - I was ignored. “She would know” - and I was ignored. Or I didn’t get the same explanation a normal person would get and because I was a nurse it was assumed that I would know things so I wouldn’t tell them because I thought they would treat me differently. [Kate]

William also mentioned that disclosing one’s RN status can lead to less information being provided if staff assume that a RN would already have sufficient knowledge thereby making it unnecessary to communicate information about health matters.

It can also work in the reverse. People can assume that you do know and doctors can assume that you do know. ... I'm always pretty guarded. I never let on ...because they do treat you quite differently if they know. But whether Dad had told them ... He may have done. I’m very reluctant to [let on] if there’s a situation where I think people might take advantage of it. [William]

When Madeline accompanied her father to the oncologist she did not disclose her RN status because she just wanted to see what information he gave her father. The implication being that the oncologist would have modified the information if Madeline had disclosed her status. Presumably Madeline thought that abbreviated information may have been given by the oncologist because he could rely on her to fill in the gaps later, or that more highly detailed information may have been given which would have
been incomprehensible to her father and would also require Madeline to explain it in layman’s terms to her father afterwards.

Claire explained that disclosure not only led to less information being given to her by RNs, but that she was also expected to explain everything to the family.

Whereas [the doctors gave extra information] the nurses I found gave beautiful simple layman’s language explanations on everything they were doing until they found out that I was a nurse and then they told me nothing; because I guess they thought: well you know what I’m doing.

It is disappointing ... of the profession of nursing and until they can accept that there’s nothing to fear in giving the information, then I think they’re still just task orientated. ... After they knew that I was a nurse ... they really left a lot of the explanation to me for the rest of the family. [Claire]

The majority view of participants was that nursing staff provided them with less information if they disclosed their RN status (with the exception of RNs who were known to them and trusted them, or CCU and ICU nurses) whereas doctors responded by providing participants with more detailed information. Claire and Cameron’s experiences were examples of this. Participants concluded that they would rather be treated as a lay relative by nursing staff but would rather be treated as a RN-colleague by doctors.

*From the doctors’ point of view it’s: oh well so you know this stuff, well I’ll give you more detail; ... whereas from the nursing point of view, my experience has been ...well we’ve got to be really careful around you it’s sort of like ...don’t give him more information. It’s: withhold information. [Cameron]*

### 5.2.1.2.4 Nursing staff give less care

Participants believed that the care of their relative could be detrimentally affected if they disclosed their RN status. Oliver says disclosure causes RNs to leave the care to you, and Adam also stated that disclosure lowers the care of the patient.

*There’s no bigger pain than a know-it-all RN. It puts staff ‘off’ and lowers the care of the patient. [Adam]*
Many participants explained that if nursing staff were aware of their RN status, they would avoid them and their parent, take short cuts and would expect participants to fill in the gaps.

Staff generally attempt to cut corners with aspects such as information, treatment etc because for whatever reason they can rely on you to fill in the gaps. [Daniel]

Andrew observed that disclosing RN status can ruin the relationship with hospital staff putting their ‘noses out of joint’ if RN-relatives start doing aspects of the nurse’s job. He also finds that when nursing staff know a patient’s relative is a RN they leave them in charge of their own relative. As with Andrew’s experience, Claire and Eliza noted the tendency of staff to avoid them and to expect them to provide nursing care to their parent.

As soon as I arrived their care stopped... they expected me to be his private nurse... they were conspicuous by their absence ... they expected I would sponge Dad and turn Dad and ... that's the impression I got; that well, you're a nurse, so like: ‘nurse!’ [Claire]

They steer clear of you and your relative [Eliza]

Jack did not disclose his RN status, but his mother told staff. The staff knew his sisters were all nurses and often left the care to them. Jack does not believe it is a good idea for family members to perform nursing care as the staff then “lose their way” to some extent, meaning that staff would then lose track of what care has and has not been given, and risk failing to detect changes in their patient’s condition.

5.2.1.2.5 Participants might be called on to assist parents with personal hygiene

Gail chose not to disclose her RN status to staff when she saw her father being sponged by nursing staff, and also when her mother was unable to take care of her own personal hygiene. Presumably Gail wanted to preserve the usual child-parent privacy boundaries and she did not want to risk being expected to assist in performing tasks for her parents that violated these boundaries by disclosing her RN status.
[I chose not to disclose my RN status] when I saw my father being washed/sponged by nursing staff. [Also] the time my mother was unable to care for herself in regard to her personal hygiene. [Gail]

5.2.2 Disclosing to activate RN power and credibility

Although all but one participant preferred to keep their RN status to themselves, there were situations during their parent’s hospitalisation which led many participants (n=19) to disclose their RN status to staff (Appendix C, Table C3). This sub-category of disclosing to activate RN power and credibility encompassed two themes: to be treated as a peer/colleague and to get action.

5.2.2.1 Disclosing to be treated as a peer/colleague

At times participants mentioned they advised staff of their status in order to be recognised as a peer or colleague. Some participants had been recognised by staff with whom they had worked previously, or because they worked at the same hospital in which the parent was hospitalised. The most frequently stated objective in wanting to be treated as a peer/colleague by medical and nursing staff was to obtain detailed information about their parent. Some participants wanted to be regarded as a credible source of information for diagnostic purposes by medical staff and nursing staff and gave examples of situations in which serving this function was helpful in achieving a good outcome for their parent. For those participants already known to staff, the quality of the relationship (particularly with regard to the extent of mutual trust) was a significant factor in the extent to which participants’ objectives (as listed below) were achieved.

- To dispense with perfunctory and basic information and obtain detailed information
- To be regarded as a credible source of information for diagnostic and confirmatory purposes (i.e. to add weight to their parent’s assertions)
- To gain staff support
Participants’ experiences regarding the degree of success they achieved with regard to the above objectives are presented below.

5.2.2.1.1 Dispensing with perfunctory information to obtain detailed information

Participants usually found that unless their RN status became known to staff, the level of information they received was very basic and at times perfunctory. Sometimes when staff began giving such information, participants thought it courteous to inform staff of their status to dispense with the need for staff to go to the trouble of providing it.

Polite to inform staff ... describing a complicated procedure. [Sophie]

Participants sometimes found it useful to disclose their status when they made telephone enquiries about their parent in order to dispel barriers and encourage staff to provide more detailed and technical information than is usually provided to lay relatives.

With phone enquiries ... easier for staff to provide information. [Ryan]

So they could give me more details than a layman. [Sam]

Kate chose not to disclose her RN status when her father was in the intensive care unit but she did disclose whenever she wanted detailed answers. It was a no-win outcome when staff felt threatened but by telling them her father’s illness was outside her area of nursing expertise it sometimes defused their defensiveness (because Kate was no longer considered a threat) and it became a win-win outcome.

I stopped telling people I was a nurse and then people would explain things and you’d think yeah but I know there’s more to it than that and that’s when I’d say look, I’m a nurse ... And that would either go for or against me. Sometimes if I said something as a nurse, people would often feel threatened and that’s when it would go against me. So it was this awkward no-win situation and yet other times I could make it a win-win for me. And so I found it quite hard. ... I think I intimidate people.

Sometimes they'd go the extreme other way and I'd say ok – while I'm a nurse I actually work in mental health. So yes speak to me as you would a nurse who is not familiar with this. And then I'd get it. So I actually manipulated it so it
wouldn’t go against me and it would go for me. And it was a conscious manipulation.

So I learnt it fairly early that there were times to expose myself and times not to expose myself and times to balance it up with my saying I’m a mental health nurse. I learnt to use disclosure to suit me; not to suit them. It’s more like if you say I’m a nurse – I’m [an] intelligent person – don’t fob me, don’t white wash it, don’t make it too technical, give me the information on my understanding … then people were great they were fine after that. [Kate]

Claire communicated with hospital staff on a peer/colleague level to ensure that the level of detail provided by staff was commensurate with her level of knowledge and understanding.

The consultants, and the pain management guy, and the palliative care lady, a doctor, they started the conversation and very much then from what I was saying back, gauged how much I could take and then adapted what they would then tell me next to how I was answering them; what jargon I was using back to them and I think as they realised I could understand what they were saying then it became very much more, the sort of conversation you have with someone that you work with. And I didn’t have any trouble with that at all. [Claire]

Eva disclosed her RN status when staff explained procedures or results to her in lay terms because she wanted to be given more medically meaningful information.

When people are explaining procedures or results to you in layman terms, I find it better to tell them I’m an RN and that if they could explain what they found in a straightforward way I’ll tell them if there’s any terminology I don’t understand, otherwise a ‘pleural effusion’, has more meaning for me than ‘some fluid in the lungs’, which is more ambiguous. [Eva]

Zac was disappointed that staff were not telling his parents much. He chose not to disclose his RN status during the three initial visits. When he discovered staff were “not providing enough information” he “pulled out the big guns” and disclosed his RN status.

Participants almost always found that detailed information was readily provided by doctors as soon as they disclosed their RN status. This was not often the case with nursing staff.
Ben explained that he did disclose in some instances to communicate with medical/nursing staff on a peer level and thereby cut through “hospital speak” (that is, superficial information that most relatives are given when enquiring about their relative’s condition either via telephone or in person). This was to gain a more detailed and complete picture of the situation and treatment plan, prognosis and so on, and be able to inform fellow relatives not in the medical field. Ben believes that the more well-informed the RN relative, the greater their power to get action if necessary. He also believes that staff nurses need to feel something positive from RN-relatives. Ben found disclosure was helpful in that doctors are more forthcoming with information and that he was given positive acknowledgement and credibility as a fellow team member.

To be treated as a peer and therefore gain a more detailed/whole picture of the situation and treatment plan, prognosis etc and be able to inform fellow relatives NOT [sic] in the medical field.

My experience has been if you go in there like a bull at a gate people focus on your emotion rather than the content of your message; and I always think it doesn’t really matter how you get it across just get it across. Just side step, be nice, back up a little bit, move around but basically in the end get the message across and I felt like I was walking on egg-shells. [For] most admissions, I would buy a big box of chocolates for the staff on discharge and a little note acknowledging their care and commitment. I think staff need to feel something positive especially from family that are working in the field. Yes, look I’ll question you, I’ll rack your brains and I want to know everything but hey thank you and I appreciate it. [Ben]

Andrew said it was helpful when his younger RN-sister disclosed their RN status to the cardiac surgeon when they accompanied their mother to see him. The surgeon seemed to drop the formal airs, was more relaxed and opened up, and they were given a lot of detailed information including side effects. Before she disclosed their RN backgrounds, Andrew had been growing impatient because the surgeon had been explaining his mother’s cardiac condition and proposed surgery in very basic terms.

Oliver was very concerned about his father because the doctors were not able to offer a diagnosis and he lapsed into a coma and died soon after being admitted to hospital with a fever of unknown origin. Oliver feels that understanding and knowing what is
happening is better than not being informed. With his mother’s hospitalisation he had not been provided with adequate information. However, he was kept well informed during his father’s hospitalisation and he was very appreciative of that.

I feel that understanding and knowing what is happening is better than not being informed. Even if it is bad news – I’d rather know. Especially regarding my father, I was totally informed, shown all test results etc. This was good to know. I think it was easier for the doctors and nurses in that they did not have to explain everything; just show me. – AND [sic] when I asked a question the answer was very detailed. I am appreciative for that. [Oliver]

Madeline like many other participants found that doctors were particularly forthcoming with additional information. Participants were sometimes also privy to ‘insider’ information that would not normally be conveyed to relatives.

I was a first year registered nurse, so inexperienced and I was in retrospect quite immature, so I probably was privilege [sic] to more information than my non-medical siblings and I knew the outcome [mother dying of breast cancer]. At the end I was spoken to by the oncologist, which my father didn’t know about, it was only that I was at the hospital visiting. [Lara]

Olivia was also treated like a colleague, an insider, and was privileged to information and a style of communication that is not normally available to lay relatives. The staff confided in Olivia and her mother (unofficially) that they disagreed with the neurosurgeon’s recommendations to continue life support for her father and supported the family’s decision to discontinue life support.

They [RNs] took Mum aside separately and the doctors even did the same thing – took Mum aside separately – and said “off the record we disagree with the neuro-surgeon and completely agree with you, and we’ll turn him off while the neuro-surgeon’s away on the weekend.” I think we got more intimacy and probably a lot of flexibility ... and no-one questioned that we stayed. We stayed for 48 hours – the whole family, on the floor on each other’s knees – no-one questioned anything we did. I think we got some kind of privileged intimacy. They just gave everything they had to give. I think it was a given because of my history with a lot of those people. Thank Christ they liked me (laughter). [Olivia]

At times the complexity of the peer level information given to the participant by medical staff may have been beyond their level of knowledge. The gravity of the situation and
the emotional state of the participant at the time may have resulted in a reluctance to request further clarification, as may have been the case for Lara.

I knew the hospital staff as my mother was in a local hospital and at one stage about nine months before she died after having a bout of sepsicaemia and bony metastases, I spoke to the oncologist alone about quality and quantity of life. I knew all the terms but not really. (Lara)

5.2.2.1.2 To be regarded as a credible source of information for health purposes

Lucy’s father relied on Lucy to communicate his problems to medical staff because of hearing and English language problems and because he was temporarily confused because of his illness. The admitting doctor was not willing to admit Lucy’s father until she presented a convincing case of the medical need to hospitalise him.

Participants also have RN-credibility when providing staff with information about their parent’s signs, symptoms, and situation, thereby adding weight to their parent’s complaints and assertions, which can result in their parent receiving more focussed care and reassurance, and prevent staff from being dismissive of their parent’s assertions. When Emma’s father told the doctor he felt as though he was about to die, Emma assured the attending doctor that this was to be taken seriously as her father would not say that lightly.

The medical officer was trying very hard to get a line in [my father] and his veins were not particularly good and Dad said “oh you know I really feel quite strange I feel like I'm going to die” and I can remember this medical Dr looking at me and I said if he’s saying that then there is something quite wrong believe me. I know my father well enough to know that he wouldn’t say that lightly and he just said “ok” and he turned around to my father and gave [him] a lot of reassurance. [Emma]

Participants had greater credibility and behaved as part of the health care team by providing diagnostically relevant information (particularly when their parent was too ill to do so) and they added weight to their parents’ assertions and confirmed or supplemented the history given by their parent. This was the case for Oliver who
provided information to doctors about his critically ill comatose father to assist the medical staff in diagnosing his mysterious life-threatening illness.

Sophie also noted that doctors treated her as a colleague in that they directed their communication to her rather than other members of the family because her nursing background facilitated the communication of medical information, and that Sophie’s family would also inform staff of Sophie’s RN status as it improved the way staff related to her relatives.

I was the one the doctors would speak to because they knew that I had a nursing background. Other family members would inform staff that I was an RN as they found that staff were able to relate in an easier way when describing complicated procedures. [Sophie]

Ben’s mother who has diabetes told him of an incident of ward staff not taking any notice of her when she told them they had made a mistake regarding her insulin medication. He followed it up and politely reinforced that his mother had been independently managing her diabetes successfully for many years and they needed to accept prima-facie that the information provided by her was credible.

[My mother] once had a problem, [staff] either omitted to give [insulin] to her or they'd given her the wrong insulin. But she realised something was wrong and she tried to tell them and it was “oh yes, oh yes, yeah, yeah” and then when the night staff came on she realised she was going beyond hyper and she alerted them. And the RN ... looks up the charts, realised there'd been an error. ... During that admission I actually sought out the nurse in charge of her that shift and had quite a chat. Not putting them on the spot, but just reinforcing that this is a lady that knows what she's doing so can you please work in with her ... she'll make your job a lot easier. I wasn't lecturing them, I was just letting them know that she's a feisty independent lady who's managed her diabetes for more years than you've probably been alive ... I wasn’t rude about it. [Ben]

Jane preferred to disclose her status because medical staff have a tendency to talk to lay relatives in a patronising way.

[Medical] staff have a tendency to ‘talk down’ to a patient’s relatives in many cases. [Jane]
5.2.2.1.3 To gain staff support: RN-relatives known and trusted versus not trusted and considered a threat

Some participants were recognised by staff RNs who were previously colleagues. If participants were liked and trusted by them they were treated like peers; staff RNs were very supportive and special assistance was offered.

During her father’s hospitalisation Emma was sometimes recognised by RNs. She found nursing staff to be very supportive and staff RNs who knew Emma, made offers of special assistance. In this type of situation, where RNs knew Emma and were dealing with her as a trusted fellow RN, it was an advantage to be recognised as a RN.

> No [I didn’t mind when staff recognised me] and often because my mother was with me she thought it was actually quite lovely "oh isn’t that lovely ... when did you know ..." so it broke up her time while we were sitting in there waiting for Dad while he was having this test and that test.

> People [staff] showed you a lot of support ... were quite respectful of privacy but they certainly said to me “look if there’s anything that we can do to help you or your parents please let us know” and things like that and they were in positions where they could have made differences if that’s what we wanted. I think it was good just knowing that you had a back up not that I ever accessed them in that way but I think if I’d been unsure about something then I could have gone to another source and found information from them. [Emma]

Olivia also described the support she and her family received from staff as “privileged intimacy”. Olivia would have chosen not to disclose her personal background; however this was not an option as she was known to staff. She was very thankful that she was well liked. Staff were extremely supportive and once the initial fear of her being there was over, and after an ice-breaking episode of black humour the staff especially wanted to look after her critically ill father and the staff became part of the loving family and treated Olivia with an increased level of privileged intimacy.

> So many of the registered nurses knew me so we got treated differently: more intimately, we got more information, we got involved in different ways... I remember when I worked with them – when they were students because I had a rapport with them – so this rapport just bubbled in.
It was so intimate and there was no misinterpretation. I could have picked up anything and people knew that I wasn’t picking up and correcting them or checking on them or marking them. By that stage we had established ourselves in our own relationships so they weren’t fearful of that. And I’m really serious – thank Christ they thought I was alright otherwise you know that would have been completely different.

In intensive care … we had a registered nurse who I’d known … and they’d watch me watching and it’s all a little bit too tense and we’re not a particularly tense family, although it’s a tense situation, and my response to it was – don’t worry about it – I don’t know anything about ventilators. And one of the things that my family use a lot is humour – and it got pretty black humour – and I think that helped. And the fact that my mum’s such a lovely warm woman, and my brother and sister are really great people … I think that helped as well. And after the first couple of days one of the registered nurses said – “people were really worried about you being here and because it was your dad” – well I bet they did – you know I could see that and then he said to me “yeah but now everyone fights about who’s going to do it.” So there was clearly a change. They brought food in for us because they knew that Mum was staying at the visitor’s quarters; they brought literature in for the probability of that kind of bleed and what to expect and everything. [Olivia]

Ten participants reported that their parent had proudly mentioned to hospital staff that their son or daughter was a RN (Appendix C, Table C3). It is possible that parents disclosed this information to staff so that they would be perceived to be on the same side as the staff and consequently be cared for as one of their own. William noted that because he was well known to staff and held an executive level nursing position at the hospital extra care may have been given. His mother also let staff know of his RN status.

... local hospital already knew so (possibly) extra care given. At [name of hospital] … knew staff there which helped with extra care. At the local hospital here I’m sure I did [receive extra care] because I was at that stage the Deputy Director of Nursing here so I think yes they were pretty careful. I felt: good! That’s the way it should be. It should be like that for everyone. It shouldn’t make any difference that I work here and I am who I am; but it certainly does help because people tended to jump a bit. And some of the staff used to work here part time so I knew them as well. So yes, that certainly had an advantage.

[My mother] certainly told people that I was a registered nurse. I had friends still there as a registered nurse and they made sure that everything was alright. They even suggested moves to different wards. [William]
Madeline had previously worked at the hospital where her father was hospitalised and she thought she would be better supported by the nursing staff (thinking caring nurses would stick together in times of crisis). Her close RN friends did provide that kind of support but other nursing staff members were “standoffish and passive aggressive” towards her and would leave the nursing care to her and the family. Madeline found the doctors gave more information to her and were very supportive.

Five participants (Amelia, Gail, Kate, Oliver and Rachel) had been working at the same hospital for some of their parent’s hospitalisations. For these participants non-disclosure was not an option because they were known to staff (Appendix C, Table C2). Two participants (Rachel and Oliver) felt it was a disadvantage and mentioned it made their situation more difficult and alienating.

Rachel was working at the same hospital for most of her mother’s hospitalisations and was well known. She mentioned the staff did not involve her in her dying mother’s care and did not connect with her as a patient’s relative. Medical politics was thought to be a factor, and the nursing staff may have felt intimidated by Rachel’s expectations. She found it a lonely experience as no one treated her as the daughter of a dying mother.

I worked at the hospital in which my mother was managed so everyone knew. The experience was very traumatic - I felt like I had no say in what happened - in fact that I was caught up in medical politics ... I think I would have been none the wiser to many things but because I was a RN I had expectations of people and I think this frightened people. The fact that my mother had breast cancer and was going to die did not help – perhaps they felt helpless but there was a barrier – no one connected with me as a daughter/relative. [Rachel]

In Oliver’s case, there were many episodes reflecting an adversarial relationship with the hospital staff: the nurse unit manager (NUM) at the hospital responded with annoyance when Oliver gave up work to look after his mother which left her ward short-staffed; when Oliver witnessed substandard care, became more vigilant and began challenging the RNs and giving them feedback if he detected mistakes or substandard care; and when Oliver asked a RN to explain to his mother the therapeutic purpose of the medications she was asking his mother to ingest:
One nurse even had the audacity to say to me: “well you should know!”

[The NUM] got annoyed because I gave up [name of hospital] to look after mum... “We need the staff” - like that. I said go to hell.

One of the RNs was petrified of me. A couple of times I said to some of them forget I’m here, and forget who [I am]... they found out who I was ... what I was doing ... just do your work. I think one of them kept looking over her shoulder saying; am I doing this right. But ... if I wasn’t there, it wasn’t done.

I used to keep calm, I was always very polite ... I never lost my temper. They used to say I was the polite one ... but I used to be forceful. Mum was in hospital for about three or four weeks. And I was there all the time. I think the hospital hated me actually. [Oliver]

The RNs did not like Oliver coming in early and at irregular times. They thought he was checking up on them, which he admits he was forced to do for his mother’s sake.

The cruelty of nursing staff resulted in Oliver lodging an official complaint which was poorly dealt with and lacked a positive outcome. After about a week ... I started to come in irregular times. I don’t think they liked me coming in about 11 o’clock because they used to think I was checking up on them. And I said perhaps I am. [Oliver]

Working at the same hospital meant that Oliver had information about the hospital’s standards and practices, and could use his insider knowledge to critique the nursing care that was given in an attempt to get the staff to improve the care they were providing to his mother and other patients in the ward.

I have lost a lot of respect for [name of hospital]. It made me feel disgusted because I used to think what’s wrong with the hospital ... see I worked at the hospital and everyone there was supposed to be considered the top range of nurse... and [they were] so picky and so pedantic about who they picked for nursing ... and I said to them ... for a hospital that's supposed to be of this standard you perceive yourself to be, to run the ward like this, it's disgraceful ... and I said not just my mother; it's the other people too. I was really disgusted. I said there's better care at lesser hospitals. And I hit that back to them; and I said I know ... because I work here remember ... [Oliver]

Oliver found the experience of his mother’s hospitalisation extremely upsetting and he lost respect for the hospital. What was of greatest concern was that doctors and nurses held back information (that his mother was diagnosed with lymphoma) when he knew
there was more information available. There was antagonism between Oliver and the RNs. He was angry they withheld important information regarding his mother’s diagnosis. After she died he felt guilty because he had been pushing her to regain her mobility and if he had known of her diagnosis he would have focussed on palliative care.

_They didn’t want to tell me anything. I went to the hospital and said look this is still not right, I said, for god sake give me the reports. And then the doctors said she’s got non-Hodgkinson’s lymphoma … eight days before she died. They were scared of me. At one stage I said could I see the documentation please and they gave it – they didn’t want to give it to me, I said I think you better._ [Oliver]

It was evident from Rachel and Oliver’s experiences that they did not have a trusting relationship with hospital staff and staff felt threatened by them. As a result they were not well supported by the staff.

5.2.2.2 Disclosing to get action

When problems arose, participants felt the need to advise staff of their RN status in order to gain added power to intervene in a way that was as influential as possible and resulted in getting their parent the care and attention they needed. The circumstances that required participants to divulge their status to get action included:

- To place the parent in the RN-son’s care to attend a family wedding
- To train the nursing staff in the use of a syringe driver to administer medication to a parent
- To address instances of incorrect and neglectful nursing care of a parent
- To justify the parent’s admission to hospital
- To ensure priority treatment was given in an emergency situation
- To correct errors in medical treatment
- To arrange urgently needed pain relief for a dying parent.
5.2.2.2.1 To place the parent in his RN-son’s care to attend a family wedding

Cameron disclosed his RN status to demonstrate he was qualified to administer his father’s IV medications so that his father could gain permission to leave the hospital to attend his youngest son’s wedding. The strategy proved unsuccessful due to hospital protocols (despite Cameron arguing the case progressively with more and more senior members of the nursing hierarchy and medical staff). However, his father walked out with Cameron and attended the wedding anyway despite missing his IV antibiotics.

My father wanted to attend the wedding of his youngest son and needed a day pass. This was refused because he would most likely miss his 1800 & 2200 IV antibiotics. I stated I was an RN and could administer these medications.

[Cameron]

5.2.2.2.2 To train the nursing staff to use the syringe driver

Claire revealed her RN expertise when the staff did not know how to work the syringe driver to administer medication to her father because she did not want her father to be deprived of timely medication. Unfortunately this move did not result in building up a collegial relationship with those RNs – they avoided Claire thereafter.

There were a couple [of staff RNs] that didn’t know how to work the syringe driver. So [after they asked me] I actually showed them so I thought great, I’m with colleagues here ... now I’ve built up a bit of a relationship with these two, so they’re going to help me out for the rest of the shift no doubt and whenever they’re on ... but ... it didn’t work. They avoided me like the plague and I think it was ‘cause they were embarrassed they didn’t know what to do ... and I thought, well Jesus you know that’s no good, maybe I should have played dumb but then [my father] wouldn’t have got [the medication]. [Claire]

5.2.2.2.3 To address incorrect and neglectful nursing care

Sarah did not wish to disclose her RN status as she had noticed that staff tend to act differently and it makes it uncomfortable for them if they know you are a RN, but in her mother’s case Sarah felt she needed to let them know so her mother would not be left in an undignified way. When nursing staff were aware of Sarah’s RN status they referred her mother to the stomal therapist who ordered appropriate bags that did not leak and
her mother’s legs were always elevated. Prior to knowing that Sarah was a RN staff had erroneously told her aunt that it was normal for stoma bags to leak.

As Mum was dying from cancer it was horrible. She went in for a palliative ileostomy and I wanted her home as soon as possible. After surgery care was ordinary and staff at one stage even taped the bag on with Elastoplast. Every lunch time and tea-time I would arrive and her legs would be dangling in a recliner and her bag would have leaked all over her. I would change her and clean her up and elevate her legs that were very swollen. After 2 days of this it was time to let staff know.

They even referred Mum to the stomal therapist. She ordered appropriate bags that didn’t leak and Mum’s legs were always elevated. Until they found out that I was an RN the staff had told my aunty that it was normal for stoma bags to leak. [Sarah]

Max did not normally disclose his RN status to staff as he believed it was not his place or necessary to highlight his past nursing experience except when he had doubts and or misgivings regarding treatment, medication or surroundings. Staff detected Max’s RN status when he expressed informed views about his father’s general care or highlighted some shortcomings.

When I had doubts or misgivings regarding patient treatment [Max] Emma found there was only one RN who was unsupportive and did not respond to her mother’s questions and need for support when her father was first admitted to the CCU, so Emma took her aside divulged her RN status and stressed the need for support – she thought it was the only way to get action.

5.2.2.2.4 To justify the parent’s admission to hospital
Lucy recounted an incident involving a medical registrar who was not convinced of the medical need to hospitalise her father and accused Lucy of “granny-dumping”. Lucy responded by divulging her status and then presented information which justified the need for her father to be hospitalised and thereby achieved the desired outcome.

... frustrated with the pre-judgement of the registrar for the need for hospitalisation [Lucy]
5.2.2.2.5 To ensure priority treatment in an emergency situation

Ben immediately disclosed his RN status to the Triage RN when his mother had fractured her femur and was waiting in the Accident and Emergency room to be treated. He did this because he noticed that staff were particularly busy and he did not want her to be forgotten or her treatment to be delayed. He then sat with his mother as a physical reminder to staff to try to expedite her treatment.

_Gail disclosed her RN status to the casualty desk clerk in an emergency situation due to their non-caring behaviour and inattention to Gail’s mother who needed immediate attention for her dislocated finger._ [Gail]

5.2.2.2.6 To correct errors in medical treatment

When Rachel’s mother was taken to hospital as an emergency case because of pathological fractures of her femur and humerus, Rachel encountered poor medical management by a junior doctor and as a result questioned and challenged his actions. This led to the doctor asking whether she was medically qualified.

_Things were SO [sic] bad I had to challenge/question junior MO’s management of my mother so had to disclose when asked a direct question... What are you a doctor or something? [Rachel]_

5.2.2.2.7 To arrange urgently needed pain relief
Chapter Five                      Findings (Part Two)

Emma divulged her status to the triage nurse on one occasion to ensure her father was prioritised appropriately despite her parents’ low-key altruistic behaviour (they were prepared to wait until other patients were seen first) which did not reflect the urgency of her father’s condition.

A big multi-trauma ... had come in and both my parents were saying “it’s ok just put us in a chair we’ll wait” ... and I said to the triage RN look I’m a registered nurse my father’s deteriorated in the last hour and a half he’s got slurred speech he’s got double vision blah blah blah he’s been conservatively managed and gave her the run down very quickly because I had this huge fear that something was going to happen with him just sitting in the seat and she was really good he got prioritised and got everything happening very quick smart ... whereas Mum and Dad were [saying] “we'll just wait because there are sicker people than your father”. It was quite bizarre really because they should have known better. [Emma’s father is a specialist doctor and her mother a retired RN]. [Emma]

Claire’s father who had end-stage cancer of the lung, wished to maintain his dignity, was frightened of dying but had made an informed choice to stop all life saving treatments. Claire disclosed her RN status when she needed to get things done for her dying father because the staff had dismissed him as ‘about to die’ and as a result his pressure area care and nutrition were neglected, and sedation and analgesia were insufficient. Claire’s most harrowing experience was arguing with junior medical and nursing staff for increased pain relief 12 hours prior to her father’s death. She was very frustrated knowing that her father was in so much pain he was begging her to give him something to kill him, but the staff kept saying they did not want to compromise his breathing, and Claire knew she could have educated them to facilitate quicker/efficient pain relief and sedation if she had been in charge of the ward. Claire had to go over their heads and rang the consulting physician to get her father adequate pain relief/sedation to have a peaceful death.

They kept saying “we don’t want to compromise his breathing.” They had to be kidding! The guy wanted to die of respiratory depression! I had to go over their heads ... I rang the consulting physician – good result no more pain for Dad! [Claire]
Eva experienced similar problems to Claire in relation to pain relief for her father and because she had worked at that hospital she felt she could be more assertive and hunted down the necessary medical and nursing staff to relieve her father’s pain.

Dad was in the hospital where I trained, so the environment was very familiar to me. Being an RN meant that I felt more assertive in being involved in my father’s care. His pain relief became an issue. He was receiving conflicting management strategies concerning his pain relief depending on who was there to administer it at the time. I felt it wasn’t good enough. I hunted down the NUM and paged the oncology registrar myself and managed to get my father’s pain relief sorted out satisfactorily. [Eva]

5.3 SUMMARY OF FINDINGS (PART TWO)

The phenomenon of being in the middle encompassed the category of disclosure of RN status, which comprised two subcategories: preferring to remain undisclosed and disclosing to activate RN power and credibility. This chapter reported the findings in relation to the category of disclosure of RN status and its associated sub-categories and themes.

5.3.1 Summary findings: preferring to remain undisclosed (disclosure unnecessary and rather be treated as a lay son/daughter)

Almost all participants preferred not to disclose their RN status to hospital staff for two types of reasons: either because it was not necessary in relation to their parent’s care or because they believed that lay relatives and their hospitalised parents receive better treatment, and that staff are more forgiving and sympathetic to lay relatives. Participants did not believe that disclosing their RN status would improve their parent’s care that disclosing could come across as big-noting themselves or it could imply that the staff had better watch out because participants would be watching them. They also believed it was not their place to interfere with the work of the hospital staff and recognised that they did not have the right to control the care given to their parent.
Identifying as a lay relative was believed preferable (to identifying themselves as a RN) to prevent staff from being fearful, threatened and defensive, hesitant and uncomfortable. Participants also thought that if their RN status was known to staff their comments and actions would not be viewed objectively or could be misinterpreted as criticism if they disclosed; that staff would communicate less and give their parent less care; and that they might be called on to assist with aspects of their parent’s personal hygiene (which they felt from a child’s perspective intruded in a particularly uncomfortable and inappropriate way on their parent’s privacy). Participants yearned to be treated as a lay son/daughter because being treated as a nurse often tended to make it a lonely unsupported experience.

One participant (Andrew) theorised that some nurses lack self confidence in their ability to provide good nursing care and that this is the reason they withhold information and display avoidance behaviours. This may explain why ICU and CCU nurses were comfortable interacting with RN-relatives (due to their high level of technical expertise).

5.3.2 Summary findings: disclosing to activate RN power and credibility (to be treated as a peer/colleague and to get action).

Most participants found it necessary to disclose their RN status to medical and/or nursing staff in an effort to be treated as a peer/colleague to achieve three types of objectives: to dispense with perfunctory and basic information in favour of obtaining detailed information about their parent’s condition; to be regarded as a credible source of information for diagnostic and confirmatory purposes (to add weight to their parent’s assertions); and to gain support.

Some participants were known to staff (because they worked at the hospital in which their parent was hospitalised or had previously worked with them elsewhere) and in some cases this affected the level of support they received from staff. Participants who had a relationship of mutual trust with staff tended to be well supported, and those who did not found the experience to be alienating and confrontational.
The strategy of disclosing RN status to be treated as a peer/colleague by hospital staff worked with the medical staff who responded by providing very detailed information, however disclosing their RN status to the nursing staff mostly resulted in the opposite effect – they tended to withhold information from participants (CCU and ICU staff were exceptions).

When nursing staff knew of participants’ RN status it lowered the care of the patient, in that most nursing staff provided less information (because it was either assumed they knew or because staff RNs felt threatened) avoided the participant and their relative, took short-cuts and expected participants to fill in the gaps. Disclosure could be used by participants to suit the circumstances of the situation and nursing staff’s defensiveness and level of perceived threat could sometimes be dispelled by participants admitting they did not have expertise in the particular area of their parent’s medical problem.

Participants also found it necessary to disclose their RN status to get staff to take action in crisis situations or to achieve a high priority outcome for their parent. By disclosing their status they were identified as a credible health professional which maximised their personal power in trying to get action to achieve the following outcomes: for the parent to be placed in the RN-son’s care (to administer intravenous antibiotics) so that he could attend a family wedding; to train the nursing staff in the use of a syringe driver to administer medication promptly to alleviate the suffering of a dying parent; to remedy instances of incorrect and neglectful nursing care of a parent; to justify the need for a parent’s admission to hospital; to ensure priority treatment was given in an emergency situation; to correct errors in medical treatment; and to arrange urgently needed pain relief for a dying parent.
5.4 CONCLUSION

In conclusion, by disclosing their RN status participants identified themselves as a registered nurse to hospital staff. In preferring not to disclose their RN status, participants had signaled they wanted to identify themselves as a son or daughter, even though this objective was seldom achieved. The boundaries between their RN identity and their identity as a family member were no longer distinct when they disclosed their RN status in response to crisis situations and used their personal power to override normal system structures to alleviate their parent’s pain and suffering.

The next chapter (Chapter Six) contains the findings in relation to the final two categories of the phenomenon of being in the middle: the RN on standby (being expertly vigilant) category which encompassed four themes: leading and staying strong at any cost; expertly observing, detecting and protecting; being adept at hospital language; and keeping it real; and the RN in action (imperative to intervene) category which encompassed two themes: filling in the gaps and fixing.
CHAPTER SIX

FINDINGS (PART THREE) BEING IN THE MIDDLE: RN ON STANDBY (BEING EXPERTLY VIGILANT) & RN IN ACTION (IMPERATIVE TO INTERVENE)

6.1 INTRODUCTION

The previous two chapters presented an overview of the phenomenon of being in the middle and provided a summary of the categories, sub-categories and themes within this phenomenon. Three categories were identified: disclosure of RN status; RN on standby (being expertly vigilant) and RN in action (imperative to intervene). Chapter Four provided a profile of participants and their parents and reported the findings regarding participants’ perceptions of being in the middle as a result of having a dual identity and role. Participants described their dual role in terms of role confusion and identity conflict between being a RN and being an offspring to the parent. They revealed a yearning to just be a son or daughter, whilst realising this was not an option, nor was it the better option in terms of achieving better outcomes in relation to their parent’s care.

Participants privately experienced the emotions related to being the child of the parent but to all appearances their RN persona projected emotional control during challenging situations and this often led to a lack of support from family (who perceived them as unfeeling and uncaring) and staff (who perceived them to be coping) and produced a high level of strain which in some cases eventually led to participants falling apart emotionally when the crisis was over. Participants needed an avenue of emotional release during the crisis but found that they were often so busy being the nurse that there was no down time to be the offspring.

The profile of participants showed the sample was evenly divided between sons and daughters of similar age and educational qualifications. The profile of the parents revealed that they were mostly in their sixties and seventies, and that almost all mothers had been hospitalised on more than one occasion whereas about a third of the fathers had only one hospitalisation. Most hospitalisations had occurred within the last five
years and the duration of the hospitalisations tended to be longer for mothers than fathers. Medical diagnoses were available for most parents and showed that they were not generally cognitively impaired, that their hospitalisations were mostly due to cancer or cardiovascular disease, that two-thirds of the parents were critically or terminally ill, and that three-quarters of these died either during or after their hospitalisation.

Chapter Five presented the findings in relation to the category of disclosure of RN status, which encompassed two subcategories: preferring to remain undisclosed (which contained the themes: disclosure unnecessary and rather be treated as a lay son/daughter) and disclosing to activate RN power and credibility (which contained the themes: to be treated as a peer/colleague and to get action). The phenomenon of being in the middle is exemplified by the plight of the participants in this study who have a dual identity. They were faced with a dilemma in relation to the issue of disclosure. In preferring not to disclose their RN status participants were thereby identifying themselves as a son or daughter to hospital staff. In disclosing their RN status participants were thereby identifying themselves as a registered nurse to hospital staff.

This chapter contains the findings in relation to the final two categories of the phenomenon of being in the middle: RN on standby (being expertly vigilant) which encompassed four themes: leading and staying strong at any cost; expertly observing, detecting and protecting; being adept at hospital language; and keeping it real; and the RN in action (imperative to intervene) category which encompassed two themes: filling in the gaps and fixing. An overview of these two categories, including their subcategories and themes is presented in tabular form below.
Table 6.1

Phenomenon of Being in the Middle: RN on standby (being expertly vigilant) and RN in action (imperative to intervene) Categories and Themes

<table>
<thead>
<tr>
<th>Categories of Being in the Middle</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>RN on standby (being expertly vigilant)</td>
<td>i) Leading and staying strong at any cost</td>
</tr>
<tr>
<td></td>
<td>ii) Expertly observing, detecting and protecting</td>
</tr>
<tr>
<td></td>
<td>iii) Being adept at hospital language</td>
</tr>
<tr>
<td></td>
<td>iv) Keeping it real</td>
</tr>
<tr>
<td>RN in action (imperative to intervene)</td>
<td>i) Filling in the gaps</td>
</tr>
<tr>
<td></td>
<td>ii) Fixing</td>
</tr>
</tbody>
</table>

6.2 RN ON STANDBY (BEING EXPERTLY VIGILANT)

Throughout participants’ experience of being in the middle, RN on standby (being expertly vigilant) was their baseline role. This baseline role entailed playing a leadership role and staying strong for the family’s benefit (leading and staying strong at any cost) which involved putting their emotions on hold while being in the middle. Being expertly vigilant while on standby included communicating with hospital staff on behalf of the family and interpreting medical information and jargon for the family (being adept at hospital language); providing reality grounding by correcting misconceptions that family members might have about the parent’s condition and prognosis (keeping it real) and maintaining a strong presence to protect the parent by closely observing the care they received, detecting changes in their condition and deficiencies in their care (expertly observing, detecting and protecting).
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The findings in relation to the four themes of RN on standby (being expertly vigilant) are described below: leading and staying strong at any cost; expertly observing, detecting and protecting; being adept at hospital language; and keeping it real.

6.2.1 Leading and staying strong at any cost

Participants usually played the most active role in their parent’s hospitalisation and maintained contact and a strong presence, even though most participants had siblings and most parents had a spouse at the time of their hospitalisation. In some instances their RN-siblings played the leading role particularly if they were older and lived closer to the parent, and for a minority of participants, their lay siblings played the leading role if they were not employed and had more time or if they lived closer to the parent. Participants reported the importance of being present at the hospital for the parent (sometimes for extended periods for critically ill parents). Telephone contact with staff was of secondary importance and it was not a good substitute for being there for the parent and making a first-hand assessment of their parent’s condition.

Participants in standby mode played a leadership role and stayed strong for the family until the parent recovered or the crisis was over. They often juggled their personal responsibilities to achieve this, and it came at significant personal cost. They suffered emotionally through their efforts to shield and protect the family from unnecessary worry and to provide ongoing reassurance and support. The impact of handling life and death situations and decision-making was especially burdensome and left a lasting impact emotionally and psychologically - in some instances still deeply felt many years after the event and included feelings of regret, guilt and inadequacy (these feelings were compounded when family members attributed blame to the participant). Participants also suffered spill-over into their professional nursing role. To some participants it served as a constant reminder of their parent’s hospitalisation and it evoked painful memories. Some participants (Eva and Lara) mentioned that their empathic skills with their patients were enhanced as a result of their traumatic experiences.
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The findings in relation to the theme leading and staying strong at any cost are presented according to the following aspects:

- Playing a leadership role
- Participants who did not play the most active role
- Siblings, seniority and playing the leading role
- Family members with nursing or medical training
- Contact with the parent and staff during hospitalisation.
- Busy being the strong one and making sure all others are okay
- Shielding the parent and family from worry
- Privately shouldering a lack of hope, hunches about diagnosis/poor prognosis, and worries about risk of complications and care inadequacies
- Playing the leadership role in life and death situations and decisions
- The aftermath of the crisis: personal and professional repercussions

6.2.1.1 Playing a leadership role

A majority (23 out of 31) of the participants reported they played the most active role (on all or most occasions) concerning their parent’s hospitalisation (Appendix C, Table C2). In five of these cases the hospitalisation of both parents was involved, and hence participants who played the most active role for their parent’s hospitalisations related to a total of 28 sick parents. Although participants mentioned the existence of a spouse in 27 of the 41 parent cases, the spouse seldom (in only three cases) played the most active role. There were five cases of widowed/divorced parents. The remaining nine cases (who were questionnaire participants) did not mention whether the sick parent had a spouse (eight of these participants did not mention any siblings either). In all nine cases the participant usually played the most active role.

In three cases (Cameron, Emma and Olivia) where the participant played the most active role, the spouse (mother) deferred the decision-making to the participant. Emma’s father had repeated hospitalisations over a period of months which exhausted her mother to the point where she asked Emma to play the leading role.
Initially I always tended to hang back. I thought it was my mother’s role initially if she wanted something done or wanted to ask a question but by the time we got to the fourth admission my mother was very, very tired and my father had deteriorated and she had gone past the point of wanting to intervene and she actually asked me to be the one that asked questions and made sure that Dad was ok because I think she was so emotionally wrung out. [Emma]

In Oliver’s case, the spouse (his father) was a fit 83 year old and although he did not play the most active role he did provide assistance and support to Oliver. Oliver (a bachelor) who lived at home and had stopped working to look after his sick mother explained that decision-making was a collaborative process involving both parents.

In Olivia’s family males make the decisions, so this was a significant departure. Olivia had been called on to give advice to family members about health matters previously. She had been very comfortable in playing this type of caring and useful role, and it made sense as she was the one with the “power and language”, but this time it was a very significant leadership role with life and death decision-making.

No ordinarily [I’m] not [the decision-maker for the family] ... Mum's of the ilk that males make decisions ... there'd been one kind of significant incident with my Mum's dad who really just had a urinary tract infection – but apart from that – no ... I mean this was a leadership role.

Because of Dad's odd bleed they did neuro-surgery and they really didn’t expect him to actually survive. We had a neuro-surgeon who was very enthusiastic about on-going treatment ... and by about the Wednesday it was really clear he started showing signs of being quite decerebrate ... and then we needed to change our focus. And we fought the neuro-surgeon to get him to not put a trachie in – to get him turned off. [Olivia]

Fourteen of the 23 participants who reported they played the most active role had one or more siblings: eight participants had one sibling (either a younger brother or sister or an older brother) and the remaining six participants had more than one sibling. Having a sibling did not necessarily result in any sharing of the role, as was the case for Oliver, who lived with his parents, and reported that he had an elder brother (by ten years) who lived about an hour away. Claire also mentioned a younger brother (described as being very squeamish) who relied totally on her expertise.
No I was their only carer. I’ve got my brother and he’s totally useless. My brother never came anywhere near [our parents]. My brother said ... “we’ll be in touch” and he hardly ever saw us ... the usual. He’d never phone up or anything. He believed that once you reached 60 or something you should be in a nursing home. [Oliver]

I have one brother and he’s very squeamish. He’s always taken what I’ve said as gospel. [Claire]

Two participants (Ryan and William) explained that the spouse’s involvement was not possible because the spouse became critically ill and was hospitalised at the same time as the other parent. Ryan had two RN-siblings to assist his parents, whereas there was no sibling available to assist William as his younger brother lived interstate.

The most significant thing was having both parents seriously ill together. Mother with chest pain admitted to hospital for further investigation and found arterial occlusion for angioplasty. Father was admitted to hospital and diagnosed with Ca secondaries of the liver. Devastating. Thought I would lose both parents at once. [William]

The family context for Emma and Andrew was that Emma was the eldest of six children, and usually played a leadership role in family matters which she ascribed to being the eldest child. Having a younger brother who is a paediatric surgeon did not affect her leadership role in relation to her father’s hospitalisations mostly because of Emma’s very close relationship with her parents and being the eldest child and possibly to some extent because he was interstate at the time. Andrew is the youngest of five children which includes two RN-sisters. His eldest RN-sister had usually played the most influential role, but because he happened to be the only sibling at the hospital when his mother had a cardiac arrest and died, he found himself in a leadership role.

My mother died. They weren’t able to bring her back, so I had to go and ring all the family and tell the news. I was totally alone [at the hospital when she died] and trying to be so brave. [Andrew]

Seven participants reported that they usually played the most active role (Appendix C, Table C2) but that on a minority of occasions the most active role was played by other family members (such as the parent’s spouse together with a younger EN sister in Eliza’s case, or in Ben’s case, an elder brother). Four of these seven participants
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reported that others had played a more active role than themselves on a minority of occasions but they did not specify who the others were.

Due to my living a good distance away, a brother (eldest) was in a position to play this role [on a minority of occasions]. [Ben]
Cameron who has seven brothers and sisters usually played the most active role, and mentioned that his mother deferred decision-making to him and usually expected him to “fix things”. His father suffered a cardiac arrest in hospital, and when asked by medical staff whether Cameron wanted his father resuscitated, he abided by his father’s wishes and advised the medical staff not to attempt resuscitation. Cameron expressed regret and felt he was blamed by the family when his father died, and concluded that a more consultative approach involving other family members in decision-making would have been best.

Most of the time ... that role that I play ... and had played it’s been ... quite useful and I’ve... liked it as well ... but with something as serious as that ... I’ve been [thinking]... should [my father] even be transferred to Sydney, to investigate the treatment? Or should he have treatment? I guess my advice would be ... don’t take on that role but let this be a collaborative decision for the whole family that yes, I can convey some knowledge about the situation but that’s not my decision. [Cameron]

Sometimes there were negative repercussions and conflict within the family as a result of the RN-sibling playing the leading role. Lara and Madeline’s sisters were resentful because the parent favoured the RN-offspring’s expert caring skills; Oliver’s brother blamed him for not detecting warning signs of their father’s fatal illness earlier than he did; and Kate’s mother criticised her as heartless and stupid and blamed Kate for her father’s heart attack. As a result of ongoing conflict Kate stopped talking to her parents for four years.

6.2.1.2 Participants who did not play the most active role
Eight of the 31 participants said they did not play the most active role (Appendix C, Table C2). Eva, Lara and Sophie mentioned that their parent’s spouse played the most active role and the other five participants [Jack, Gail, Patrick, Ryan, and Zac] mentioned
that a sibling played the most active role. Three of these cases involved RN-siblings: an older RN-sister in Gail’s case; a younger RN-brother who lived closer to their parents in Ryan’s case, and two RN-sisters (one younger and one older) in Jack’s case.

My older sister who is also a registered nurse tended to orchestrate my parents’ hospitalisations. [Gail]

My younger brother is a RN, he lives in Sydney where my parents live. I live in [a country town five hours away]. I often discussed my parents’ hospitalisation with him, rather than staff. [Ryan]

The circumstances of the other two participants (Patrick and Zac) whose siblings played the most active role, were that Zac’s younger sister (not a RN) was not working and had more time to spend with their hospitalised father. In Patrick’s case, he lived interstate whereas the two siblings who played a more active role lived locally, and his sister’s higher status within the family was also a factor.

Sister and brother were more proximal. Sister holds higher status in family. [Patrick]

Of the 26 (known cases) of parents with spouses at the time of their hospitalisation, only three participants (Eva, Lara and Sophie) reported that spouses played the most active role, and a fourth spouse (Kate’s mother) did this on a minority of occasions (aided by Kate’s younger sister). Participants explained the reasons for this. Lara explained that she was being shielded by her father because she was quite young, had just qualified as a RN and her mother was dying of breast cancer secondaries.

I was a first year registered nurse, so inexperienced and I was in retrospect quite immature. [My father] was trying to shield us. I don’t think he knew what to do. [Lara]

Eva and Sophie explained that the spouse (who was the parent’s second wife) and not the participant’s mother did depend heavily on the participant for emotional support, and in Sophie’s case for guidance regarding medical knowledge when her father’s wife could not accept that he was dying and that he was beyond treatment. In those instances where the parent had re-married, the next of kin was their current spouse but they still consulted the RN-daughter for advice.
My stepfather is next of kin so he was always the one to be consulted first and then he would discuss Mum’s condition with the siblings but would always ask my advice. [Sophie]

Sophie was the second eldest, with a sister and three brothers (one of whom was the eldest child). She always played a leadership role within the family. She did so willingly, and explained that she was the family member best suited for that role.

... for everything. I’m the bossy one. I’m not pushed into it. I’m quite happy to be in that role. My sister is 12 years younger than me and my older brother is a very quiet person that really wouldn’t cope very well to be given all of that information and then be expected to pass it on to all the family. He’s not that sort of person who could do that. [Sophie]

In Eva’s case her father’s wife (not Eva’s mother) played the most active role but relied on Eva to trouble-shoot (for example in relation to her father’s pain relief) when necessary.

My father’s wife, (not my mother) who supported him emotionally, and was at the hospital all day every day [had the most active role]. The rest of us work and would visit intermittently, not always daily [Eva].

6.2.1.3 Siblings, seniority and playing the leading role

Emma, who was the first participant interviewed, indicated that being the eldest child was an important factor in relation to taking a leading role in her parent’s hospitalisation. As a result, all participants who were subsequently interviewed were asked whether they usually played a leadership role within the family, whether they had siblings, their age in relation to other siblings, and whether other members of the family were RNs or had medical training. As the mailed questionnaire was completed nine months prior, and questions regarding siblings had not been included, this information is not available for ten of the 31 participants.

Fundamentally that comes about because I’m the eldest of six. I’m the only nurse. There is a medical doctor but he was not in the state at the time when things first happened. I’m also very close to both my father and my mother and because this was an experience for my father, my mother needed a lot of support so for those reasons I got pulled in and was the main support for both of them. [Emma]
Twenty one (67%) participants reported that they had siblings (Appendix C, Table C2). All 14 of the interviewed participants reported that they did have siblings, and a further seven participants had mentioned siblings in their responses within the questionnaire. None of the participants mentioned that they were an only child, although it is possible that this may have been the case for any of the ten participants who did not mention siblings in their questionnaire responses.

6.2.1.4 Family members with nursing or medical training

Eight participants mentioned that other family members had nursing or medical training (Appendix C, Table C2). Eliza mentioned that her sister was an Enrolled Nurse (EN); Ryan’s brother was a RN, his sister a psychologist/RN and his hospitalised mother was a retired RN; William mentioned a RN sister-in-law; Sophie mentioned a RN-aunt; Gail an older RN-sister; Jack spoke of having four RN-sisters; Andrew mentioned two older RN-sisters and that his hospitalised mother had been a RN; and Emma spoke of a paediatric surgeon brother, a retired RN-mother and that the hospitalised father was a retired doctor. In four families (Andrew, Emma, Jack and Ryan) there were two or more family members with nursing or medical expertise. Three participants also mentioned that their RN-relative (who was older in Gail’s and Jack’s case) and/or lived closer (in Ryan’s case) had played a more active role in their parent’s hospitalisation for at least some of the time, and Eliza reported that her EN sister had a more active role on a minority of occasions. The other four participants (Andrew, Emma, Sophie and William) played a more active role in their parent’s hospitalisation than the other members of their family with nursing or medical training for the reasons given above (being the eldest or best suited for the role, and being the only RN available at the time).

6.2.1.5 Contact with the parent and staff during hospitalisation

6.2.1.5.1 Contact with the parent

Typically participants had face-to-face contact with their parent (93% n=29) either during all their hospitalisations (73% n=23) or if not, for some of their hospitalisations (20% n=6). In those cases where the participant did not visit the parent during some or
in rare cases for any (7% \( n=2 \)) of their hospitalisations, their parent was not critically ill, or contact did occur by either the parent’s spouse who had been playing the more active role or by other available siblings (such as a RN-sibling, the eldest sibling, an unemployed sibling or more geographically proximal siblings). In many cases (59% \( n=18 \)) the participants had telephone contact with their parent for some if not all hospitalisations.

6.2.1.5.2 Contact with staff

Participants tended to have face-to-face contact with hospital staff (93% \( n=29 \)) for all (66% \( n=21 \)) or at least some (27% \( n=8 \)) of their parent’s hospitalisations. A minority (7% \( n=2 \)) of participants did not have face to face staff contact for any hospitalisations. Some participants had telephone contact for all (32% \( n=10 \)) or some (39% \( n=12 \)) hospitalisations. In 29% (\( n=9 \)) of cases, participants did not telephone staff at all. Participants were less likely to telephone staff than have face to face contact, unless this was not possible (such as when the participants lived interstate). Some participants (for example Ben and Ryan) mentioned they were reluctant to telephone as they were mindful of busy staff and confidentiality policies.

In sympathy for busy nursing staff often one family member would be in touch and would relate all information to other family members/friends. [Ben]

Knowing about confidentiality, and available time hospital staff have, has made me less inclined to make direct inquiries about my parents. [Ryan]

To obtain updates regarding the hospitalised parent’s condition, Ryan (who lived interstate) mentioned that he was more likely to telephone his RN-brother who played the more active role.

I often discussed my parents’ hospitalisations with him [RN-brother], rather than staff. [Ryan]

William who found he was not getting adequate information about his parent on the phone was influential in obtaining direct telephone numbers to speak in detail with staff.

I had problems with trying to get information when ringing up. I wanted direct lines to wards ... and staff nurses [said] oh no privacy dah dah dah ... and I
just sort of over-ran that ... and I was given telephone numbers and things that aren't given to the public normally. [William]

Jack mentioned that he had lost confidence in the staff and questioned the value of information they might provide over the telephone.

_No I didn’t ring - no. I suppose after being there for a while I just couldn’t see the point. Because ... well if they did know how [my mother] was they probably would be obliged not to tell you on the phone, and I doubt very much if they'd know ... they'd only be having a guess._ [Jack]

Telephone contact was unnecessary for some participants (for example Oliver and Olivia) who were especially vigilant and remained with the parent constantly during their hospitalisation.

_I was present at the hospital – ALWAYS [sic]. [Oliver]

_Basically myself and my family stayed at the hospital and spent most of the time with Dad including sleeping at the bedside._ [Olivia]

Sophie explained that she would telephone early each morning to ask about her father’s condition during the night and to ask the staff to advise her fretting father that she and his wife were on their way to be with him for the day.

_We would ring in the morning as soon as we'd get up ... and just see how he was ... how he'd been through the night and then to let them know that we were on our way in because Dad was fretting really badly. He really didn’t like to be by himself and he would fret really badly if he didn’t know how long we were going to be. So that was the only telephone contact because we were there all day._ [Sophie]

6.2.1.6 Busy being the strong one and making sure all others were alright

Participants felt they had to be strong for the family and make sure that they were alright during the crisis of their parent’s hospitalisation. During the crisis they were so busy looking after and supporting their parent and family members, that they had not allowed themselves to experience the emotions of a child with a sick parent. At times they recognised that other family members were dealing with the crisis on a familial level and participants felt upset that there was no time for them to deal with the experience as a son or daughter.
I didn’t fall apart until much later and it was because I had to be strong and be there to make sure that everyone else is ok and once I knew that we’d gotten through things and everyone was ok that was when I basically just fell to pieces. When I fell apart everyone was totally there for me so that was ok. I would have been a bit upset if that [didn’t happen]. ... It wasn’t until after my mother died and then my father died that I said ... you know I haven’t got a mother and father anymore and I felt just like a little girl and I hadn’t actually been allow[ed] ... not that I hadn’t been [allowed] I hadn’t allowed myself to have those feelings of this is my mother here ... I was so busy just being responsible and holding everyone else together and I think that it probably doesn’t hurt to let yourself fall apart a bit sooner than what I did because I fell apart very badly. That’s the sort of person that I am anyway. I tend to be big and strong and I can do anything and then just crash after. [Sophie]

There was the role of being the daughter but I wasn’t allowed that role ... because I had to be the strong one [Kate]

Uncle John said ... your father said goodbye to us all; and I must admit that upset me at the time. Because I didn’t have any time for dealing with it myself because I was busy looking after them [seriously ill mother and dying father]. It wasn’t until afterwards that it all sort of hit. [William]

It was usually left to the participants to notify relatives of the parent’s condition. In some cases (as was the case for Andrew and William) this information had to be given by telephone which made the participant feel helpless and drained because they tried to do this in a way that was as painless as possible, but they were unable to be with the relative to comfort them in person.

I was totally alone (at the hospital when she died) and trying to be so brave. ... after ringing all these people and having to tell them ... I was trying to get the correct words and description ... [for family members] to cope with it as quickly as possible. [Andrew]

I had to tell my brother [that dad was dying]. He knew that [my father] wasn’t well and I had to tell him by telephone and I can remember he burst into tears. That was very difficult and I didn’t really know what to do. Well there was nothing I could do. I was just on the telephone. [William]

Coping with two seriously ill parents, and then the death of his father, William was in RN-mode throughout the crises and did not take time-out or allow himself to feel the full impact, nor did anyone offer him any support or check that he was all right.
The most significant thing was having both parents seriously ill together. Organising other family members, getting help, home care etc. Trying to be positive and not falling in a heap. Remaining positive for them. No one asked how I was going. It was just making sure everyone else was alright. And I didn’t really ... think about falling in a heap but just sometimes I thought ... I just wish things would hurry up and take their course I wished it was over.

During the time I didn’t have time to ...I just thought I had two seriously ill parents. One [Dad] that was definitely dying, and one [Mum] ... with the heart attack. I did all the nurse things and then saw she gets through six weeks and then if she lasts another month ... now right she’s reached that stage, now it’s twelve months. There was that and I just didn’t have time. I had to keep working ... just making sure my mother was alright that dad had everything and it wasn’t until after he died there was still in the background well my mother could die at any minute and [I] ... had to get the funeral out of the way and then you know people coming and going, and telephone calls and then yes coming back to work after because I had a week off when he was dying and the funeral and then dealing with people ... you know ... oh how are you and all that sort of thing. There was no time just for me while it was all happening I was looking after my mother and I can’t really remember anyone saying well how are you going? How are you coping? [William]

When Andrew saw his mother post operatively he was outwardly positive although he was still very nervous and quite shocked by his mother’s appearance.

We were shocked about how she looked when she came out and went to ICU. My mum was intubated and all that full thing and it’s like ... shit this is pretty serious. I was pretty positive, but I was still very nervous ... about the outcome of the whole exercise. [Andrew]

In addition to playing the leadership role concerning her father’s repeated hospitalisations within a four month period Emma had significant responsibilities of her own to meet as she worked full-time, her husband was working interstate and she had three young children to look after. She remained strong for the family throughout the crisis: “You do what you have to do”. [Emma].

6.2.1.7 Shielding the parent and family from worry

The RN-offspring often shielded the family by keeping much of the information to themselves such as their hunches about the parent’s diagnosis and prognosis. William had read the doctor’s referral letter but decided to follow proper procedure and leave it
to the doctor to advise his parents of his father’s terminal diagnosis. William also did not want to alarm his parents in case there was even a remote possibility he had overestimated the implications of the referral letter, pathology results and so on, and thought it best to leave it to the doctor who had greater depth of medical knowledge and treatment options.

There was a problem when my father was first admitted to hospital for diagnosis. Waiting to be told I knew what the problem was because I read his referral letter of course and both my parents [asked] ‘what’s it say what’s it say’ … and I said oh I don’t really know we’ll have to wait until the test results knowing full well that it would have been a Ca thing. I didn’t want to say anything or frighten them because Dad wasn’t particularly worried. My mother was: she was beside herself. And I didn’t really want to add to the worry of it all I thought it would be better to go through the proper procedure and let a doctor [explain] When I was reading my father’s referral letter, I knew but I thought well perhaps I’m wrong perhaps it’s something else. You know, what if it is treatable all those sorts of things [William]

William anticipated his father was about to die, and rather than have the hospital staff telephone his mother (who was also unwell with cardiac problems) to come to the hospital quickly, he drove home and did his best to get his mother to the hospital quickly without placing too much stress on her.

My father actually became fully conscious … looked around at everyone in the room … and I thought uh oh … any minute now …his condition had changed. I asked the nurse have you rung my mother to say get back here really quickly and they said “no”. And I said …look don’t worry I’ll drive home and get her. I went back to get her … and I said I think we better go back without agitation her and saying hurry up quick, quick, quick. One of the first things she did she went and got her Anginine tablets and put them in her bag. [William]

Cameron noticed his father suddenly deteriorated and he suspected his father might have a cardiac episode or suffer an arrest. He caught up with the cardiologist to alert her to this change in his father’s condition. The cardiologist assured Cameron that his father would be fine and Cameron did not press the point in case he was over-reacting as this would upset his father who was scheduled for cardiac surgery in the morning.

I didn’t want to panic and over-react and what I was trying to work out was, was it me being too emotional or was it really that serious … Yeah [I didn’t want to over-react for his sake in case it was not that serious] [Cameron]
At times they kept the knowledge of possible complications to themselves to spare the parent from too much worry.

Going through mother’s recovery - for example, first 24 hours waiting to see if another infarct etc. Watching ECG etc. Pretending everything is OK. A little knowledge is frightening. (William)

They were careful not to destroy or weaken the parent’s confidence in the hospital staff and the care being provided even when they witnessed deficiencies. They often protected the family’s faith in the hospital system despite its known flaws which were readily detected due to their RN expertise.

I even found that I was critical of some of the priorities that I saw. I did not communicate this to the staff involved or my mum. [Amelia]

6.2.1.8 Shouldering: lack of hope, diagnosis/poor prognosis hunches, risks, care inadequacies

Participants often did not share their hunches about their parent’s likely diagnosis, and they privately worried about the possible complications their parent may develop or their likely prognosis. They were also well equipped to detect errors and deficiencies in the hospital care of their parent but carried these burdens alone. At times their medical knowledge removed any hope of the parent’s recovery and they sometimes carried the sadness of it privately.

William had a difficult and anxiety provoking experience waiting all day at the hospital with his parents for the doctor (who was unexpectedly delayed for most of the day) to provide his father with the cancer diagnosis. This was especially difficult because the sick parent’s wife was unwell herself and was extremely anxious, though she was good with William’s support.

That whole day of just waiting ... literally just waiting ... to be formally told. My mother because of her heart problem was stressed worrying about that as well as dad and she found it very difficult too - the waiting. She just said “how much longer is this going to go on for” ... and she was good really with my support but it was difficult. [William]
Participants kept their worries about risks and possible complications to themselves. They privately critiqued the care and treatment administered by the staff, and worried about how the treatment might impact on their parent’s quality of life. Sometimes they were aware that there was no hope of recovery for their parent but did not share this depressing information with the rest of the family, knowing they were still hopeful that their mother would again recover as she had done on a previous occasion.

My family are still holding onto the hope that she [mother] will make a recovery like she did before. Unfortunately I know there has been too much brain damage this time and she will not improve. I also worry about the effects of being unable to move freely, that is, pressure areas and chest infections (of which she suffers both). [Sophie]

6.2.1.9 The leadership role in life and death situations and decisions

Olivia found it very difficult being responsible for life and death decision-making. Her mother, sister and brother looked to her for guidance continually during her father’s hospitalisation. In Olivia’s family males make the decisions, so this was a significant departure. She was also being very protective of her mother: thinking she would not allow the neurosurgeon’s recommendation [to continue with life support] to be pushed onto her mother. Olivia has no regrets and believes the decision to withdraw life support was the best outcome for her father, but she felt heavily burdened and felt personally responsible for the decision and therefore felt responsible for his death.

I felt bad about being responsible – but I never questioned it in terms of being the best outcome for Dad. The skills I had just complemented the situation I was in – which was I could advocate for the nurses, I could advocate for my family, I could advocate for Dad, I could explain, I could interpret, I could be assertive about having things done or not done that I’d seen so often in my life. And it was like that’s not happening to my family – well basically it’s not happening to my mum ... and therefore my family [Olivia]

RN participants were sometimes called upon or found themselves in situations where they had to make critical decisions including whether they wanted the staff to resuscitate their parent. In Cameron’s case he knew his father had advised the doctors he did not wish to be resuscitated, and that it was documented, and yet when his father did arrest, the doctor still gave Cameron the responsibility of deciding whether to let his father die
or to try to revive him. The stress of this situation was further increased by the manner in which the doctor interrogated Cameron. Cameron felt he did not have the right to make that decision, and he is still burdened by the enormous responsibility of it.

[My father] had explained to the doctors that he did not want to be resuscitated. [The doctor] said “it’s documented he’s not for resus” ... and they said that they could do active things if I wanted to. I remember the doctor being very black and white ... just this clinical decision ... know the facts... and it was funny ‘cause that’s often what I want to know in this situation. It was very, very difficult and I would have preferred it to be raised in a different way but it was just ... this is what’s stopping me ...we can address that ... if you want to ... so do you want your dad to be resuscitated and receive active treatment and if you don’t he’s going to die.

I felt a bit frozen ... it’s my dad ... things were going through my mind that that was most likely what he wanted ... I was thinking of the possibility of keeping him alive for the rest of the family so ... it was really a shock. ... I remember struggling to think ... why do I have that right to do that?

It was just standing in the corridor ... and there was a lot of pressure on us from the doctor ... because I was a bit frozen just thinking of all the different options ... what it would look like and he was saying “we need a decision now. Is it yes or no?” ... I remember I was pretty annoyed at the doctor because I said no we won’t and he said something like ” I can’t hear you” ... and I said no. He said “I’m taking it you said no you don’t want your dad to be resuscitated” ... it was like being in a court of law ... and he [the doctor] said ... “do you agree that’s what you said” and I said yes. [Cameron]

Cameron felt angry with himself for becoming so emotional when called upon to make a decision on behalf of his large family about resuscitating his father.

I guess I can be pretty detached in that sort of situation normally just do the rational thing, but I remember being ... almost angry with myself when I was getting so emotional about everything that was going on at the time. Yes, that responsibility for ...like being detached and being head of my ...[choked up] [Cameron]

6.2.1.10 The aftermath of the crisis: personal and professional repercussions

The consequences of being the decision-maker particularly for life-death decisions can be enduring and devastating. RN participants felt burdened and personally responsible for the outcome some years after the event.
I felt incredibly responsible for the decision making. I felt like I’d made the decision to turn dad off – and I was the one with the power. At the time I thought if anyone else in the family had had the same knowledge as I had but had a different belief about the value of life then the whole scenario would be completely different. If they had exactly the same knowledge as me and went but yes life’s life and it’s so important and I’d rather have Dad in a nursing home or something so let’s keep him going and let’s put a trachie in and whatever then we’d in fact not be grieving over Dad’s death he would probably be in a nursing home. It’s like I’m responsible for ultimately a decision that myself and my family took about withdrawing life support from Dad, who could clearly not have survived without it. So that was hard. We sat with him and he died. But that’s pretty hard stuff. I never question the path of events in terms of it being the best outcome for Dad. I don’t question that. I mean I actually never questioned it ... I felt bad about being responsible – but I never questioned it. [Olivia]

It was a horrible situation and [even] now it’s terrible ... I haven't talked to my mother about Dad [since his death] but I just wondered whether she deferred that decision [whether to resuscitate Dad] to me. I’m just thinking the word unfair springs to mind [to describe the decision I was asked to make about resuscitating my father]  [Cameron]

Multiple hospitalisations over a four month period involving a critically ill father were a particularly exhausting and overwhelming experience for Emma whose siblings and husband were away during her father’s crisis, and had the added burden of working and single-handedly looking after her three children.

It was an awful time. All of my siblings were interstate or on holidays and I was the only one here, and that was when my father was admitted to intensive care so that was pretty awful and my husband was interstate. I got very tired with all the running around and trying to work ... because by the end of the fourth month it was pretty draining. I was absolutely exhausted and I don’t think I’ve ever, ever felt that tired. It was just an overwhelming feeling and I lost weight and you can see why it happens to people because it is just so overwhelming. It involves a lot of your head space and connecting with your mum and your dad about what their needs are trying to support them as well as manage whatever else is happening in your own day to day life. It wasn’t as if I was a single independent person I had other responsibilities (3 school-age children). [Emma]

Madeline mentioned the stress of working full-time and not being able to afford to take leave. Her NUM was unsupportive and objected to Madeline taking a day off to attend
her father’s funeral. Madeline’s situation was compounded by the lack of a supportive family.

[I] probably always will be [upset and angry about my father’s hospitalisation]. My family aren’t real good ... my work place wasn’t very sympathetic ... I didn’t take a lot of time off because I couldn’t afford to at that stage. Well I think in hindsight I probably would have taken a week off. But I didn’t get that opportunity. [I was] still at work still had a job and trying to work and you’re still expected to be there at work ... which I found really hard. I basically came back to work the day after the funeral ... and that’s what was expected. I think you just do [cope] don’t you – you go on auto-pilot. [Madeline]

For some participants, continuing to work as a RN was a constant and painful reminder of the parent’s hospitalisation, and its tragic outcomes.

I think that the sadness of it; the horrendous unexpectedness of only a few more months and that’s the end. And it takes ... a certain amount of concentration and hard work to keep going and say no I still can nurse people. [Claire]

Andrew still works as a nurse part-time but would rather do something else now. The job is too depressing as he is reminded of his painful experiences every day and Andrew would not be subjected continually to stimuli that trigger these painful memories if he was not a RN.

I don’t really like [nursing] now. I’d rather do something else but I’m doing it because I have to do it ... The job it’s just awful, I just hate it, it’s too depressing. I think of Mum a lot at work, because ... she died in a hospital and you have to go and work in a hospital. Every day I’m reminded of it. [Andrew]

When asked what Sophie and William might do differently in retrospect, they identified the need to talk about the experience to unburden themselves and to allow themselves some emotional release during the crisis rather than waiting until it was all over.

After Dad had died I was just driving home and I was thinking about things but suddenly it just started and I couldn’t stop I just burst into tears cried all the way home. But that helped ... I felt so much better after that because thinking about it there had been no release for me. Perhaps I would talk to people more about it. I think I would - yes I think I would discuss it more. Because I just ... you know it’s a very private thing ... but I think you do need to debrief a bit and sort of unburden yourself. [William]
She [mother] passed away in November. My son died Christmas day and that was totally just unexpected, and my father [in January]. So I actually took four months off work because I, as you can imagine, wasn’t functioning very well. That’s why I had to take time off work. I had to have my time of just actually falling apart. I just suffered such a major depression. But then you know it was not only the loss of my mother but the loss of my son and my father as well. So they had huge impact on ... you know we didn’t really feel that we’d gotten through one major crisis before the next one and then the next one after that. I just found my energy and my strength and I’m still not ... I mean I can work ... do all the things that I do in my day to day life but I can’t take on that sort of emotional stress like I probably could have done a couple of years ago.

After Andrew’s mother died he was drinking a lot and not able to get on with his everyday life in an effective way. He was offered free professional help by a psychiatrist at work which did help. Andrew’s advice to other RN-relatives is not to be afraid to show your emotions at the time. It does not matter if you do break down.

I went to our psychiatrist’s at work. I had a chat to him a couple of sessions with him which was really good - ... no payment, no medicare nothing, just come and speak to me. ... It was just excellent support ... from all sides ... I went and saw this guy in February and March and then I saw someone [the following year] because I was drinking a lot and that was why; because I was just not getting it together. Don’t be afraid to show your emotions ... you are a human being as well. [Andrew]

6.2.2 Expertly observing, detecting and protecting

The RN on standby was ever expertly vigilant, keenly and expertly observing every aspect of the parent’s care and treatment, and being present by the bedside as much as possible. Participants described observing the care of their parent, and observing the way the nurses cared for the patients as a general indication of their caring behaviour and competence.

As an RN you are aware of procedures and I found myself looking and watching the care of my mum and not being able to participate at all. [Amelia]

She got things done real quick and as I watched her, as you do, you watch nurses if you’re a nurse, I watched her with other patients, I listened to her on the phone ... she was good, real good. [Claire]
Many participants described their bedside vigil and they tried to ensure their parent was not left alone.

*It’s emotional –* I have always acted as an observer and just watched. I was present at the hospital – ALWAYS [sic]. [Oliver]

It was very much a vigil … somebody was there 24 hours a day. [Claire]

We were there all the time and tried to be present as much as we could … There was always someone there. [Madeline]

The familiarity of the hospital was seen as an advantage by participants and as a result of their nursing expertise they demonstrated expert vigilance.

Dad was hospitalised in the hospital where I trained, so the environment was very familiar to me. I think the experience is much less foreign if you are an RN. You understand what the bedside charts mean … You also become quite critical of the deficiencies of the public hospital system. [Eva]

6.2.2.1 Expertly observing

Being vigilant served a number of purposes. One purpose was observing the parent’s condition and progress and having the expert knowledge to interpret their signs and symptoms.

I wanted to know the full story of her condition and progress. I looked at IVs, drains etc to ascertain patency. I probably was more inquisitive to the nursing staff than had I not been an RN. [Adam]

I knew the signs, symptoms, medications, tests that they were having etc. If I was not an RN; I would have been unaware of what was *REALY* [sic] happening. [Oliver]

For Olivia and her family it was a vigil. They stayed at the hospital and were by the bedside of her unconscious dying father around the clock. Olivia closely watched over his treatment and progress and did her own nursing assessments on her father. She also noticed that one of the intensive care RNs was not attending to her dying father’s care, but she did not intervene.

We stayed for 48 hours – the whole family, on the floor on each other’s knees … I watched his inter-cranial pressures, I watched his urine, I watched every
medication they gave him ... made sure that they wrote not for resuscitation on his charts – and the charts were open all the time – and there were times when I just needed to know. And that's what I did. I did my own nursing assessment of Dad. And I watched their nursing assessments.

[One of the ICU RNs] was off all the time, he was raving round flirting and doing all things in intensive care and like – Dad’s bags were just filling up and filling up and he didn’t suction him and he sounded like a train but you know – I didn’t get into any of that – I didn’t suction him I didn’t empty bags. It was just dreadful. It actually made us all laugh and said ’oh Jesus thank Christ we’re turning him off on Saturday because otherwise this boy would kill him. [Olivia]

Access to the parent’s medical file was not usual and often communication was inadequate, especially with nursing staff and in one case with medical staff (regarding Oliver’s mother). Participants did not usually have automatic or easy access to all the medical records information regarding their parent’s condition.

I was tempted just to go and grab [my father’s] chart and just have a look at where things were at. I’m talking about the more detailed file. I think one day we did get it [Cameron]

6.2.2.2 Detecting changes, errors and deficiencies in care

In addition to expertly observing, a second purpose of participants’ vigilance was to detect changes in the parent’s condition, and deficiencies in care or errors in treatment. Eliza and Madeline mentioned that they found it especially frustrating because they had the expertise to recognise their parent was not receiving the care they should have been receiving. Ben talked about keeping his “finger on the pulse” to detect substandard care, neglect and errors.

When Olivia’s father became decerebrate it was clear that they needed to re-assess his chances of recovery. She had to interpret the signs of her father’s deteriorating condition for her family. Olivia’s family initially thought it was a good sign when her father’s foot moved until she told them it was a bad sign.

He started showing signs of being quite decerebrate ... and then we needed to change our focus. All those interpretations of what the signs meant [my
siblings] were like that's fantastic – Dad's foot moved – and I looked and went – but that's actually a really bad sign. [Olivia]

On the night prior to his father’s surgery Cameron approached the cardiologist because Cameron noticed that his father had suddenly deteriorated and looked about to die. Cameron’s insightful reading of the situation (which was dismissed at the time by the cardiologist) led to feelings of failure and isolation, and an inability to explain his father’s death to the rest of the family.

He suddenly got really ill... and he started to get really cold and shaky and claiming that he got chest pain - the cardiologist went off to do rounds, and she came back and said “oh no you'll be fine with the angio” and whatever and she was about to go, and he just had that look, like some people do when they're about to have a ... coronary. And so I went and ... I got her just before she was about to get in the lift; and I said to her what I thought was going to happen, and she said “oh no, he's ... he's fine, and go home” and she left and he died about 9 o'clock [3 hours later]. My honest sense is that she knew what was going on but she just wanted to not be there. After Dad died I felt overwhelmed just because people wanted to know what happened. And I couldn't really explain it to them. But most of the time in the past I hadn't felt bombarded. [Cameron]

Sarah’s nursing expertise allowed her to detect errors and substandard care in the nursing care provided to her mother (as reported in section 5.2.2.2.3) and Amelia felt uncomfortable when she noticed that her mother’s nursing care and procedures were performed below the standard she expected.

Because I am an RN I was aware of some procedures not being attended as I would do them and although there was no adverse outcome I found that I was uncomfortable at times. [Amelia]

Claire could not bear to be present in her father’s room when an inexperienced staff member insisted her dying father take his oral hypoglycaemic medication even though he felt he would vomit. Claire later returned to the room and quietly threw away her father’s medication rather than cause upset by openly confronting the staff member about her inappropriate demands and lack of compassion.

One girl was insisting that Dad try to swallow his oral hypoglycaemic drugs. And I thought I’ve got to get out of the room; because this man is dying, even though it's ordered, he's just said that he thinks he’s going to throw up if he has
it. By the time I came back the tablets were sitting on the table and I just chucked them away. I thought I won’t go and tell her he didn’t take them let her think he took them if that makes her feel better, it’s not going to do anything for him. [Claire]

Claire described her harrowing experience when her dying father was in extreme pain and begging for drugs to put him out of his misery. From her nursing experience she knew that her father’s pain and distress could have been treated more effectively.

I was standing arguing with people that were telling me “oh no we can’t up the Morphine and Midazolam, it may affect his breathing” and I’m thinking that’s what I’m asking you to do. ... and my dad’s laying there saying “just tell them to give me something” ... and they’re standing there hearing that and yet still not responding at all except in... “well, I’m sorry that’s all we can do.” And really we know that it isn’t. [Claire]

Participants who kept vigil by the bedside were often angry and disappointed with the quality of care their parent received. In being expertly vigilant, several participants easily recognised when their parent was being neglected (as already described by Cameron, Eliza, Gail, Jack, Madeline, Oliver and Sarah in earlier sections). Some of the aspects they mentioned were poor pain management, no pain relief (mentioned by Claire and Eva); absence of basic care (neglect) mentioned by Jack, Madeline and Oliver; offhand attitude of staff, staff unresponsive to parent’s needs (such as ignoring the sick parent’s basic requests for a pan) mentioned by Jack; poor standard of care as reported by Sarah; treating the sick parent with contempt (when Eva’s dying father asked staff to keep the noise down in the middle of the night); lack of information regarding their parent’s condition; and overworked staff due to shortages and the rundown environment.

My dad was very unwell ... constantly vomiting. He had wasted away to skin and bone. It seemed the only time anyone came near him was when either the drip or feeding tube alarms went off. I also had trouble dealing with another aspect of his times in hospital. Even though Dad was 75 years old ... we were made to feel as if we shouldn’t be trying to find out why he was so unwell/vomiting all the time. It got to the stage where we felt he was being fobbed off with the old “he’s been through a lot” – geez ....we’ve been with him all the time - watching him suffer. We just want someone to find out what is causing this and stop his pain and distress! I’m sure if I wasn’t a nurse I
wouldn’t realise how things could be (or were when I was still in the hospital system). [Eliza]

6.2.2.3 Protecting

The third aim of participants maintaining a physical bedside presence was to serve a protective function: a reminder to staff to be attentive to their parent’s needs. It also served to provide support and reassurance to the hospitalised parent and the family. When Ben arrived at the hospital accident and emergency department and found that his mother had been on a trolley for four hours in a corridor adjoining the department, he was protective of her. Similarly, Madeline was protective of her dying father who suffered a fall because he had been left alone in the toilet by staff and as a result was frightened of being left under their care.

I just decided that I’d stay there and be the face of the relatives. [Ben]

Frightening, no-one cares as much as we do ourselves. I was very protective. I think it was just the fact that we were there all the time and tried to be present as much as we could. There was always someone there. [Madeline]

Sometimes the main motivation for being by the bedside constantly was to support and reassure the parent even though it made one son feel as though he was intruding on staff members’ territory.

[My father] really didn’t like to be by himself ... we were there all day. [Sophie]

It seemed that [my father] needed me at his bedside at all times. I felt at times I was intruding on my colleagues’ territory. [Matthew]

Patrick felt angry when he detected that his parent was being mismanaged, but recognised that he was not in a position to control or interfere with the work of the staff.

There were some glaring and startling mismanagement practices on each and every visit and I was not only concerned for my parent but also had to contend with upsetting anger on my part. I do not want to sound like the picky know-all RN, but really did have mismanagement to observe and not be in any position to do something about it. The staff in attendance were doing their job – not to my satisfaction but it was not my situation to control or interfere with. [Patrick]
In some cases the neglect by staff was seen as life-threatening. Jack, who had come down from the country when his mother’s condition deteriorated post-operatively, stayed with her around the clock. He described his extreme frustration at the dilemma which faced him of whether to standby or intervene.

I just saw what I thought was absolutely bad practice. It was extremely frustrating to watch and ... you don’t know whether to jump in or ... just shut up which I chose to do. Yeah it’s a hard situation to be in because you’ve got to weigh up the pros and cons. It was damn hard to sit there and take it knowing that the lack of care could have caused [my mother] to die. That’s what was in my mind all the time. It was quite disturbing to see it wasn’t just my mother who was being treated like that. It was really appalling what I saw and it didn’t get any better. I spent 2 or 3 days around the clock with her. It was absolute neglect. I think this operation almost took her. It was a fairly grave situation. [Jack]

Claire was protective of her dying father and gave him reassurance that she would not let him down. Despite the unwillingness of the medical staff to increase the dosage of his medication for pain relief, Claire assured her father that she would not rest until she obtained drugs to alleviate his pain and suffering.

It was actually [my father], not in a stupor or anything but him alert, looking at me and saying “I’m just telling you just kill me.” And I’m saying Dad, if I could kill you I would. And I promise you that no matter what they say you are going to get some more morphine whether it be in the form of heroin, I will get something for you. And he said “yeah, beauty.” And he knew that I would. And that was good, I was so glad that he knew that I’d fight for it. [Claire]

There were times when participants experienced extreme frustration and anger: as qualified nurses they knew what care their parent needed and through their expert vigilance quickly detected deficiencies in the care being provided. Claire knew how quickly and easily the care could be provided but she was powerless to make the nursing staff provide that care.

Well, it made me very angry because I knew exactly how long it would take. I knew exactly that they had the time, if they had the time to sit at the desk and natter about other things they had three minutes in which to bring a sheet in, hold a person on his side while I cleaned him, washed him, dried him, changed the bed, turn him over, it takes three minutes. And you know that, and they
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know that, and I know they know that, and that’s what was so frustrating.  
[Claire]

Ben has often been and continues to be the understanding one who provides an ear for his disabled mother to vent her anxieties, fears and frustrations due to her condition. Ben’s background in nursing has set him up for this role and his three brothers tend to opt out by re-directing his mother to him for advice (actually emotional support) which is very taxing at times but he does not see that he can do anything about that. It is relentless - there is no escape from the role. He acts as a sounding board regarding the wisdom of his mother’s medical decisions. Ben feels his mother is overly dependent on him, and says that the parent-child relationship is reversed and has reduced the degree to which Ben’s mother interacts with him as a son.

Sometimes ... I’ve been very much put upon by Mum. She’s been quite unhappy and has leaned on me more than I thought was acceptable And through just being a bit firm with her I think somewhere along the lines the parent/child relationship has sort of evolved; to where at times I feel like I’m almost taking on a parental role and she quite happily gives over to that.  [Ben]

6.2.3 Being adept at hospital language

In addition to monitoring their parent’s care closely, the RN-on-standby understood ‘hospital talk’ and could interpret it for the family. Participants had expert knowledge to advise the parent and family about treatments and of the parent’s progress and prognosis.

The rest of the family needed me to interpret the language that the doctors and nurses were using – the staff could not seem to explain anything easily in layman’s terms – thank god I could or confusion would have been greater.  [My brother] was listening and being very polite to the doctors and nurses and then as they’d walk out the room sometimes he’d cross his eyes and say “what the heck was that?”  [Claire]

My father had never been hospitalised before. It was a shock to himself ... He suffered a heart attack and needed treble bypasses. His lack of mobility and freedom affected him the most, and he asked [me] to explain all hospital procedures and all treatment. [Matthew]

The experience would have been more distressing if I had not been able to understand the ‘hospital talk’.  [Sophie]
At times participants needed to explain to their parent the effects of medical treatment ordered by the medical staff.

He said “if this is life I don’t want it.” And he asked for something to make him die; and then god love him when they hooked up the first syringe driver he said to me “so goodbye”; and I said no Dad it’s not euthanasia, it’s not something that they push into you, and he went “oh my god, I thought it’d be like putting our cat down”. And I said “no Dad, it’s not quite that simple.” But he understood that it was but slower. [Claire]

6.2.4 Keeping it real: providing reality grounding

At times participants spoke up to correct the family’s misguided ideas about the parent’s prognosis or expectations of improvement and this sometimes challenged family members who were in denial, or dramatically altered or shattered the family’s hopes of the parent’s recovery, and at times resulted in conflict between the participant and family members. Claire clashed with her mother because her mother was in denial and could not accept what was happening and Madeline also experienced some conflict because her mother was in denial concerning the necessity to keep up the pain relief for her father. Olivia corrected her family’s misinterpretation (they thought they observed signs of recovery in her father) to prevent the family developing false hopes.

I remember that feeling ... knowing that my sister and my brother were going – “oh that’s fantastic the sedation’s finally lifted and that’s really wonderful” and I’m thinking - well you know I’ve gotta - I don’t really want to do this but I think I’m going to have to be really honest about what it means because otherwise your family progresses into - Dad’s going to get better. I was really conscious if I had said at any point (even though I mean, you wouldn’t have to be really aware of a lot of medicine to know how unwell Dad was). But if I had persisted with any glimmer of oh well maybe or oh you know let’s just do it anyway or any of those things – the whole segue of events would have been completely different. [Olivia]

Lara’s mother was dying of breast cancer and talked about what she was planning to do in the future which prompted Lara to bring her back to reality by telling her mother that she would not live long enough to do those things.

Mum coped by pretending it wasn’t happening and of course she didn’t want to see her children or my father suffer. I was immature so I couldn’t see that. The
only regrets I have ... when my mother was saying to me “oh look you know I’ll do this, this, and this in the future” and I remember at one stage saying to her, but Mum you won’t, and her saying to me – “well I know that but I want something to look forward to – I’m allowed to have a dream” and I thought that was dreadful of me. I was only 20 ... but [now] I always say you’ve just got to leave a bit of hope. [Lara]

Correcting misconceptions was done as gently, quietly and as comfortingly as possible by Sophie. She knew that the family trusted her word and it would have been devastating for them in the long run if Sophie pretended her mother was going to recover.

I just very quietly would say don’t get your hopes up too high just expect that things aren’t going to be good. But just very quietly and comforting really ... because ... I knew that if I were to say yes she’d be ok then they’d literally take my word for it and it would have been devastating for them to have discovered that she wasn’t going to be ok. And because they trust my word so much I couldn’t pretend that things would be ok but at the same time I had to be very gentle and not direct and really well I’m sorry this is it sort of thing. So just tried to soften it by saying look don’t get your hopes up too much just try to think the worst because then that way if something else happens well it’s a bonus. [Sophie]

6.3 REGISTERED NURSE IN ACTION (IMPERATIVE TO INTERVENE)

RN in action describes instances of participants taking action and intervening in their hospitalised parent’s care. This involved fixing urgent or significant problems and filling in gaps in their parent’s care (see Table 6.1). Taking on an active nursing role sometimes involved over-stepping the normal child-parent boundaries and intruded on the parent’s privacy. RN participants were at times also closely involved in handling life and death situations and decisions which resulted in enduring negative consequences for participants.

As was reported in Chapter Five, the consequences of disclosure included nursing staff communicating less and giving less care to the parent, and participants at times resorted to disclosure to get action (details of participants who disclosed to get action were
provided in section 5.2.2.2 of Chapter Five). Some participants (for example Cameron) who took action did not disclose their status to do so, although it would have been obvious to staff in most cases that the participant had nursing/medical expertise.

6.3.1 Filling in gaps: over-stepping boundaries and gender differences

Sometimes the care that was provided by the staff was inadequate, pressure area care was neglected, and attention was not paid to general cleanliness and elimination of soiled linen, used pans and urinals. Male participants rarely assisted with hands-on nursing care and did so only at the request of the staff RN attending their parent. This occurred on one occasion for two participants: Jack and William. Female participants mentioned that staff avoided them and their parent as soon as they knew of their RN status and some female participants were expected to be their parent’s private nurse. As a consequence of their parent being neglected by staff, female participants resorted to filling in the gaps in care themselves by performing nursing care for their parent and minimising their parent’s pain and suffering.

But after they knew that I was a nurse; I think they really left a lot of the explanation to me for the rest of the family; they didn’t come in as often and I guess I have no problem with it but they expected I would sponge Dad and turn Dad and ... that’s the impression I got; that “well, you’re a nurse so like nurse.” I had to get things done for Dad. Pressure area care was neglected, nutrition was neglected – it was as if they thought ‘He is dying soon anyway why bother’. This was heartbreaking. [Claire]

Once past the admission stage, staff were very helpful although most of my father’s needs were taken care of by myself and my sister. [Lucy]

My father shared a bathroom which had in it old pans/urinals/used linen for days. Awful for someone who is sick. I knew where the pan room was and I got rid of it for him. [Eva]

Madeline’s mother disapproved of her daughter filling in the gaps in nursing care because there was discomfort about taking over and intruding on the nurse-employees’ territory, and Madeline’s mother believed that taking on the nursing care implied that the staff’s efforts were inadequate, unsatisfactory and unappreciated. However, the sick
parent’s needs over rided these reservations in the end. Claire’s mother was also initially resistant to the idea of filling in the gaps in relation to Claire’s father’s care.

But in the end [my mother who was ex assistant-in-nursing] wasn’t pulling me back when I was doing it. In fact I suppose she thought well at least I’m not the one, it’s her. [Claire]

Participants sometimes overstepped the usual child-parent boundaries and this intruded on the parent’s privacy and led to feeling uncomfortable or embarrassed and had the potential to alter the way the child and parent related to one another. It did not feel right for the participant and embarrassed the parent (because it involved assisting with toileting, sponging the parent, and cleaning up and changing soiled bed linen of incontinent parents). Sophie’s father was embarrassed by having his daughter assist him with toileting and preferred staff to assist him with this (as quoted in section 4.5.1.2).

When Claire’s mother was present, she performed the more intrusive nursing tasks however there were occasions when Claire’s mother was not present. Claire experienced discomfort performing personal care tasks but on the other hand she also found it satisfying to be able to do something to help her beloved dying father.

It was a funny thing because I thought well I’ve nursed and washed so many men, is it different to do that for your father? and I thought yes, it definitely is different, but I sort of slipped into ... let’s just do it; ... if he’d had his bowels opened or needed suppositories or something like that I was more likely the person that was sort of hanging on to the top half of him having a chat, rolling him over for mum to do that sort of stuff ... I think it was because, well, he might have changed my nappy when I was a child ... but he was my dad. It was hard, in the hospital though I had to do it because there were times when Mum wasn’t there and it was just my brother or my sister-in-law or myself. I felt like you know this is my father and he’s aware that I am seeing his bare bottom and to me it wasn’t quite right ... from just that oedipal sort of thing, you know, it wasn’t quite right.

In some ways they’re very happy memories ... I think maybe sometimes we just give up our family members when we put them in hospital, we expect somebody else to be doing ... everything ... but at least we had that. [Claire]

Some female participants did not feel the need to perform care for their parent because the care provided by the staff was described as excellent or impeccable (by
Emma and Sophie) or was of a satisfactory standard (in Kate’s case) and there was no adverse outcome for the parent (for Amelia’s mother) or because the participant had not worked as a nurse for 20 years (in Eliza’s case) or because the participant was young and newly graduated as a RN (in Lara’s case); or because the participant trusted the staff and had confidence in the care they provided and the parent was about to die (in Olivia’s case) and/or because they were not willing to intrude on their parent’s privacy (as was the case for Gail and Olivia). Female participants who did engage in filling in the gaps (Claire, Eva, Lucy, Madeline and Sarah) did so in response to their parent being neglected by the nursing staff.

Male participants sometimes mentioned they were mindful of not interfering directly with the work of the nursing staff and they were more likely to take action by drawing shortcomings to the attention of staff to fix problems (as described in the next section). Patrick believed it was not his “situation to control or interfere with”; William was very conscious of not abusing the status and power of his nursing position and never corrected staff in relation to his parents’ care. Jack believed it was important for staff to perform the care so that they would not miss opportunities to detect changes in the parent’s condition (however the gaps in care were filled by Jack’s RN-sisters because the staff left the care to them).

On one occasion William was called upon by the nurse to assist in performing personal care for his father which he later regretted doing because it intruded on this father’s privacy.

When [the nurse] arrived I assisted her to change my father because he had been slightly incontinent when she was putting the syringe driver in and I regret that I had done that because Dad was a very, very private person and he would have hated me doing that. ... and it’s just something that I think about now and again and I just wished I hadn’t done it because he wouldn’t have liked me doing it. I think she should have asked for one of the other nurses to come and help her not me. It was her request and it was a spontaneous thing and I just did it without thinking - and I can remember thinking - we were finishing the task and I was thinking - oh I wished I hadn’t done that - I just thought it was invading his privacy in a way that I don’t think he would have liked. [William]
6.3.2 Being the fixer and fixing

Participants sometimes felt compelled to intervene in the management of their parent’s care. As mentioned in the previous section, male participants did not take action by filling in the gaps themselves. When male participants (for example Ben, Cameron, Jack, and Oliver) detected high priority aspects of their parent’s medical or nursing care which needed attention they assertively drew it to the attention of staff to fix the problem (with varying degrees of success).

Male participants were also more likely than female participants to lodge a formal complaint, or mentioned that they considered doing this. Cameron was “angry about the attitudes and standard of care ... and was tempted for months afterwards to go back there and formally complain”. Jack was “pretty stirred up still ... thinking of writing to all sorts of people ... but ... [my mother] might have to go back again and it might jeopardise care and it probably wouldn’t have any effect anyway”. Daniel wrote a letter to the hospital manager questioning treatment measures and Oliver also submitted a letter of complaint.

[I] wrote an official complaint but nothing ... they phoned and said ‘we’re sorry about the loss of your mother but we felt we did everything we possibly could and perhaps you might have been affected because you were too close to you mother’... I thought oh no. [Oliver]

One female participant, Eve, was “highly indignant on [my father’s] behalf” at the contemptuous manner of the nurses and “thought how can a nurse [sic] be so insensitive?” However she did not believe it would be helpful to lodge a complaint: “I never followed it up ... what good would it do?”

Participants (male and female) felt the imperative to intervene regarding aspects of their parent’s management in response to:

- Family expectations
- Lack of attention, neglect, unreasonable requests or errors in relation to the parent’s care
- High priority immediate needs to prevent death, and alleviate suffering of critically ill or dying parents
6.3.2.1 Family expectations

Some participants were called upon (usually by the parent’s spouse or the parent) to intervene. In some cases this entailed taking the parent home (that is, when the parent wanted to discharge themselves) or by arranging a transfer to another hospital for better treatment.

Cameron’s mother and large family usually expected him to fix things in relation to health/medical matters. He negotiated with medical staff of a country hospital to transfer his father to Sydney to be assessed for cardiac surgery.

I'm one of a big family and what tends to happen is when my parents and my brothers and sisters get to a point where they don’t feel anything’s happening; they ring me up and say can you come out and see what’s going on. And so I went out to [country town] and when I asked the doctors what was going on it was like “we're not sure” ... so I talked them into transferring [Dad] down to Sydney [Cameron]

The family called on Cameron to see what could be done for their father. They later blamed him for negative outcomes and this continues to weigh heavily on his mind.

... I said, why don’t we ... look and see if this is an option or not ... and they said “ok” ... we'll get someone to do this, send him to a cardiologist in Sydney. And that's when he died, when he came down to Sydney, and I think there was a bit of blame on my part that I shouldn't have done that. I think that the main thing they thought was that ... I should have said: well yes ... the best thing for you [Dad] is to stay where you are, so that’s how they see it. I think that's why ... I always ... I felt a lot of guilt and I was blamed because it was my dad, you’re the one recognised suddenly with those decisions and so then when it was seen as not the right decision at all and well you were the one that made it ... so it's your fault. It hasn’t (kept coming up). It’s in my mind. [Cameron]

William was expected to arrange home help when his mother discharged herself from the hospital at short notice because she was placed in a shared room with a noisy patient and could not sleep. William clearly knew the hospital system well enough to recognise what was and was not possible to fix.

The staff said there might be a single room later on.. and she's a public patient .. Medicare ... so I knew there was really no point in saying she must have a single room ... because they just won’t do that. The director of nursing ...
perhaps may have tried but I really think it wasn’t worth making a fuss about. [My mother] was recovering well but she was changed into a room with an older woman who kept her awake all night coughing and spitting and she just said” I will not stay here any longer” ... I nearly had a fit because ...another few days in hospital would have been good ... because you know I was at work ... and then I had to suddenly start arranging home help and she wasn’t too fussed about any of that at all. She was coming home. [William]

Madeline’s father pleaded with her to take him home because he was terrified that the hospital’s neglectful care would kill him.

His biggest thing was “get me out of this hospital before they kill me.” He obviously felt they were neglecting him. He obviously was scared, being left there. He knew that they’d left him in the toilet and that he’d fallen. [I] took him home. [Madeline]

6.3.2.2 Parent’s care: inattention, neglect, errors, unreasonable requests

At times participants intervened in relation to matters involving the medical staff. William had been waiting all day with his parents for the doctor to see his father to be told he had a terminal illness. William was told the doctor had been to the hospital and had left without seeing them. William was assertive and persistent until a satisfactory outcome was achieved: he phoned and demanded the doctor return to the hospital to see them.

It wasn’t until I spoke to some staff and demanded that [the specialist doctor] return to come and speak to us that he eventually came back. [William]

Participants were well placed to confirm the accuracy or otherwise of the history given by the parent, or at times to give the history on their behalf and justify the need for hospitalisation when the parent had language, hearing and cognitive deficits. Lucy was accused of “granny dumping” by the admitting doctor who did not want to admit her sick father to the hospital, but did so when Lucy offered medical justification for her father’s admission.

Frustration from registrar’s assessment of the social situation not the medical ... I had to justify the need for admission. My father had hearing difficulties, English is his second language and not very mobility (sic) because of age (need help to get on examination bed etc) disorientated. GP wrote a referral letter
suggesting IV medication was needed and observation due to related heart conditions. On casualty admission, the registrar pulled me aside and accused me of “granny dumping.” [Lucy]

At the risk of alienating the staff there were occasions when participants did intervene. They applied their RN knowledge when they judged it to be absolutely necessary to have a positive impact on their parent’s care. In Rachel’s case she challenged the doctor’s (incorrect) medical management of her mother’s pathological fractures.

I worked in the hospital so everyone knew. There was one time that Mum went to another hospital as an emergency. I was prepared not to tell them [of my RN status]. BUT [sic] things were SO [sic] bad that I had to challenge/question their (JMOs’) management of my mother and so had to disclose my professional status - when asked a direct question “what are you a doctor or something!” [Rachel]

Madeline’s father was dying and the family experienced difficulties spending time with him as he was sharing a six-bedded room within the ward. Madeline challenged the doctor and convinced him to use his influence with the nursing staff to have her father placed in a separate room. This strategy worked in the short term, but unfortunately her father was moved right back into a shared room as soon as Madeline returned to work.

I knew he was palliative ... and I think that’s all the more reason that they should have a single room where family can spend time with them. So I got rather obstreperous with them. I spat the dummy basically with the doctor and what not. He said his hands were tied and he couldn’t do anything and I said well I think you can. ... and so they basically put him in a single room until I came back to work ... and [then] moved him straight [back] out into the ward. [Madeline]

Neglect or lack of nursing attention in relation to the parent’s care also led to participants fixing by intervening on their parent’s behalf to provide the necessary care. Participants sought out the nursing staff if staff repeatedly failed to respond to their parent’s buzzer or if their monitoring alarm did not attract RNs’ attention.

After listening to the ‘beeping’ for several minutes and having no-one coming, I usually stopped the alarm and went and found a nurse. I don’t know what happened when either myself or my sister (who is an EN) were not there. [Eliza]
[My mother] buzzed and buzzed and buzzed and then I went down to the desk and said doesn’t the buzzer work, doesn’t it get this far, and “oh yeah yeah, we’ll be there in a moment” and they didn’t come. And I went back ... And they were getting quite angry with me, but it was obvious that they were just sitting chatting and laughing behind the desk. The lack of just basic nursing care upset me. I was really stirred up about it. They didn’t seem accountable for anything they did. [Jack]

Jack felt powerless and angry knowing that the staff had dosed his mother up with Morphine and that they did not expect her to survive.

There was a certain air that they might take her out with it (Morphine). It was a matter of “shut her up so that’s one we don’t have to worry about tonight.” [My mother] was not expected to make it. [Jack]

Sarah’s mother was left in an undignified mess due to a leaking ileostomy appliance. Sarah showed patience, restraint and tolerance towards the nursing staff when her mother was not being cared for correctly, so after tolerating three days of incorrect care which the nursing staff had unscrupulously (or in ignorance at best) had defended as normal practice to a non-RN aunt, Sarah then let the staff know.

As Mum was dying from cancer it was horrible. She went in for a palliative ileostomy. ... I would change her and clean her up [every lunch-time and tea-time] and elevate her legs that were very swollen. After 2 days of this it was time to let staff know. They even referred Mum to the stomal therapist. She ordered appropriate bags that didn’t leak and mum’s legs were always elevated. [Sarah]

Claire ensured that her mother’s request to stay overnight was made possible by not allowing the ward staff to deter her, and following it up with the nursing supervisor to ensure they provided a pull-out bed for her.

It was very much a vigil. Mum really didn’t want to leave at any time so, they arranged for a little pull-out bed to be bought in... which was really nice; but it was something I had to go searching for and find it, find the evening supervisor and all this sort of stuff because they didn’t know whether it could be done and I said oh come on. I was getting a little bit frustrated and in fact I wouldn’t have liked to have me as a visitor. But, there comes a time when you just say: I’ve had enough of this. [Claire]
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Cameron was assertive in stating that he and his mother would stay longer in the room when his father died despite (what he considered) an unreasonable request by the priest for them to vacate the room.

When the priest was ... hassling a bit ... he'd done the last rites and Dad's dying and my mum was feeling a lot of pressure. So that was a great relief [for Mum] to know that we don’t have to vacate the premises within two minutes and so when he came back and said that they actually want to straighten him up and do that ... in ten minutes .. and he came back to say that again ... it was from my palliative care experience I was able to say ... you know we're fine ... would you go .. I'm sure you’re busy ... and my mum was really pleased at that time. .. my mum had her own internal pressure being that they probably need the bed ... and I was saying no, we can stay here for ... all that time.

Generally people find hospitals very scary intimidating places where they tend to leave all their rights as a human being at the door when they walk in, so being an RN ... you’re open to that it's just another work place in a way, so you are able to say ... no, I still have my rights, as a human being ... so, it's probably your RN positive thing and ... as far as helping my family, it's not a matter of ... put this thing down I want it now, it's a matter of being able to say well that's an unreasonable request, this is a reasonable one. [Cameron]

The burden was especially onerous in Olivia’s case where she led the decision to withdraw her father’s life support, particularly because of opposition from the neurosurgeon whose recommendation to continue life support was seen by Olivia to be unreasonable.

The neuro guy wanted [my father] to live and we actually said to him one day: No. You know my dad would shoot a dog like that and we’re not talking metaphorically. This man would not want to live like that. [Olivia]

6.3.2.3 Critically ill/dying parents: preventing death, alleviating suffering

Some participants felt the imperative to intervene to alleviate a dying father’s distress, or to attract the attention of staff for a father who was having chest pain as a prelude to having a cardiac arrest, or to remedy the inadequate pain relief of a dying father in severe pain. When William’s dying father became very distressed and hypoxic, William arranged to get oxygen for him, to have him admitted to hospital and arranged for the palliative care nurse to come and put in a syringe driver.
Towards the end [my father] became hypoxic and he woke late one night very confused and agitated. I couldn’t really help him. I tried ringing doctors ... That was very difficult. ... ended up I did get onto his doctor and she organised for some oxygen. That didn’t help and I had to ring again and then he was admitted to hospital. I wanted him to have a syringe driver because I knew the end was coming. He didn’t seem to be in pain but he was distressed. The local doctor (who I wouldn’t let treat my animals) came and I said no thank you very much you can leave. I then tried to get on to the palliative care unit here which serviced the area and I could not get the palliative care nurse. I rang and rang and rang and rang. She eventually came and put in a syringe driver. [William]

Participants acted to fix problems especially during a crisis. Cameron was persistent and made several insistent requests of nursing staff to come and have a look at his father who had deteriorated suddenly, was having chest pain and looked critically ill.

People... things were so laid back [on the ward] to the point where I actually found it hard to get things happening, even just getting some Anginine and when he first started having chest pain and trying to make the nurses aware that this was quite a serious situation so it was more like “oh yeah ... he gets chest pain all the time” and I’m saying no ... I think it’s more than chest pains ... I’d like you to have a look at him. So to get someone to do the blood pressure and that sort of thing ... I had to jump up and down a fair bit ... [My father] became really cold and he was shaking so the first thing was asking ... looking for a blanket and then he told me he had chest pain so it was probably a series of requests that I had. And for every request it was a matter of where are the nursing staff, and trying to find them, I rang the bell, and there was no response ... and I found people doing things in other rooms and so that was possibly an annoyance for the nursing staff that I was asking them to stop what they were doing and do this. [Cameron]

Eva tried to be the fixer by being insistent and exerting influence over senior staff to achieve a much needed outcome for her father.

His pain relief became an issue. He was receiving conflicting management strategies concerning his pain relief depending on who was there to administer it at the time. He was still in pain. I felt it wasn’t good enough. I hunted down the Nurse Unit Manager and paged the oncology registrar myself and managed to get my father’s pain relief sorted out satisfactorily. [Eva]

Claire described her harrowing experience when her dying father was in extreme pain and begging for drugs to put him out of his misery. She felt helpless and felt that she was letting her father down. Claire had very high expectations of herself: “with all my experience/knowledge ... I should be able to ‘fix’ everything”.

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It was really bad and he died probably 12, 16 hours later; after he finally got the Midazolam upped. I feel really sorry for the young doctor. He was a resident that I was screaming toe to toe with ... actually not screaming but just saying you're going to do something and you're going to do it now or I'm going to do it. And he was saying: “no I'm sorry I can't do anything else.”

Well I really felt I was letting him down. I thought what is it I can do? Where will I find drugs? This is what was going through my mind ... and I thought this is ... totally illegal. That actually would be murder and I thought I don't care. In the end I just ... went above everybody else, rang palliative care people, I rang the consultant at home ... and when he came in and just held onto Dad's hand and he said: “mate you know we're just going to give you more and more and it might kill you quicker.” And Dad said “just do it” And then they did it. But for at least a stretch of six hours it was excruciating and I was powerless, I really just was powerless and I've never in my working life felt like that [Claire]

6.4 SUMMARY OF FINDINGS (PART THREE)

The phenomenon of being in the middle which was introduced in Chapter Four encompassed three categories: disclosure of RN status, RN on standby (being expertly vigilant) and RN in action (imperative to intervene). The findings in relation to disclosure of RN status were presented in Chapter Five. This chapter focused on the findings in relation to the final two categories of the phenomenon of being in the middle: RN on standby (being expertly vigilant) which encompassed four themes: leading and staying strong at any cost; expertly observing, detecting and protecting; being adept at hospital language; and keeping it real; and the RN in action (imperative to intervene) category which encompassed two themes: filling in the gaps and fixing.

6.4.1 Summary findings: RN on standby (being expertly vigilant)

6.4.1.1 Leading and staying strong at any cost

Participants usually played the most active role in their parent’s hospitalisation regardless of whether the parent’s spouse was available to play this role. Spouses tended to defer to the participant’s expertise: particularly if the participant was the eldest child, was the only RN in the family, and lived geographically close to the parent. The only
instances where the parent’s spouse played the leading role was where the participant was not the offspring of the spouse (however this amounted to a de-facto leading role for these participants) and in one other case, where the participant was young, had just qualified as a RN and was being shielded by her father because her mother was dying. In some instances their RN-siblings played the leading role particularly if the RN-siblings were older and lived closer to the parent. For a minority of participants, their lay siblings played the leading role if they were not employed and had more time or if they lived closer to the parent.

Where possible, participants usually had face to face contact with parents and with staff. In many cases they had telephone contact with parents but this was not a substitute for being present. Where possible participants tended to have face-to-face contact with parents and the importance of being there for the parent was reported. Many participants also had telephone contact with staff. Telephone contact with staff was reported by some participants to be an unsatisfactory means of obtaining useful information, and for some participants, telephoning the hospital staff was confined to routine checks of their parent’s condition and to pass on messages to their parent that they were on their way to visit.

Participants kept their emotions under control and remained strong and positive in their support and assistance to the family until the parent recovered or the crisis was over. They often juggled their personal responsibilities to achieve this. Their nursing expertise led to continually worrying privately about the parent, but they shielded the parent and family as much as possible from worry by acting as an intermediary between the hospital staff and family members and by keeping their hunches about the parent’s poor prognosis, knowledge of possible complications and observations about the inadequacies of hospital care to themselves. Participants sometimes played a leading role in life and death situations and decisions, and the impact of decision-making was especially burdensome leaving feelings of regret, guilt and inadequacy. There were sometimes negative repercussions (such as being blamed by family members) and at times conflict within the family as a result of the participant playing the leading role which in some cases resulted in feelings of guilt and inadequacy in the participant.
Participants also suffered spill-over into their professional nursing role. For some participants, continuing to work as a nurse was extremely difficult and served as a constant reminder of their parent’s hospitalisation, and evoked painful memories. However some participants noted they had more empathy for their patients and their patient’s relatives as a result of their experiences.

6.4.1.2 Expertly observing, detecting and protecting

Participants were protective of their parent by being present and vigilant. The importance of being present by their parent’s side was reported (for extended periods in some cases where the parent was critically ill). The RN on standby was ever expertly vigilant, keenly and expertly observing every aspect of the parent’s care and treatment, and being present at the bedside as much as possible with the purpose of reassuring and supporting the parent and the family emotionally. Participants described expertly observing their parent, and observing the way the nurses cared for the parent and the other patients (as this provided an indication of the caring manner and competence of staff toward patients generally). Being vigilant served a number of purposes. One purpose was observing the parent’s condition and progress and having the expert knowledge to interpret their signs and symptoms. A second purpose of participants’ vigilance was to detect changes in the parent’s condition, and deficiencies in care or errors in treatment. Participants often detected instances of neglect in their parent’s care, errors in the care provided by staff, and ineffective pain management practices. On occasion life threatening changes in the parent’s condition were brought to the attention of staff but were sometimes treated casually (by nursing staff) or dismissively (by medical staff). Maintaining a physical bedside presence served a protective function: a reminder to staff to be attentive to their parent’s needs, and ensured they were available to speak up on their parent’s behalf if necessary.

6.4.1.3 Being adept at hospital language

Participants acted on behalf of the family and interpreted medical information and terminology for them. They also represented the family and communicated with staff on
their behalf. Using their expert knowledge they advised the parent and family about treatments and of the parent’s progress and prognosis.

6.4.1.4 Keeping it real

Participants found it necessary to correct any misconceptions that family members had about the parent’s condition to keep them in touch with reality and to avoid the devastating effect of subsequently having their hopes dashed. At times participants spoke up to correct the family’s misguided ideas about the parent’s prognosis or expectations of improvement and this sometimes challenged family members who were in denial and altered the family’s hopes of the parent’s recovery, which sometimes sparked conflict between participants and family members.

6.4.2 Summary findings: RN in action (imperative to intervene)

6.4.2.1 Filling in the gaps

Female participants mentioned that staff avoided them and their parent as soon as they found out that the participant was a RN and some were expected to be their parent’s private nurse. Sometimes the care that was provided by staff was inadequate and neglectful. This led some female participants to provide hands-on care for their parent to fill in the gaps. Some participants did not engage in performing nursing care for their parent because the care provided by the staff was acceptable or in some cases excellent; because the participant lacked the relevant experience; because they were not willing to intrude on their parent’s privacy; or because the parent was dying and the participant trusted the staff and did not think it was appropriate to interfere by performing nursing care for their parent.

Male participants were especially mindful of not interfering directly with the work of the staff. They rarely assisted with hands-on nursing care to fill in the perceived care gaps and only did so when staff requested their assistance. Male participants usually attempted to address gaps in care by asking staff to give the care needed.
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In some cases the care given by participants to their parent over-stepped child-parent boundaries embarrassed the parent and did not feel right to the participant (and in William’s case led to regret). This involved assisting with toileting, sponging the parent and providing care related to incontinence. The spouses of some participants’ parents were worried about upsetting the staff when the participant performed nursing care for the sick parent and initially disapproved of this. However they eventually relented because the sick parent needed the gaps in care to be filled.

6.4.2.2 Fixing

Participants sometimes felt compelled to intervene in their parent’s medical management. Participants felt the imperative to intervene in response to family expectations; lack of attention, neglect, unreasonable requests or errors in relation to their parent’s care; and high priority immediate needs to prevent death, and alleviate suffering of critically ill or dying parents.

Some participants were called upon (usually by the parent’s spouse or the parent) to intervene. In some cases this entailed taking the parent home (that is discharging them) or arranging a transfer to another hospital for better treatment.

At times participants intervened in relation to matters involving the medical staff: William demanded the doctor return to the hospital to see his parents; Rachel challenged and rejected the doctor’s incorrect medical management of her mother; Lucy provided the medical evidence to overturn the doctor’s inclination to reject her father for hospital admission; and Madeline influenced the doctor to arrange a single room for her dying father.

Participants were sometimes compelled to intervene by requiring staff to attend to their parent’s needs when the nursing care for the parent was lacking: failing to respond to the parent’s repeated buzzing for a pan; failing to notice an alarm beeping; using incorrect ileostomy appliances which caused embarrassment and discomfort by allowing leakage to occur all over the parent; and ward nurses giving excuses for not arranging a pull-out bed for the parent’s spouse who wanted to remain with the parent over-night. When
Cameron’s father died, his mother wanted to stay in the room a little longer, so he rejected the priest’s suggestion that it was time for them to leave the room. Cameron did this because (from his palliative care experience as a RN) he recognised this as an unreasonable request.

Some participants felt the imperative to intervene to alleviate a dying father’s distress by mustering all the necessary personnel to attend to the parent’s various needs; to hunt down the staff and impress upon them the urgency and seriousness of the situation: for a father who was having chest pain as a prelude to having a cardiac arrest; or to remedy the inadequate pain relief of a dying father in severe pain by ignoring the unwillingness of ward staff to alleviate their parent’s suffering by directing their requirements to nursing staff members’ superiors and/or more senior medical staff.

6.5 IN CONCLUSION

Participants played a leadership role in their parent’s hospitalisation. They denied themselves emotional release during the crisis and directed their attention and their energies to supporting the parent and family members by being positive and staying strong and shielding them from as many of the worrying elements of their parent’s hospitalisation as possible. They tended not to share their hunches and worries with anyone, and sometimes commented that no one inquired how they were coping. They spent as much time as they could with their parent and closely and expertly observed the parent and their care and detected changes in their condition or deficiencies and errors in their treatment. They protected the parent by their presence and by providing reassurance and support. Participants sprang into action mode when they felt the imperative to intervene.

Gender differences were noted in that female participants who perceived important gaps in the parent’s care usually acted by filling in gaps themselves, whereas male participants acted by bringing these gaps to the attention of staff to fill them. In some cases male and female participants identified that immediate action was needed to fix
high priority problems relating to their parent’s medical management which required intervention by staff. Both male and female participants engaged in assertive behaviour to fix the problem by ensuring that staff responded to their parent’s needs.

The next chapter (Chapter Seven) returns to the research question and contains a summary and discussion of the major findings linked to relevant literature, notes the limitations of the study, and concludes with recommendations for practice, education and future research.
7.1 DISCUSSION OF MAIN FINDINGS
This chapter returns to the research question and contains a summary and discussion of the main findings linked to relevant literature, notes the limitations of the study, and concludes with recommendations for practice, education and future research.

7.1.1 The research question
The research question for this study was:

- What are RN-sons’ and daughters’ experiences of their parent’s hospitalisation?

The purpose of this qualitative study was to describe and interpret registered nurses’ experiences as relatives during their parent’s hospitalisation. In the context of their parent’s hospitalisation, RNs had a dual identity: they were sons or daughters and they were off-duty health professionals.

7.1.2 The main findings
The overriding phenomenon identified in the findings chapters was being in the middle. Participants were never just a son or daughter, nor were they ever purely a RN, they were both, and aspects of each identity surfaced in response to their experiences. This dual identity was evident in describing their experience of parent hospitalisation. The RN-identity of almost all participants became known through various means to hospital staff and as a result participants were publicly balancing their dual identity and role, and therefore had the added pressure of managing their dual identity in their interactions with hospital staff.

Disclosure of RN status to staff by a RN-offspring of a hospitalised parent has not been reported in the literature to date. It was identified in this study as an important aspect of
participants’ experiences of parent hospitalisation because it signalled their RN identity to staff members who then interacted with them as a RN. For disclosed participants, the response of nursing and medical staff and the nature of participants’ interactions with staff varied according to the extent of mutual trust between them, and according to the level of confidence and competence of the nursing staff.

In situations of urgent or high priority need there were advantages to the parent if the participant disclosed their RN status (particularly to medical staff) in that a successful outcome was usually achieved. However there were disadvantages of disclosure for the participant and sometimes to their parent unless a relationship of mutual trust had been established between the participant and the nursing staff.

Participants were RNs on standby (being expertly vigilant) throughout their parent’s hospitalisation, and if the need arose they switched to RN in action mode with the imperative to intervene because of gaps in their parent’s care (filling in gaps) or because action was needed to meet a pressing need (fixing). Sons and daughters both engaged in fixing behaviour regarding their parent’s medical management. With regard to nursing care, daughters tended to fill the gaps themselves whereas sons sought to get staff to fill the gaps.

The main findings regarding the phenomenon and its categories and themes are summarised in Figure 7.1 below and are then discussed in relation to the literature.
The phenomenon of being in the middle:

Participants experienced identity conflict and role confusion; they yearned to be the offspring but wanted the power of a RN; they behaved as the rational RN and yet privately they experienced the emotions as a child of the parent. As a result, emotional support for participants was lacking because family and staff members perceived them to be coping. Findings for the categories and themes of being in the middle are summarised below.

Disclosure of RN status:

Participants preferred to remain undisclosed: because disclosure was unnecessary; and they preferred to be treated as a lay son/daughter: because if they disclosed, their actions could be misinterpreted as criticism and not viewed objectively; staff became hesitant, uncomfortable, fearful and felt threatened; nurses communicated less and gave less care; and because participants might be called on to assist parents with personal hygiene.

Participants disclosed to activate RN power and credibility: Participants disclosed to be treated as a peer/colleague in order to: be regarded as a credible source of information and obtain detailed information from staff by dispensing with perfunctory information (participants succeeded with doctors but not with most nurses); to gain staff support (participants known and trusted were supported, and those not trusted were considered a threat, avoided and not supported). Participants disclosed to get action in order to: place the parent (on day leave) in the care of the participant; to train the nurses to use the parent’s medical equipment; to address instances of incorrect and neglectful nursing care; to justify the parent’s admission to hospital; to ensure priority treatment in an emergency; to correct errors in medical treatment; and to arrange urgently needed pain relief for a dying parent.

RN on standby (being expertly vigilant): Participants engaged in leading and staying strong at any cost: They usually played a leadership role especially if there were no other more senior, proximal, not working and RN-siblings; they maintained contact with the parent and staff during hospitalisation and spent extended periods with the parent especially for critically ill parents; participants were busy being the strong one and making sure all others were alright and neglected their own needs; they shielded the parent and family from worry; privately shouldered a lack of hope, hunches about diagnosis, poor prognosis, and worries about possible complications and care inadequacies; they played the leadership role in life and death situations and decisions; and they experienced personal and professional repercussions in the aftermath of hospitalisation crises. Participants expertly observed and detected changes in their parent’s condition and protected the parent. They adeptly interpreted and used hospital language and kept the family in touch with reality about the parent’s condition (keeping it real).

RN in action (imperative to intervene): Daughters filled gaps in nursing care especially as staff often left the care to them; sons asked staff to fill in the gaps and only assisted at the request of nursing staff. Filling in the gaps was sometimes uncomfortable and embarrassing when it involved over-stepping child-parent boundaries. Participants fixed medical mismanagement in response to family expectations; to prevent death, alleviate suffering, and handle life/death situations; and to address shortcoming in care such as inattention, neglect, unreasonable requests and errors.
7.1.2.1 Identity conflict and role confusion

Participants experienced role confusion when aspects of their identity as a RN clashed with their identity as a son or daughter of a sick parent. As described in Chapter Two, role confusion had also been reported in RNs’ personal accounts and studies of caring for a family member in home settings (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Stoner, 1998; Ward-Griffin, 2004); and in relation to a RN’s account of a hospitalised relative (Rufano, 1985). A recent study by Lee (2009) also highlighted tensions between RNs’ professional and personal boundaries in caring for a dying family member at home; as did a study involving doctors, nurses, physiotherapists and social workers who provided care at home for elderly relatives (Ward-Griffin, Brown, Vandervoort, McNair & Dashnay, 2005). Unlike caregiving within home settings where professional caregivers are outsiders, the situation is reversed within the hospital setting: the family members are the outsiders (Lindhardt et al., 2006; Surpin & Hanley, 2004). In the present study, the added constraints on participants’ behaviour within the formality of the hospital context intensified the frustration and helplessness they experienced when they witnessed unacceptably substandard care of their parent.

Similar problems have been reported by physicians in personal accounts noting their inability to display emotions, and their experiences of conflict between their role as doctor and their role as son or daughter (Anonymous, 2002; Gordon, 2006; Lancaster, 1996). Physician-relatives found they could not carry out either of their roles to their satisfaction: internally there was conflict between their ideal role as a family member and their ideal professional identity and externally they experienced conflict from the uncomfortably high expectations of family members and the expectations of other physicians (who either regarded them with suspicion due to their intrusiveness or expected them to take part in their parent’s care). The physicians found it difficult to reconcile these differing expectations when they encountered inadequacies within the health system. Identity conflict and role confusion have also been identified as posing significant difficulties in a qualitative study of physicians’ personal experiences of their fathers’ health care (Chen, Rhodes, Green & Graham, 2001; Chen, Feudtner, Rhodes, & Green, 2001; Villarosa, 2001).
In a similar vein, Campbell (1999) cautioned fellow doctors against acting as the attending physician for a hospitalised family member because of the difficulty (or the impossibility) of remaining objective and separating the parent-child relationship from the physician-patient relationship. The difficulty of being objective was also reported by participants in the present study. On the other hand, Klein (1997) Slater and Wells (1997) doubted the wisdom of completely dissociating the role of family member from that of physician family member on the basis of their personal experiences involving critically ill hospitalised relatives. Klein would have liked to be able to abide by the maxim: “You be the husband and let me be the doctor”, however his retort was: “Right, if you’d be the doctor, I could be the husband”. This exemplifies the situation which arose for some of the participants in the present study who were compelled to intervene to serve their parent’s best interests. The confusion between being an offspring and a nurse was sometimes defused in the present study by explicitly stating a re-definition of the boundaries along the same lines as the maxim quoted by Klein. This was achieved in situations where the staff (or a trusted RN-friend) could be relied on to look after the parent by a statement of intent: “You be the daughter, I’ll be the nurse”. This meant that the participant was not required to come to the parent’s rescue. This approach was also effective in defusing the anxiety of staff and dispelling their defensiveness by the participant saying “I’m actually a daughter at the moment – that’s all I can be” even though the daughter privately was still thinking like a RN. This strategy was effective because the RN-offspring was able to trust and rely on others to be the nurse and therefore did not feel any imperative to intervene in the care provided by staff.

In a North American survey of 1500 nurses at eight diverse hospitals (30% response rate) Gillies, Child and Biordi (1993) investigated how nurses’ experiences of their own hospitalisation (or the hospitalisation of a family member) had affected their nursing practice. Most respondents reported they had gained insight through “being on the other side” (p. 70) as a result of personal or family experiences of hospitalisation and had become more compassionate and attentive to patients’ needs as a result. This was also the case for some participants in the present study who noted their empathic skills were enhanced as a result of their experiences of parent hospitalisation, although continuing to work as a nurse in a hospital setting was reported to be very difficult as it was a constant reminder to participants of their parent’s suffering and their own. Similar problems were described by cancer nurses
in Baird’s (1988) community-based study who found it difficult to nurse cancer patients because they had the same diagnosis as their parent; and by Nicholson, (1995) a community nurse, who was no longer able to nurse cancer patients after her husband died of cancer at home in her care.

Further examples of dual role difficulties which were experienced by health care professionals have been reported in the literature for HCPs who found themselves in the anomalous role of ‘patient’. The experiences of RNs in the dual role of patient and nurse have been described in personal accounts (Anonymous, 1993; Coleman, 1995; Edler, 1985; Eisen, 1984; Evans, 1995; Mayer, 2008; Motzko, 1988) and in research studies (Cotter, 1990; Harker, 2000; Morris & Mendias, 1985; Williams, 1998; Zeitz, 1999). RN-patients referred to their role confusion, and noted that staff usually treated them as a nurse first and a patient second and expected them to act more like a nurse than a patient.

Cotter (1990) described the liability of being a nurse when they became a patient. This involved RNs’ dawning realisation that they were not immune to illness, did not possess superior coping skills, and also had to contend with “their own and other people’s expectations of how nurse-patients should behave” (p. 173). Nurses tried to be (and were expected to be) good patients: to look after themselves (and sometimes their fellow patients); and to tolerate pain without complaint; and to be uncomplaining generally. The basis of their role conflict appeared to be their distinct delineation of the two roles which are traditionally perceived to be at opposite ends of the continuum between wellness and illness, and between the active, capable nurse versus the passive vulnerable patient. RN-patients were tense due to the “double consciousness” (p. 171) of observing and evaluating their care and treatment from the perspective of patient and nurse, and were given minimal information by staff. They felt trapped in the nursing role and would have preferred to be treated like a patient. RN-patients’ resulting status as ill nurses was described as being “in between” the two roles (p. 173) which prevented them from being able to express their feelings. The situation of nurse-patients is analogous to the situation of nurse-relatives in the present study: RNs had difficulty expressing their feelings as RN-relatives; their information needs in the present study were generally not met; they tended to be avoided by staff and left to look after their parent; they wanted to be treated like a lay son/daughter to avoid negative consequences; and
they experienced being in the middle from the dual perspective of a RN and as a son/daughter.

Illness narratives of 25 health providers (mostly physicians/medical trainees) in the challenging situation of being both a consumer and provider of health care were analysed and reported by Kempainen, Bartels and Veach (2007). They found that health providers experienced fear, stress and helplessness, shock and disbelief when they became consumers of health care, and they also reported role reversals when health providers switched from provider to health consumer; they experienced role enhancements because one role informed the other, and also experienced role conflicts because the boundaries between the two roles became indistinct. These findings are analogous to the findings in the present study: participants also expressed emotions of fear, stress, helplessness, powerlessness, shock and disbelief in response to their parent’s hospitalisation; there was a tendency for participants to experience incompatible elements of their son/daughter identity and their RN identity; their RN expertise enhanced their role by expertly observing, detecting and protecting their parent, and by interpreting and representing the family using hospital language; and when participants intervened to address high priority needs in relation to their parent’s care their two roles (as RN and son/daughter) became indistinct.

In a study by McKevitt and Morgan (1997) of the experiences of doctors who had become ill, doctors were described as anomalous patients because the two roles which are generally held to be separate – ‘patient’ and ‘doctor’ – were confounded, and thereby created identity confusion. As with nurse-patients, patient-hood was incompatible and inimical with doctors’ professional identity (which reinforced the idea that doctors and patients have mutually exclusive roles). Some doctors minimised their symptoms, and did not want to be perceived to be misjudging their symptoms or over-reacting to them. Models of the relationship between the treating physician and the medically qualified patient were proposed by McKevitt and Morgan which assigned a low or high level of control to either doctor or patient. One model was based on the view that medically qualified patients are extraordinary patients with extraordinary needs derived from their status as a doctor. Doctor-patients’ desires for autonomy and involvement in decision-making were found to be similar to that of lay patients, however, doctors were reported to need more reassurance because their medical
knowledge produced added fears; and they needed to be treated in a non-subservient manner by a doctor who possessed more advanced knowledge than their own.

The findings of previous studies reported in this section provide points of similarity with participants in the present study regarding the identity confusion experienced by RN-sons/daughters with hospitalised parents. Participants also reported that their nursing knowledge produced added fears about the parent’s diagnosis, prognosis, possible complications and the inadequacies in hospital care that they detected. Participants worried about misjudging their parent’s signs and symptoms (especially because participants thought their judgement may have been impaired due to their lack of objectivity) and did not want to overreact in case they were mistaken as this would cause unnecessary worry for the family and could lead to inappropriate treatment if hospital staff acted on the participant’s judgment.

7.1.2.2 Disclosure of RN status to hospital staff

The issue of disclosure of professional status by RN-relatives to hospital staff has not been reported in the nursing literature. Some information has been published concerning disclosure when RNs are patients (Coleman, 1995; Edler, 1985; Morris & Mendias, 1985; Williams, 1998; Zeitz, 1999). In a North American survey of 61 physicians and 131 nurses, only 34% of nurses reported that they routinely disclosed their professional status when they themselves were patients, and 23% reported they make a point of not mentioning it (Morris & Mendias, 1985). The preference of almost all participants in the present study (97%) to remain undisclosed is a more extreme finding, and may indicate that RN-relatives are even less likely to disclose their RN status to hospital staff than are RN-patients, or that Australian RNs are far less likely to disclose their RN-status to hospital staff than North American RNs.

In contrast to nurses’ preferences regarding disclosure of their professional status, Morris and Mendias (1985) found most physicians (64%) did routinely disclose their status and only 2% did not do so. Nurses and doctors were also asked how confident they were in their clinical abilities when treating a colleague as compared to a lay patient. The responses showed that 14% of nurses lost confidence when treating nurses and 19% lost confidence when caring for physicians, whereas only 3% of surveyed physicians felt less confident treating nurses, but 16% felt uncomfortable treating fellow doctors. Nurses’ lower levels of confidence when
treatment of fellow health professionals (compared to physicians’ lack of confidence) may be due to the disparity in the levels of professional expertise and education between nurses and physicians. Similarly, nurses’ lack of confidence in treating fellow nurses may reflect such disparity they perceive in relation to the nurse-patient they are treating. Morris and Mendias’ (1985) finding regarding nurses’ lack of confidence when treating fellow nurses is consistent with the views of participants in the present study. Specifically, that nursing staff who lacked confidence in their clinical abilities responded in negative ways to participants whose RN status was disclosed, whereas nursing staff who were confident in their clinical abilities did not exhibit avoidance behaviour or act defensively when dealing with participants who were known to be RNs. Participants found that disclosing their RN status to nursing staff often created discomfort but that this was able to be defused at times by the participant admitting lack of specialty expertise and thereby being perceived as less of a threat to the nursing staff.

Zeitz (1999) found that the response of nursing staff to knowing that their patient was a nurse varied from indifference to defensiveness (as was the case in the present study) and Coleman (1995) proposed three reasons to explain why nursing staff tend to avoid RN-patients: firstly because it may allow RN-patients to retain some control of themselves; secondly, because staff expected RN-patients were likely to be assertive or aggressive toward them in order to exercise control; and lastly because nursing staff typically avoid deviant patients (and staff would classify RN-patients as deviant).

Williams’ (1998) qualitative study focused on the power relations between the female nurse-patient and the female nurse providing care, by interviewing six female RN-patients about their experiences of hospitalisation and why they chose to disclose or withhold information about their professional status. Williams’ reason for disclosing her status when she was a nurse-patient was to gain more control and involvement in decisions concerning her well-being (although this aim was not always achieved). However she reported that nurses often do not disclose their RN status when they are hospitalised with an acute illness. The findings of Williams’ research reinforced the view that RNs tend to hide their professional status because they do not want to be ignored and left to care for themselves, and they want to be provided with information and explanations. These findings are consistent with some of the findings in the present study in that participants preferred to be treated as a lay son/daughter
because they did not want to risk being ignored or being provided with less information. Participants also did not want their parent discriminated against by being ignored and deprived of nursing care.

Williams (1998) also reported that RNs who did disclose their RN status did so to avoid being treated “like an idiot” (p. 35) and some disclosed in an (often unsuccessful) attempt to obtain the care they desired. This is also consistent with some of the findings in the present study: participants disclosed to activate RN power and credibility; to be treated as a peer or colleague; and to get action. Williams reported that RNs who disclosed tactfully were advantaged (they established rapid communication links, and were offered privileges by nursing staff) because “they had adhered to the rules of compliance and dependency” (p. 35) whereas RNs who boldly disclosed their status thereby demonstrated their rejection of the staff’s compliance expectations of them, and because they did not succumb to staff coercion by becoming submissive, they threatened the power base of the nursing staff and were ignored by them.

These findings are also consistent with the findings of the present study in that participants who did not announce their RN status (but it became known to staff through other means) and who had established a relationship of mutual trust with nursing staff were supported by staff. Williams noted that nurse-patients were more vulnerable than lay patients and in being oppressed, nurse-patients did not trust or respect the nursing staff’s care. Although nurse-patients were aware that being docile and dependent was the way to affect a better outcome, some nurse-patients were not willing to play this game of being subservient. Williams found that the nurse-patient’s frustration and marginalisation were consequently increased when she knowingly rejected these rules. In the present study there was also evidence of marginalisation as a result of openly adversarial behaviour toward nursing staff by one participant who was appalled by the poor standard of care his parent received.

7.1.2.3 RN on standby (being expertly vigilant)

All participants were in the middle. Their baseline mode was RN on standby which involved playing a leadership role in their parent’s hospitalisation by maintaining a strong presence and being expertly vigilant. Being expertly vigilant involved: expertly observing; detecting
changes in their parent’s condition, and any errors and deficiencies in care; protecting the parent; representing the family by communicating with staff using hospital language and interpreting hospital language for the family; keeping the experience real by correcting any misconceptions of family members regarding their parent’s condition or prognosis; and leading and staying strong at any cost for the family during the crisis.

According to the literature, the leadership role of ‘primary caregiver’ is likely to be allocated to (or voluntarily adopted by) the sibling most competent for the caregiving role of the parent (Matthews & Rosner, 1988; Willyard et al., 2008). Other factors such as being the eldest child, being female, having fewer competing commitments, and being geographically available were also identified in the literature as factors which increased the likelihood of being the main caregiver (Matthews, 2002; Matthews & Rosner, 1988; Willyard et al., 2008). This was found to be the case in the present study. Participants were clearly professionally competent caregivers, and in families without other RN-siblings, the responsibility fell to participants who were sometimes assisted by the parent’s spouse or by a sibling who was not working at the time of the parent’s hospitalisation, or who lived closer to the parent. Despite the availability (in most cases) of the parent’s spouse, the leadership role was performed by the participants who reported that the parent’s spouse continually sought the participant’s advice and deferred to the participant’s expertise. This differs from the situation of lay caregivers in that the spouse, as next-of-kin, is usually the primary caregiver and plays the leading role (figures provided by the AIHW in 2008 show that 42% of primary caregivers are spouses and 26% are offspring) whereas offspring play a secondary role (Abel, 1990). In the present study, the family did rely on and expect the RN-son/daughter to take charge and be the strong one because participants were the most competent family member and in some cases they were also the eldest offspring. RN-sons/daughters also had this expectation of themselves.

The shock of seeing a parent vulnerable, helpless or dying and the sadness, grief and anxiety of it were muted by being in charge as a consequence of being the most competent family member by virtue of being a RN. The burden and responsibility of advocating for their parent was in some cases overwhelming when it involved making life and death decisions on behalf of the parent and the family, and left long-term scars of lingering doubts and feelings of
inadequacy, guilt and anger. Feelings of guilt have also been reported in end-of-life care by lay caregivers as a result of “not having done enough” for their dying relative (Andershed & Harstade, 2007, p. 64).

The participants’ priority was to achieve the best possible outcomes for the parent. Participants sometimes yearned or entertained thoughts of being just a son/daughter but acknowledged that being a RN was an advantage in relation to achieving the best possible outcomes for their parent. Participants shouldered the responsibilities of being in charge by behaving with the dispassionate rational professionalism of a RN whilst privately suffering pent up emotions of the child of the parent.

According to Issa (2003, p. 946) health care professionals acting as “double-agents” can trigger conflicts within the family and conflicts with health care providers by acting as surrogate decision-makers of cognitively intact relatives. Most participants in the present study did involve other family members in decisions regarding the sick parent, however, conflict did occur with family members at times because they were in denial concerning the sick parent’s condition or they disputed the parent’s need for analgesia. Family members sometimes blamed the participant for decision-making which resulted in the death of the sick parent and for failing to detect signs of their parent’s deterioration earlier; or in some cases because the participant’s sibling resented the participant’s favoured status with the sick parent. The finding regarding conflict with siblings accords with Abel’s (1989) findings reported in Chapter Two, that sibling rivalries sometimes re-emerged during parental caregiving.

The most prominent themes across the literature for lay caregivers of hospitalised relatives described caregivers’ need to be vigilant which encompassed the need to be physically present for the relative; the need to be well informed by health care professionals; the need to manage their feelings due to the presence of emotional upheaval; the resultant major changes evident in the caregiver’s lifestyle, role and daily rhythm as a result of the relative’s illness and hospitalisation; and the need for the caregiver to look after themselves to be resilient. (Åsted-Kurki et al., 1997; Carr & Clarke, 1997; Carr & Fogarty, 1999; Hall, 1989, 1990; Higgins et al., 2007; Jacelon; 2006; Lemieux, 1996; Li, 1998; Li et al., 2000; Lindhardt et al., 2006; Thorne & Robinson, 1988; Walters, 1995). The importance of being there for their
relative was also often stressed by RN-relatives caring for a family member in home settings (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Nicholson, 1995; Perovic, 1999; Stoner, 1998; Ward-Griffin, 2004).

In the present study the importance of being vigilant was also identified by participants which involved being physically present for the parent especially if the parent was critically ill. The need to be informed at a level which matched participants’ expertise was also identified as very important. Whilst the need for information from HCPs was identified by Mills & Aubeeluck (2006) there was no mention in their study of RNs’ needs for information which was consistent with their level of expertise. Participants usually found they needed to disclose their RN status if they wanted to be given more detailed information by staff. In the present study, medical staff almost always provided more detailed additional information if they became aware of the participant’s RN status, but this was not the case for most nursing staff – they withheld information from participants unless they were confident of their own nursing competence or unless mutual trust had been established between the participant and the nursing staff.

The extent of participants’ emotional upheaval was particularly striking and burdensome as they tended not to allow themselves any emotional release until the crisis was over, mainly because participants were in the role of the strong, rational, dispassionate RN while they were playing the leadership role for their family.

As in previous studies the parent’s hospitalisation did result in major changes for many participants whose parent subsequently died. They were often drained physically and emotionally by the experience and fell apart after the crisis. Unlike previous studies (Carr & Fogarty, 1999; Lemieux, 1996; Li, 1998) participants did not look after themselves during the crisis: they remained the strong one for the family and were kept busy making sure that the rest of the family was alright. No-one questioned their coping skills and because they did not show their emotions they were perceived by family members as coping and (sometimes) uncaring and they were also perceived to be coping by the staff. As a result, participants experienced family conflict and lack of emotional support from both staff and family. No-one asked how they were coping; presumably because they were the strong one and gave no outward sign that they needed support. They also did not actively seek emotional support by
seeing a counsellor – perhaps because they were professionally used to dealing with sick people and did not categorise this experience of their parent’s hospitalisation sufficiently differently as to require special attention, and did not anticipate the significantly greater physical and emotional impact on them of parental caregiving. Participants recognised in retrospect that it would have been very helpful to have someone to confide in during the crisis and to allow themselves some emotional release much earlier than they did.

It has been reported in the literature that RN caregivers of sick relatives experienced emotional upheaval which was intensified because they were under extra pressure (self-induced and due to family expectations) to perform at an expert level (even though they often were not familiar with the relevant specialty) which led to feelings of inadequacy and guilt (Baird, 1988; Harris, 1999; Mills & Aubeeluck, 2006; Perovic, 1999; Ward-Griffin, 2004). This was found to be the case for participants in the present study who also suffered feelings of guilt and inadequacy and were pressured by family expectations and by high expectations of themselves: that they should be able to “fix things”. Participants’ expectations of themselves were very high due to their expertise, and if they fell short of these expectations it preyed on their minds. As with findings in the lay caregiving literature (Mezey, 2004) they wondered whether they could have been more effective, detected earlier signs of illness in their parent and prevented negative outcomes for their parent generally. Levine and Murray (2004, p. 181) also identified this type of deep reluctance by caregivers to acknowledge their “limitations and vulnerabilities in the face of their relative’s more desperate need” as a defining characteristic of the caregiving culture, however there was added pressure for the participants in the present study because as qualified health professionals, they felt that it was unacceptable to acknowledge their limitations and vulnerabilities.

Participants were so busy being the nurse that there was no respite, there was no down-time to allow emotional release. They were emotionally and physically exhausted, and as most participants were simultaneously working and had responsibilities to their spouse and children, the impact of their parent’s hospitalisation was acutely felt (as also reported by Read and Wuest, 2007). Some were supported in their workplace, some were not. Doctors were found to be more supportive within the hospital workplace than nurses. As a result, participants suffered emotional upheaval and health problems after the crisis was over. The
impact on lay caregivers’ health (Mezey, 2004) and on RN-relatives’ health in the aftermath of caring for a critically ill relative has also been noted in the literature (Baird, 1988; Lee, 2009; Mills and Aubeeluck, 2006). Even in the aftermath, participants unintentionally underplayed the impact of the crisis on their own health. Participants mentioned almost in passing such after-effects as suffering a major depression (Sophie), being on anti-depressants (Claire) problems with alcohol intake and consultations with psychiatrists (Andrew) recognising a need for counselling yet not responding to this need (Gail) losing weight, and suffering mental and physical exhaustion (Emma) and experiencing psychological torment over a period of years (Cameron, Kate and Olivia).

For some participants, family members assigned blame to the participant for negative outcomes, and at times self-reckonings were evident years after the event. Life and death decisions were particularly burdensome. The burden of responsibility was overwhelming in instances where the son/daughter conveyed the decision to staff which led to their parent’s death. Regardless of whether the son/daughter was carrying out the parent’s wishes regarding resuscitation, or making the decision to withdraw life support based on their knowledge of their parent’s philosophy regarding the value of life without quality, the responsibility of making the decision was unbearable and continued to trouble them years later. Even if they were convinced that the decision itself was the right one, participants sometimes needed their family’s re-confirmation (even years later) that they supported the decision and were appreciative of the role that the RN-son/daughter had played during the event.

Participants felt the emotions as a child of the parent but maintained a facade of control and did not allow themselves adequate emotional release until the crisis was over. Whilst being the nurse brought an emotional cost to participants, it did provide them with a safety zone in which they could exert some power to improve the care and situation of their parent. Participants switched back and forth between being the distraught son/daughter and into their safety zone of being the RN in control. This experience of switching from being distraught to feeling safe and in control reveals the emotional turmoil experienced by participants due to their dual role and its accompanying high expectations (by self and others), and also provides insight into mechanisms whereby participants are able to find short term refuge and greater
power within their nursing identity during periods of extreme stress such as when the priority is to achieve an important outcome for their parent or family.

7.1.2.4 RN in action (imperative to intervene)

According to the literature there is uncertainty regarding whether relatives want to participate extensively in the direct care of a cognitively intact hospitalised relative (Laitinen, 1993, 1994) or a hospitalised elderly mentally ill relative (Sharp, 1990) or for a relative residing in a nursing home (Russell & Foreman, 2002). Nursing home residents reportedly preferred to be given care by staff rather than by family members (Russell & Foreman, 2002). Lay caregivers of hospitalised relatives sometimes engaged in activities aimed at securing their elderly relative’s safety, and if they were not satisfied with the performance of staff they also performed activities which were usually performed by hospital staff (Lindhardt et al., 2006).

Lay family caregivers of nursing home residents often performed care for their relative to fill in perceived gaps in addition to providing special care tailored to their relatives’ individual needs (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2006; Fleming, 1998; Mahoney, 2003) and sometimes their efforts to engage in caring activities were restricted and constrained by the unwelcoming attitudes of staff (Foner, Henderson, & Vesperi, 1995; Kellett, 2000).

In the current study, female participants sometimes engaged in hands-on care to fill in the gaps left by hospital staff. The gaps in nursing care sometimes occurred because nursing staff left the care to female participants (or to RN-sisters of male participants). Some participants reported it was satisfying to be able to comfort and assist their parent by performing some of the nursing care, however assistance from staff would have been appreciated particularly for tasks which crossed child-parent boundaries and intruded on the parent’s privacy and modesty and caused embarrassment (such as assistance with toileting or changing a soiled bed or seeing a parent’s naked body). In situations where the parent was not being adequately cared for by the staff, some RN-daughters felt compelled to perform these tabooed tasks but felt uncomfortable in doing so. There was only one instance of a son performing this type of care for his father (done to assist a staff member at their request). The son immediately regretted his actions.
If able, the parent may reject the RN-offspring’s nursing assistance due to embarrassment. In the present study, a preservation of the child-parent boundary was achieved on one occasion between a father and his RN-daughter when the father rejected the RN-daughter’s assistance with toileting due to embarrassment and called on the nursing staff for assistance instead. This allowed the participant (Sophie) to keep her daughter-identity and role in the foreground, and allow her RN-identity and role to recede into the background (their RN on standby mode) in her experiences of her father’s hospitalisation.

The content and emphasis of experiences of being a relative to an elderly hospitalised person have been reported to differ between spouses and offspring. Role reversal has been described in previous studies (when offspring take on additional responsibilities in response to a parent’s increasing dependence on the offspring although it appears that this term only reflects the offspring’s perspective and not the parent’s perspective (Fischer, 1985; Lindhardt et al., 2006). One participant in the present study (Ben) did describe aspects of his relationship with his chronically ill mother as role reversal; and there was some evidence of a child’s need for the parent’s approval and acceptance (some participants, for example Claire and Cameron, indicated that their parent’s approval regarding the caregiving leadership role they played was important to them). Information about role reversal from the parent’s perspective was not provided by participants (or purposefully sought because it was outside the focus of this study).

Bowers (1987) found that caregivers identified the protective function of caregiving to be of greatest importance with respect to caregiving of mildly cognitively impaired parents living within the community. This protective function related to preserving the parent’s self-image and dignity. Some participants in the present study felt strongly about not performing direct nursing care tasks for the parent that would cause embarrassment and loss of dignity for the parent and would be counter to their parental image and role. In this respect, Bowers’ protective care category is of relevance for RNs’ parental caregiving and is consistent with Qureshi’s (1990) position on the subject: that personal care may be acceptable from a spouse but not from children.

In the present study participants engaged in fixing in response to medical mismanagement of their parent or to address shortcomings in high priority care. This was not handled in the
same way as lay caregivers who sometimes tried to warn hospital staff to avert errors. The frustrations experienced by lay caregivers as reported by Lemieux (1996) Lindhardt et al. (2006) and Thorne and Robinson (1988) were different in that lay relatives did not possess the same familiarity with hospital processes and systems and did not have the knowledge and credibility to influence staff and to achieve major changes in their relative’s treatment.

Participants in the present study were not easily deterred by staff opposition to their demands for urgent attention particularly in cases where the parent was suffering and needed urgent attention (such as pain relief). In such situations, participants did not take ‘no’ for an answer: they took their demands to more senior or more powerful staff if necessary to achieve the required outcome for their parent. This assertive behaviour by RN-sons/daughters contrasts with the behaviour of lay caregivers who are usually more accepting when staff members are dismissive of their input and requests (Lemieux, 1996; Lindhardt et al., 2006; Soderstrom, Saveman & Benzein, 2006; Thorne and Robinson, 1988). Some lay caregivers are referred to as experts in the literature due to their long-standing experience as family caregivers (Nolan, 2001). Allen (2000) found that the negotiation of a formal-informal caregiving boundary for “expert carers” (p. 166) was difficult for these carers, and took place in an emotionally charged context, and despite the rhetoric of advocating for family involvement in the caring process and valuing and recognising the informal expertise of informal carers, the hospital nursing staff found it difficult to draw on the knowledge of informal carers “in a way which did not undermine their professional identities” (p.167). According to the literature, it appears that despite expert carers’ assertiveness, they too are relatively easily rebuffed by staff when compared to RN-relatives, presumably because they lack the credibility and power of a RN-relative (Allen, 2000; James, Andershed & Ternestedt, 2009; Neufeld, Harrison, Stewart, & Hughes, 2008; Nolan, 2001).

7.1.3 Complementary care

When a parent is admitted to hospital the implication is that the responsibility of providing care for the parent now lies principally with the hospital’s professional caregivers. Kitson (2003) believes that professional caregiving and family caregiving (meaning lay family caregiving) share the same main attributes, and that professional caregiving has a legitimate role only when the lay family-carer (or the sick person themselves) cannot provide the
necessary aspects of care because of lack of commitment, resources, knowledge or skill. When the family carer is a RN, it is possible that their commitment, knowledge and skills may be equal to or greater than that of health professionals employed by the hospital. RN-family-caregivers are professionally competent to provide care and they are also bound to care about their parent in a familial sense. The relationship between the professional caregivers and the family could be seen as complementary where the shortfalls of one are supplemented by the other. Participants in the present study were expertly vigilant and their nursing expertise made it easier to detect errors and neglectful care, and hence shortfalls were typically encountered and provided participants with ongoing opportunities (or imperatives) to supplement the nursing care provided by staff. Within the hospital system the care given by the staff is legitimised and attempts by lay relatives to argue against aspects of hospital care tend to be casually and readily dismissed. In contrast however, RN-relatives’ attempts to override hospital staff care (for example to improve a parent’s pain relief) can be met with hostility and defensiveness but staff cannot be as dismissive towards RN-relatives because of their professional status and because they know the hospital system, and know how to appeal to higher authorities in order to address important shortfalls and errors in their parent’s care.

7.2 LIMITATIONS OF THE STUDY
Limitations regarding the research design include the criteria for inclusion of participants in the study, which was limited to RNs on the register of the NSW, NRB. Some of these participants had not practised nursing for some years at the time of their parent’s hospitalisation, even though they were still registered with the Board, and this factor may have affected their experiences. (For example, there may be differences in the likelihood that they would intervene in their parent’s care with the same level of confidence as currently practising RNs). There was also no time limit specified regarding when the participants’ parents had been hospitalised. In some cases participants within this study were recollecting events which occurred many years ago and particularly for those whose parent had died their grieving process had progressed and may have affected their recollections of their experiences at that time. In contrast, RNs whose parent had died in hospital within 12 months of
participating in the study may still have been actively grieving and this may have intensified their recollections of their experiences.

RNs who volunteered to participate may not represent the experiences of RNs generally. It is possible that some volunteers may have chosen to participate because they had unusual or extremely distressing experiences regarding their parent’s hospitalisations, and therefore the findings may provide a somewhat distorted view of RNs’ experiences of parent hospitalisation generally. This limitation relates to the generalisability of the findings which suggests that as with qualitative studies generally, caution is to be exercised in applying the findings to the general population of RNs.

My influence as the researcher in framing the research question based on my personal experiences of parent hospitalisation is clearly a significant element in the decisions that I made regarding the focus and conduct of this study. I also considered the stage I had reached in grieving for my parents who had both died in hospital (my father died in 1997, and my mother in 2002) and concluded that I was ready to undertake the study. Despite the great care and attention which I have paid to rigorous processes, the analysis and interpretation of the data may have been inadvertently biased by my experiences, and may have also influenced the conceptual parameters of my search of the literature for useful insights from other fields. On the other hand, my personal experiences provided me with valuable insight regarding the research topic which had the advantage of providing me with added receptiveness and perceptiveness concerning the phenomenon being studied.

There was no opportunity with questionnaire respondents for follow-up questions or clarification of answers as they had responded anonymously. Interviews were either conducted in person or by telephone depending on the participants’ preferences. There are some limitations to conducting interviews by telephone in that non-verbal cues are missed. However in deciding to offer participants a choice of communication medium, this weakness was offset by the advantage of providing participants with added distance and anonymity which facilitated more candid reporting of their experiences; and by the knowledge that participants’ preferences with respect to opting for a face-to-face interview or a telephone interview were accommodated to maximise their comfort level.
This study focussed only on the RN-relative and did not include the experiences of the hospital staff (RNs and doctors) or the experiences of the hospitalised relative. It is reasonable to suggest that the preferences and perspectives of parents (of having a RN-son/daughter) and those of the hospital staff (dealing with the RN-son/daughter) would be enlightening when designing strategies to achieve a collaborative team approach in order to maximise the quality of care to hospitalised people.

7.3 RECOMMENDATIONS FOR PRACTICE, EDUCATION AND FUTURE RESEARCH

7.3.1 Practice and Education

Recommendations for RN sons and daughters resulting from this research include the importance of sharing critical decision-making with family members to avoid feeling isolated and personally responsible for negative outcomes, and the benefits of having someone to confide in for emotional release during the stressful episodes of caring for a parent. The advice given by experienced clinicians, academics and unit managers (readers of the Journal of Gerontological Nursing in response to the question of how to deal with a RN family member who attempts to manage the care of their relative) identified three main areas of action to be taken: to treat the patient in the context of the family group and build trust by involving the RN-relative as a partner in the care of their sick relative; to meet the RN-relative’s needs for information; and to provide them with emotional support in recognition of their stressful situation (Mastro et al., 1997).

Involving the RN-relative includes understanding their need to have some control and treating them as a colleague by joining forces and using their knowledge and connection with the patient to enhance the patient’s care (rather than shutting them out and treating them as adversaries) by asking their opinion concerning their parent’s care; and asking them about their role as a RN-relative (a strategy that was suggested by a participant in the present study). Providing for RN-relatives’ information needs includes recognising that being a RN “does not equate to all encompassing knowledge” (Mastro et al., 1997, p. 45) and therefore there is a need to share information and explain as much as possible using terms with which they are
familiar. In many cases RN-relatives in the present study were not familiar with the specialty relevant to their parent’s case, and therefore they needed to be provided with comprehensive information.

The recognition by staff that RN-relatives are likely to be stressed and experiencing heightened levels of anxiety and helplessness; in addition to reminding the RN-relative of their need for support as a family member; and offering them emotional support (which they are likely to appreciate) may also help build a foundation for mutual trust and collaboration (Mastro et al., 1997). Explicit statements by staff and by RN-relatives of a re-definition of role boundaries at the outset of their parent’s hospitalisation may also be effective in reducing the stress experienced by both parties, particularly if this occurs within a context of mutual trust.

Ronch (2004) identified major issues typically responsible for creating friction between a hospitalised person’s relatives (which he calls the problem team) and the health care team (which he calls the solution team). Ronch suggested that this idea of competing teams can also create significant stress among health care professionals when their own relatives become patients because they are torn between their motivations to act primarily as family members and their usual roles as health care providers within the hospital setting. He argues for the adoption of key principles to create an institutional culture of conflict resolution partnership. These principles emphasise valuing the expertise that each stakeholder contributes to achieving the common goal, they remind us that all stakeholders are also family members, and that “everyone wants to be informed as completely as possible about the situation because ignorance breeds anxiety, fear, and anger, and fuels the conflict cycle” (p. 158). This need for information appropriate to a relative’s level of understanding was acutely felt by RN-sons and daughters in the present study. Partnership does not require RN-sons and daughters to perform nursing care. The most important elements are maintaining a dialogue to ensure they are being kept informed and consulted on an ongoing basis about their parent’s condition and care.

Information about RN-relatives’ needs and strategies to improve communication and partnership skills could be incorporated into training programs for HCPs to address the problems identified and an evaluation cycle could be incorporated for the purposes of
continuous quality improvement. Family members could also be made aware of the significant added pressure and stress that RN-offspring can experience as a result of a parent’s hospitalisation. The staff and family members may be able to defuse tensions by providing RN-offspring with emotional support and acknowledging the difficulties that RN-offspring can experience as a result of their dual identity. RN-relatives could also be encouraged to confide in an impartial third party (as was suggested by a couple of participants in the present study who thought in retrospect that this would have provided them with the kind of outlet they needed during the stressful periods of their parent’s hospitalisations).

7.3.2 Future research

Literature regarding the incidence, circumstances and consequences of disclosure by health professionals of their status is lacking and could explore RNs’ and other health professionals’ disclosure in various health related contexts. The experiences of hospital RNs and doctors in dealing with RN-relatives of hospitalised family members would be useful in providing their perspectives concerning RN-relatives disclosure of RN status and its impact on hospital staff. The tendency for some RN-relatives to perform some aspects of nursing care for their hospitalised relative could also be explored in relation to its impact on hospital staff, and could include the perspectives of hospital RNs in relation to relatives assisting with aspects of personal care for their parents.

A systematic analysis of the relationships between hospital nurses and RN-relatives of a hospitalised family member could be useful in shedding light on the dynamic nexus between hospital nurses and RN-relatives and its influence on the experiences of these stakeholders. The interactions between RN-relatives and their siblings is also an area for future comprehensive research as instances of both cooperative and uncooperative behaviours and conflict between the participant and their RN-siblings and lay-siblings were found in the present study. The experiences of male and female RNs of their hospitalised parents-in-law may also provide a different perspective because of their different family attachments which can impact on the RN-relatives’ role and identity and be a source of conflict within the family. In the present study, hospitalised parents were found to reveal their son’s or daughter’s RN status to hospital staff. The motives of hospitalised parents in passing on this information to staff have not been comprehensively studied and research regarding this aspect
could add to our understanding regarding the complexity of family relationships and the way they interface with hospital staff during a family member’s hospitalisation. Research is also lacking about parents’ preferences regarding whether they want RN-offspring or other RN-relatives to perform any of their nursing care and if so whether there are gender differences regarding their preferences.

The identification in the present study of gender differences in RN-offsprings’ caregiving role provides a basis for further research. The lack of qualitative research regarding the experiences of male RNs of their hospitalised family members is evident and their targeted inclusion in future research is a priority to add comprehensiveness to our understanding of RN-relatives’ experiences.

7.4 CONCLUSION

This research study identified being in the middle as the central phenomenon of RN-sons’ and daughters’ experiences of parent hospitalisation. Some aspects of their experiences were not unique to RN-sons/daughters such as the importance of being there for the parent and the importance of being kept informed about the parent’s progress and condition; however their needs for information were at an expert level and their need to be there (particularly for seriously ill parents) was more pronounced and purposeful and was driven by their RN knowledge (including knowledge of what can go wrong) and this increased and intensified their fearfulness, watchfulness and protectiveness.

Aspects of the experience which were unique to RN-sons and daughters when compared to lay sons and daughters were the presence of identity conflict and role confusion, which have also been identified as a feature in studies of doctors and nurses engaging in other types of dual roles (such as health practitioner-patient). The issue of disclosure of RN status to hospital staff by RN-relatives has not been identified in the literature to date, and was closely linked to participants’ identity and role in relation to their hospitalised parent, and to the way they were treated by hospital staff. By disclosing their status to staff, participants ran the risk of being discriminated against by nurses (but not by doctors).
Other aspects of RN sons’ and daughters’ experiences were qualitatively different to the experiences of lay sons and daughters such as the differences resulting from RNs’ expertise: they had the ability to expertly observe, detect changes and protect their parent; they were able to adeptly use and interpret hospital language for the family; their medical knowledge made it possible to keep their family in touch with reality regarding their parent’s condition; and their knowledge of hospital processes and systems facilitated their ability to get action urgently for their parent when necessary. RN-sons’ and daughters’ nursing expertise created higher expectations of themselves (and higher expectations by others) and they were under increased pressure to perform at an expert level in a leadership role on behalf of the family. Unlike lay caregivers they had increased emotional needs which they neglected when they responded to crises and as a result they suffered severely in the aftermath of their parent’s hospitalisation.

RN sons and daughters had difficulties coping and became distraught when they shouldered difficulties alone; when they were blamed by family members whose expectations were not met; and when nursing and medical staff were not responsive to their requests for information and action when their parent’s condition was serious, treatment was poor or errors occurred. They sometimes found it easier to cope emotionally in the short term by reverting to their RN identity and role as they intellectualised the experience, and gained a measure of control and an avenue of providing their parent and family members with expert assistance. Intellectualising was also a mechanism for distancing themselves from the impact of experiencing their parent’s crises, however it was important to ensure RN sons and daughters had ongoing support from others and that they had avenues of ongoing emotional release during stressful periods in order to avoid severe repercussions to their emotional health and wellbeing in the longer term. RN sons and daughters coped best in a context of mutual trust and shared decision-making with hospital staff regarding their parent’s care, and when hospital staff were welcoming and responsive to their input and requests. This partnership with staff was particularly effective where RN sons and daughters had confidence in the staff and within this context of mutual trust it was helpful when staff made explicit statements regarding a redefinition of boundaries thereby relieving them of the need to be the ‘nurse’ and allowing them to focus on their son/daughter role.
Hospital staff members need to recognise that RN-relatives of a parent in hospital experience significant stress and emotional upheaval, which can affect their personal and professional life. The impact on RN-sons and daughters of playing a very challenging leadership role requires staff and family support, and also requires external support structures to be put in place in order to provide opportunities for emotional release, and to prevent the RN son or daughter from suffering negative health effects in the aftermath of the crisis.
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Appendix A
Participant Stories in Summary

Participants’ stories are more detailed for those interviewed (14) than for those (17) who only completed a questionnaire. Participants’ names have been replaced with pseudonyms.

[1 Questionnaire] Adam is 41 years old and has worked as a RN for 20 years. His 60 year old mother had one brief hospitalisation for elective (not life-threatening) surgery 5 years ago. Adam played the most active role in his mother’s hospitalisation, and he had face to face and telephone contact with her and with staff for all her hospitalisations. He did not mention any siblings or whether his mother had a spouse at the time. Adam did not disclose his RN status to hospital staff (although he did mention he was recognised by a RN acquaintance) because he believes it turns staff off and lowers the care of the patient. Adam was very inquisitive and closely observant. He wanted to know the full story of his mother’s condition and progress.

[2 Questionnaire] Amelia is 44 year old woman and worked as a RN for 22 years. Her 61 year old mother was hospitalised 2 weeks ago, and has had multiple long hospitalisations over 3 years (for cervical fusions and knee replacement). Amelia always had face to face and telephone contact with her mother and with staff, and always played the most active role. She did not mention any siblings or whether her mother had a spouse at the time.

Amelia chose not to disclose her RN status when she witnessed incorrect practices such as when her mother had to have drains removed and Amelia was not asked to leave the room, and also when housekeeping staff had a bucket and cloth and were wiping all the bed tables down from the one bucket. On one occasion when visiting, Amelia was recognised when a nurse walked in that had worked with Amelia at another hospital, and on other occasions her mother told some of the nurses that Amelia worked at another hospital.

Amelia worked at the same hospital for some of her mother’s hospitalisations. Being a RN Amelia was aware of procedures. She found herself looking and watching the care of her mother and being in the unusual situation of not being able to participate at all and having no control over the situation or the care of a loved one. Amelia found that she was critical of some of the priorities that she saw but she did not communicate this to the staff involved or her mother. She was also aware of some procedures not being done as she would do them and although there was no adverse outcome she found that she was uncomfortable at times.

[3 Interview] Andrew is 41 years old and has worked as a RN for 10 years. Three years ago his then 82 year old (widowed) mother died in hospital when she haemorrhaged after cardiac surgery. His mother was a retired RN, and over the last 3 years she had some brief hospitalisations. Andrew is the youngest of five children. He has two brothers and two RN-sisters. Andrew had face to face contact with his mother and staff during her hospitalisations. He had a very close relationship with his mother. His father who had been a doctor (GP) died before he got around to having cardiac surgery and this was a factor in his mother’s decision to have her operation.

Andrew and his younger RN-sister accompanied their mother to see the cardiac surgeon. Until the surgeon knew that they were all RNs he was explaining his mother’s cardiac condition, and what was involved in the operation in very basic terms, and Andrew was growing impatient, thinking: get on with it. It was helpful when Andrew’s younger sister disclosed their RN status as the surgeon seemed to drop the formal airs, was more relaxed and opened up and they were given a lot of detailed information including side effects. Andrew’s
sister was also keen to disclose their RN status to ICU nurses from the start so that they could get their information more efficiently and not just in lay terms. Andrew does not like to disclose his RN status unless it becomes necessary as he thinks it sounds as though he is big-noting himself and it can go down badly with some staff who may become defensive, and although he thought his sister’s disclosure sounded a bit like that, it did put them all at ease a little. One of Andrew’s prior experiences of disclosing was that as soon as it was said, the staff all turned around as if he had revealed he was gay, and then it was as though they immediately thought: What have we been saying in front of this RN-relative? Andrew thinks that RNs need to have more self-confidence as this would facilitate a more transparent relationship with RN-relatives. He suggests that tact is also important when disclosing and interacting with RNs (it is not a good idea to make a grandiose statement) and he has observed that it can ruin the relationship and put their “noses out of joint” if RN-relatives start doing aspects of the nurse’s job. He also finds that if staff members know you are a RN they leave you in charge of your own relative.

Because of his RN background Andrew observed surreptitiously, silently and closely making sure everything was ‘ship-shape’. He was shocked at how sick his mother looked straight after the operation but viewed it from a nursing point of view and says he had to remain calm. He found it was really difficult to keep composed: “when it is your mum”. He engaged in self-talk to be positive whilst still feeling very nervous.

In considering having surgery, there was a lot of discussion (within the family) regarding whether his mother should have it. Andrew and most of his siblings supported his mother’s firm decision to have the operation particularly because the surgeon/professor said that it was urgently required. His eldest sister was opposed but was swayed by their mother’s insistence and poor performance during a cardiac stress test. Three years later his eldest sister said they should not have allowed their mother’s operation to go ahead (due to her age). Andrew’s RN-sisters played a more active role than he did, but not on this occasion as Andrew happened to be at the hospital outside his mother’s room when she died after a failed resuscitation attempt. He saw the look on the nurse’s face saw the resuscitation equipment in the room and immediately knew what was happening behind the curtains. He remembers hoping they would not bring her back in case she had suffered a lot of brain damage.

He played the most active role on that important life-changing day during which he felt so isolated and totally alone. As a RN he was comfortable with the hospital surroundings and was thereby insulated to some extent. It was his task to contact other family members to advise them their mother had died. This was extremely stressful and draining. He knew he had to be stoic and brave. He was not going to allow himself to cry partly because he felt as a RN he had to act professionally and partly because he had so much to deal with. Having to tell them, knowing he cannot just say something’s wrong with Mum, he must tell them the facts and was trying to find the correct words to help his siblings cope with the bad news as quickly as possible. When it was all done, he surprised himself in the way he held it together and did a good job by acting in a professional way. It was all hell with everyone “crying and carrying on”. He thought he had done his bit and was now just going to be a son. He just wanted time alone with his deceased mother to be just the son. But this was not possible as his siblings were also present by the bedside.
Appendix A  
Participant Stories in Summary

There was some conflict with one of his sisters because he objected when she proposed an investigation into their mother’s death to see whether the surgeon had been at fault. However in the end this was not pursued: her death was just accepted and further action was considered not worth taking.

Andrew still works as a nurse part-time but would rather do something else now. The job is too depressing as he is reminded of his painful experiences every day and says he would not be continually subjected to stimuli which trigger these painful memories if he was not a RN. In the period after his mother died he burst into tears watching a film (in response to a scene of a relative dying), he was drinking a lot, “not getting it together”. He was offered free professional help by a psychiatrist at work which did help. Andrew’s advice to other RN-relatives is not to be afraid to show your emotions at the time. It does not matter if you do break down.

[4 Questionnaire + Interview] Ben is a 44 year old bachelor who has worked as a RN for 22 years specialising in mental health. He has three brothers and is the only one with a health qualification. Ben almost always played the most active role in his 69 year old widowed mother’s hospitalisations, and his eldest brother (who lived closer) played this role on a minority of occasions. Ben had face to face and telephone contact with his mother and with staff during some of her hospitalisations. His mother had multiple long hospitalisations over 3 years, for complications of diabetes, and 17 years ago Ben’s father died at age 72 during one long hospitalisation (for cancer of the liver and lungs 2 years after removal of skin lesions from scalp i.e. secondaries). Ben had some face to face contact with his father and staff.

Ben chose to be undisclosed during his mother’s hospitalisation to observe the general care of nursing staff especially when informed by his mother of less than caring attitudes of certain nurses. Ben did disclose in some instances to communicate with medical/nursing staff on a ‘peer’ level and thereby cut through “hospital speak” (i.e. superficial information that most relatives are given when enquiring about their relative’s condition either via telephone or in person). This was to gain a more detailed and complete picture of the situation and treatment plan, prognosis and so on, and be able to inform fellow relatives not in the medical field. Ben believes that the more well-informed the RN relative, the greater their power to get action if necessary. He has found disclosure helpful in that doctors are more forthcoming with information and that he is given positive acknowledgement and credibility as a fellow team member. Ben’s mother had informed nursing staff that one of her four sons was a RN.

Ben has often been and continues to be the understanding one who often provides an ear for his disabled mother to vent her anxieties, fears and frustrations due to her condition. Ben’s background in nursing has set him up for this role and his three brothers tend to opt out by redirecting his mother to him for advice (actually emotional support), which is very taxing at times but he does not see that he can do anything about that. It is relentless - there is no escape from the role. He acts as a sounding board regarding the wisdom of his mother’s medical decisions. Ben feels put upon by his mother, and says that the parent-child relationship is reversed. To get action to improve his mother’s situation he has been outspoken and this created friction with family members. He has also felt resentment towards them as his actions are taken for granted and he is not financially compensated even though
he is less well-off than his brothers. Ben believes that staff nurses need to feel something positive from RN-relatives. Ben has found it difficult to keep giving as a RN when he is drained from caring for a relative (and he cared for a dying partner) and that RN-relatives need a safety valve/outlet.

Ben is aware of the short-comings of the health care system such as staff shortages and some uncaring nurses. He worried and hoped that his mother would be under the care of caring health professionals and as an older Australian not be seen as a burden on an already stretched system. Ben believes by being present it acted as a constant reminder to staff to be attentive to his mother’s needs. He keeps his finger on pulse: detecting and acting on substandard care, errors, negligence and so on. When Ben arrived at the hospital accident and emergency department his mother had been 4 hours on a trolley in a corridor adjoining the department. Ben always goes straight to the staff member in charge when he needs action taken, but because he is a RN it is like walking on eggshells and diplomacy and tact are necessary. Using his credibility as a RN he intervened to prevent staff being dismissive of his mother’s input. He mentioned his mother had tried to tell the nurses they were making an error regarding her insulin medication but the nurses ignored her, so he let them know she has a high level of expertise and has been independently managing her diabetes for decades.

[5 Questionnaire + Interview] Cameron is 42 years old and has worked as a RN for 15 years (which included substantial experience in palliative care) but now works in the private sector in a health related field. He is a middle child with 7 siblings and is the only one with a health qualification. He is married with two children. He almost always played the most active role in his 82 year old father’s hospitalisations which occurred over a 5 year period. Even though his father lived in a country town some distance away Cameron always had face to face contact with his father and with staff, and telephone contact for some hospitalisations. Cameron’s father had two hospitalisations, one for aortic aneurism repair, and the second for angioplasty two years ago which was not done because his father died in hospital pre-operatively.

Cameron does not think it is usually relevant to disclose his RN status, and his past experience is that it causes RNs to become uncomfortable or to communicate less. On the other hand, doctors are more forthcoming with information. There was a sense of injustice that RNs are disadvantaged by identifying themselves as a RN to nursing staff. On one occasion Cameron did disclose to establish his ability to give IV medication to his father to enable him to attend his youngest son’s wedding but this strategy proved unsuccessful.

Cameron did hold back at times not wanting to over-react because he questioned his own professional judgement and wondered whether he was accurately assessing the seriousness of his father’s condition, or whether he lacked objectivity because he was being too emotional. He was angry with himself for getting emotional when the crisis occurred. Cameron’s father had advised his doctors that he valued his quality of life and did not wish to be resuscitated. In spite of this advice, when he did arrest, Cameron was asked (more like interrogated) by the doctor whether he wanted his father resuscitated. Cameron felt he did not have the right to do this (he said that he was placed in an unfair position: frozen due to being torn between keeping him alive for the family and abiding by his father’s wishes, which he ultimately did).
Consequently there was some blame directed at him from family and he has felt guilty ever since his father’s death.

His father’s hospitalisation was a very unpleasant experience for Cameron not only because his father died, but because he was very disappointed with the level of care his father experienced and Cameron had to be very assertive to get action from the nursing staff when his father’s condition suddenly deteriorated. During his father’s hospitalisations, Cameron was called upon by family to intervene. He was placed in a decision-making role and regrets not involving the family in important decisions concerning his father’s hospitalisation. He felt overwhelmed when his father died because family members wanted to know what happened and he could not really explain it to them.

[6 Questionnaire + Interview] Claire is 42 years old and has two young children. The stress of her father’s illness affected her marriage (separated 12 months ago). She has a younger brother. Claire suffered a number of crises and losses within a three year period, and was on antidepressants before her father died. She has worked as a RN for 23 years and is currently a university nursing lecturer. Working as a nurse has become difficult as it is a constant reminder of her father’s hospitalisation. Claire’s 66 year old father died during his one brief hospitalisation for end-stage cancer of the lung. He wished to maintain his dignity, was frightened of the experience of death but had made an informed choice to stop all life saving treatments after having cardiothorocentesis performed with good results – but being informed that it was just a matter of time before the fluid reformed around his heart.

Claire disclosed her RN status to staff when she needed to get things done for her dying father, because the staff dismissed him as ‘about to die’, pressure area care and nutrition were neglected and sedation and analgesia were insufficient. Claire found disclosure was a mistake because as soon as she arrived their care stopped and they expected her to be his private nurse. Disclosure also led to less information being given to her by RNs and they expected her to explain everything to the family. The doctors discovered her RN status during family-physician talks from her questions and the language she used. The nurses recognised her nursing technique in performing care for her father.

As a RN Claire knew too much, and knew the outcome was not going to be that a miracle would occur. She found herself stepping out of the daughter role whereas she just wanted to be the daughter yet retain the power that comes with being a RN. Claire found it hard to be objective and it was painful talking about her father in the abstract when explaining his condition to the family. Claire’s mother has about 15 years of assistant-in-nursing experience: she began nursing training when young (at a time when nurses gave unquestioning obedience) and gave it up to nurse her own dying father. Claire clashed with her mother because her mother was in denial and could not accept what was happening.

Claire played the most active role in her father’s hospitalisation, and because she lived many hours away from the hospital she stayed at her mother’s place. It was a horrible experience. She felt helpless that she was letting her father down because with all her experience and knowledge, she should have been able to “fix” everything. Claire’s most harrowing experience was arguing with junior medical and nursing staff for increased pain relief 12 hours prior to her father’s death. She was very frustrated knowing that her father was in so
much pain he was begging her to give him something to kill him, but they kept saying they
did not want to compromise his breathing, and Claire knew she could have educated them to
facilitate quicker and more effective pain relief and sedation if she had been in charge of the
ward. Claire had to go over their heads and rang the consulting physician to get her father
adequate pain relief/sedation to have a peaceful death.

Claire’s father had faith in hospitals, nurses and doctors but died well only because he got
good nursing care from his wife and daughter. Claire felt she over-stepped parent-child
boundaries when she changed her father’s soiled bed – it was definitely different and it did
not feel right. She did not always intervene directly, and on one occasion she chose to
remove herself from the room when an inexperienced RN was insisting her father take oral
medication even though he wanted to vomit. Claire quietly disposed of the medication when
she returned and found it untouched. Claire worries about patients whose lives are ending in
pain and anxiety because they do not have knowledgeable advocates for their needs. She was
very gratified that her father knew she would do whatever it takes to alleviate his suffering.

[7 Questionnaire] Daniel is 50 years old and has worked as a RN for 23 years. His 78 year
old father had several brief hospitalisations over 10 years. Daniel’s experiences relate to
hospitalisations which occurred 8 years ago. Daniel usually played the most active role in his
father’s hospitalisations, even though he has siblings and his father had a spouse at the time.
Daniel had telephone and face to face contact with his father and with staff for all his father’s
hospitalisations.

Daniel chose not to disclose his RN status because in his experience staff members generally
attempt to cut corners with information, treatment and so on because they can rely on you to
fill in the gaps. However, it never went long before staff knew he was a RN either because
his father (being very proud of his son) wanted to tell everyone, or because Daniel gave
himself away by his familiarity with procedures, using medical jargon and so on. If asked,
Daniel never denied that he was a RN.

As a RN Daniel knew what should happen and what could go wrong, and he added that he
has little confidence in the service delivered by the average nurse and doctor (because of their
training, the way they are managed, the way they think and operate). The main issue for
Daniel was the conflict between being a health care professional and being a son. He
especially mentioned the area of emotional detachment and separation issues interfering with
good judgement. Daniel described his parents as non-complaining, accepting of their fate,
and belonging to the school of thought that doctors are God and nurses are angels – so how
could a mere mortal question anything they do or want. On one occasion Daniel wrote a
letter to the hospital manager questioning treatment measures.

[8 Questionnaire] Eliza said she would have participated in an interview but still gets very
teary when talking about her recently deceased father. She is 42 years old and has been a RN
for 21 years but has been away from hospital nursing for about 20 years, and commented that
things have deteriorated since she worked in the hospital system.

Her 74 year old father, divorced since the mid 70’s and who lived alone, died 6 months ago of
pancreatic cancer (diagnosed 20 years ago and treated with chemotherapy and then
radiotherapy). Eliza was finishing high school when her parents divorced so she had a few
years with/looking after her father before she did nursing. Her father had multiple hospitalisations over 4 years, and especially throughout his final 2 years. He had struggled for many years with his health and loneliness, and had a history of diabetes, depression, and then alcoholism. He was never nasty or violent: a real gentleman and “nice bloke” to all who knew him.

There were times when Eliza chose not to disclose her RN status because she found that if nurses know you are a RN they tend to steer clear of you and your relative. She finds this understandable to some extent as she has witnessed the odd very pushy and overpowering nurse. Also, that some RNs feel their every move is being watched and may feel threatened in some way. Eliza felt more at ease telling the doctors because they “tend to be more open and forthcoming in explaining your parent’s problem and what they are doing regarding treatment/prognosis when they know you are a nurse”. Eliza thought it weird that if she said nothing to the nursing staff about being a RN and they later found out, they were much more friendly and helpful than if you did say so. She now never lets on, except to doctors.

Eliza usually played the most active role in her father’s hospitalisations, and on a minority of occasions her sister (an Enrolled Nurse) played this role. Eliza had face to face contact with her father and with staff for all hospitalisations - she would visit once a day and ring at the other end of the day to ask the nurses how his day had been and so on.

Eliza is sure that if she was not a nurse she would not have realised how things should be. She found it really frustrating and found that she got very emotional at times. As a child who loves her parents Eliza knows it can be an emotional time when they are very unwell: naturally she could not help being worried and concerned for her father. However, for her it was even more frustrating because she recognised he was not getting the care he should be getting.

Eliza stated that the hospital did not have enough nursing staff to give the care they have been taught to give, and to have time to sit with a patient and ask them how they really feel (she noted this is also the case in hospitals generally). Her father did not want to be a nuisance and would never complain regardless of how badly he felt. Eliza was saddened to find that elderly, non-complaining patients tend to get neglected in hospital. She will never forget those few nurses who took the time (even just a few minutes) to show her father real compassion.

Eliza’s father was very unwell and because of a blockage in his duodenum was being fed via a tube. He was constantly vomiting and was also on a drip. He had wasted away to skin and bone. It seemed the only time anyone came near him was when either the drip or feeding tube alarms went off. After listening to the ‘beeping’ for several minutes and having no-one coming Eliza usually stopped the alarm and went and found a nurse. She wondered what happened when she and her sister were not there.

Eliza also had trouble dealing with another aspect of his times in hospital. Even though her father was elderly and had been through a lot in his medical and personal life, Eliza’s family were made to feel as if they should not be trying to find out why he was so unwell and vomiting all the time. It got to the stage where Eliza felt he was being fobbed off with the old
“he’s been through a lot”. Eliza and the family had been with him all the time watching him suffer and just wanted someone to find out what was causing it and stop his pain and distress.

[9 Interview] Emma is 41 years old and worked as a RN for 21 years. Six months ago her 69 year old father was hospitalised. He had multiple hospitalisations (varied periods) over a 7 year period. Emma’s father had a subarachnoid haemorrhage 7 years ago, and four recent admissions within a 4 month period for cardiac surgery and related problems. Emma is the eldest of six children. One of her brothers is a paediatric surgeon; her father is a retired specialist doctor, and her mother a retired RN. Emma’s mother initially played an active role but became exhausted and then asked Emma to take on the most active role. Emma had face to face contact with her father and with staff during his hospitalisations.

Emma found it best not to announce her RN status as it gives a different impression than if staff later find out you are a RN. Her mother and sick father were given a lot of support by the staff. The nurses in intensive care unit and the cardiac ward were very comfortable with her RN status – “it was no big deal”. There was only one RN who was unsupportive and did not respond to her mother’s questions and need for support when her father was first admitted, so Emma took her aside divulged her RN status and stressed the need for support – she thought it was the only way to get action. She also divulged her status to the triage nurse on one occasion to ensure her father was prioritised appropriately. She was recognised by RNs at times, and when her father told staff on a couple of occasions, she told him there was no need for the staff to know her status as some may be hesitant or uncomfortable or more distant relating to them.

Emma found the leadership role was overwhelming, a bit of a nightmare and pretty draining and she was absolutely exhausted by the end. The staff didn’t pull her into the loop, they did not directly ask her how she was. There are some advantages to being a RN as some patients miss out on care because they do not know the system. On the other hand, lay relatives are cocooned by lacking the knowledge to detect problems. Emma stepped in on one occasion to convince her father to remain in hospital overnight (to reduce the stress for her mother) when he was chomping at the bit to be discharged. Emma believes that being the eldest is of foremost importance and perhaps gender plays a role, as her brothers (having that macho image) found it a bit hard not knowing quite what to do. The family filtered their communication through Emma (her mother was exhausted) and her father tended to confide in her more than with his wife or other offspring: saying: you’re a nurse and will understand what I’m thinking.

As a nurse, Emma observes very intently. She believes nurses are more focussed and acutely aware of what is happening in the hospital setting. At the time her father was ill and having repeated hospitalisations which were very tiring, she had significant additional family pressures to contend with as her husband was interstate and she has three young children. But she stayed strong for the family: “You do what you have to do”.

On one occasion when a doctor was drawing blood from her father, her father said he thought he might die then and there. Emma was a bit shocked and said to the attending doctor that her father wouldn’t say that lightly – thus lending weight to the seriousness of his remark, which immediately focussed the doctor’s attention on this potential crisis. Being one of six
children she recognised the need to involve her siblings when her father’s condition was critical, and on one occasion this led to her doing a big ring-around at 3am one morning.

[10 Questionnaire] Eva is 42 years old, currently works in an intensive care unit, and has been a RN for 21 years. Her father had one long hospitalisation two years ago and died (at age 69) two months after being diagnosed with an inoperable cancer. He was an extremely fit and health-conscious man who felt a lump in his abdomen and was soon told the mass was inoperable and that he may be dead within a month. Then he started chemotherapy, developed a bowel obstruction, dramatically lost weight and became dependent on Morphine for pain control. Eva’s father had always been a man very much in control of his health and his life and because he felt he had no control over his hospitalisation this was hugely stressful for him. He was frightened and panicked, and was desperately trying to put his affairs in order, while full of disbelief that such a terrible thing was actually happening to him. He had no time to grieve for himself as he dealt with his illness and pain and business/legal affairs. He also became alienated from some members of the family at this time. Eva mentioned that her father’s wife (not her mother) played the most active role and was at the hospital all day every day supporting him emotionally. Eva and others visited intermittently as they work, and Eva also had telephone contact with her father and with hospital staff. She did not mention having siblings.

Eva normally likes visiting people in hospital. If they are not there for a life-threatening illness she is fascinated with the different ways things are done, different equipment and so on. This was not the case during her father’s hospitalisation where she and the family all felt so helpless and so stressed, because her father’s health deteriorated suddenly and dramatically which was a great shock and very frightening. The worst thing about her father being hospitalised was that he knew he would die shortly and was not accepting of that. Eva hated seeing her father so distressed. Eva now has greater empathy at work for stressed out relatives who may behave aggressively when they are trying to gain some measure of control in a calamitous situation.

Eva trained at the hospital where her father was hospitalised, so the environment was very familiar, and the experience was much less foreign because as a RN she understood how the system works, what can be done and what cannot, and what the bedside charts mean. On the other hand she was quite critical of the deficiencies of the public hospital system. Being a RN meant that she felt more assertive in being involved in her father’s care. His pain relief became an issue. He was receiving conflicting management strategies concerning his pain relief depending on who was there to administer it at the time, and he was still in pain. Eva felt it was not good enough so she hunted down the Nurse Unit Manager and paged the oncology registrar herself and managed to get her father’s pain relief sorted out satisfactorily. Once, she was highly indignant on her father’s behalf at the staff’s insensitivity and abuse of power when he was woken one night by the noise and laughter of nurses admitting someone down the hall. He asked them to tone it down and was rebuked and treated with contempt. Eva never followed it up thinking - what good would it do. Disgusting used pans, urinals and dirty linen had been left in his bathroom for days so Eva removed them to the pan room and is now very conscious of the importance of clean surroundings for her own patients.
Eva does not believe it necessary or helpful in achieving better care for her father to announce her RN status to staff as the implication is that they had better watch out because she is watching them. On the other hand her father would tell everyone in sight that she is a RN and knows everything about everything, and as it was Eva’s training hospital she was also known by friends who worked there. Eva did disclose her RN status when staff explained procedures or results to her in lay terms because she wanted to be given more medically meaningful information.

[11 Questionnaire]  Gail is 53 years old, is currently a nurse practitioner, and has worked as a RN for 23 years. Gail’s experiences relate to her mother’s hospitalisation which occurred 10 years ago. Her then 69 year old mother was mentally ill (incarcerated for life post Gail’s birth to a mental hospital under the Governor’s Pleasure) and had multiple hospitalisations (of varied duration) over a 44 year period. Gail had face to face contact with her mother and with staff during all her mother’s hospitalisations. Sixteen years ago Gail’s then 75 year old father had multiple long hospitalisations over 12 months (he had a medulla tumour). Gail had face to face contact with her father and with staff during all of his hospitalisations. Gail mentioned that her elder sister is also a RN and played the most active role in her parents’ hospitalisations. Gail worked at the same hospital for some of her mother’s admissions.

Gail’s experience was very anxiety provoking because all her intellect as a nurse practitioner became intertwined with the emotions of being a helpless child of the parent. Her distress at the role confusion led to her appearing aloof to other siblings therefore being criticised by them for not showing that she cared. It was a very traumatic experience and all Gail’s coping skills were tested just to be able to deal with the experience. If she had not been a RN she believes that she would have been able to emotionally show her feelings better; she may not have analysed as much as she did; she may have been able to seek out counselling and to deal with her distress and disbelief at what was happening; she may not have felt so deeply unable to be of assistance; and she may not have felt that she had failed her parent in some way.

Gail chose not to disclose her RN status to staff when she saw her father being sponged by nursing staff; and also when her mother was unable to care for herself in regard to her personal hygiene. Gail did disclose her RN status to the casualty desk clerk in an emergency situation due to the non-caring behaviour and inattention to what needed immediate response (i.e. her mother’s dislocated finger). Gail was detected as a RN when her mother was admitted to a unit in a hospital where Gail had been employed.

[12 Questionnaire]  Harry is 45 years old, of ethnic minority group background, and has worked as a RN for 10 years. Harry believes that at times ignorance is bliss when it comes to the hospitalisation of a loved one. His 73 year old mother was hospitalised some weeks ago and she had experienced long hospitalisations over a three year period. The reason for her hospitalisations was not mentioned. His mother’s hospitalisation was described as a pleasant experience made possible by the understanding and wonderful support of the staff, though he did mention that staff should take into account cultural values when caring for a patient from a different culture. He suggested that visiting hours should not be regimented, and that limiting the number of visitors per patient is a questionable practice.
Harry usually played the most active role in his mother’s hospitalisations. He had face to face contact with his mother and staff and some telephone contact. He did not mention any siblings or whether his mother had a spouse at the time. Harry chose not to disclose his RN status as he strongly believed that any concerns voiced by him would not have been taken objectively by staff as it would have been seen as ‘stepping on their toes’. There were no circumstances causing Harry to disclose his RN status, and he was not detected as a RN.

[13 Interview] Jack is 51 years old and has worked as a RN for 30 years mostly in mental health but has not worked in a hospital for about 5 years. His 87 year old widowed mother had multiple long hospitalisations over 15 months for knee replacement surgery and during the latest hospitalisation 6 weeks ago was critically ill post operatively. Jack has six siblings (two brothers and four sisters who are all RNs). Jack’s RN-sisters played the most active role in his mother’s hospitalisation. Jack lives in a country area quite a distance from his mother’s residence and came down to Sydney to be constantly with his mother. He had face to face contact with his mother and with staff during most of her hospitalisations.

Jack was by his mother’s bedside around the clock post-operatively and he was appalled by the nursing care he witnessed and is still quite stirred up about it. It was a big effort for anyone to do anything for his mother. He witnessed absolute neglect. There wasn’t even a thought to get a special mattress to relieve pressure (she developed pressure sores during a recent admission), and when Jack’s brother arranged to get a special nurse and an eggshell mattress through veteran affairs, staff were surprised and seemed indignant that the family would ask for extras. Pain management was poor and on one occasion he overheard staff say they would give her Morphine to shut her up for the night. It was extremely hard to sit there and take it knowing that it could cause her to die. The staff would come storming into the room and say get out. There was no courtesy; just rudeness. Jack found it very hard and extremely frustrating to stand by and watch this happening. He weighed the pros and cons of intervening and on one occasion he went to the desk to ask for a pan for his mother who had repeatedly rung the buzzer to no effect. When there was still no action he went back to the desk to get action, and the nursing staff were getting quite angry with him. His mother was run down at this stage and just accepted it whereas normally she would “go crook”.

Jack did not disclose his RN status, but his mother told staff when she wanted Jack to assist them in lifting her to sit up in bed to minimise the pain they were inflicting through poor lifting technique. The staff knew his sisters were all nurses and often left the care to them. Jack does not believe it is a good idea for family members to perform nursing care as the staff then lose their way to some extent. Jack considered complaining to the hierarchy about the poor care his mother was receiving, but he believes action is difficult to get unless high profile people are affected. He also thought that complaints might jeopardise her care and would probably have no beneficial effect. Jack still thinks about it and wishes he had stepped in but recognises it may have served his needs more than improved his mother’s situation. One of his sisters was more accepting of the poor care and neglect his mother suffered, and this exacerbated the existing friction between them. The nursing staff members were antagonistic towards him and the continuous coming and going of relatives seemed to be an added irritation to the nursing staff.
In considering the operation, his mother rang him, and rang everyone to ask what to do. Jack did not want her to go ahead but his four sisters are RNs and are more influential these days. Jack’s mother always consulted him until he moved away to the country. Jack did not find it a burden (giving medical advice to his mother) however there was resentment on his wife’s side and it was instrumental in why he and his family moved away in the end because it became a little bit too demanding.

[14 Questionnaire] James is 43 years old with a family and has worked as a RN for 21 years. Four years ago his then 59 year old father had multiple hospitalisations (some brief some long) over a 2 month period for cardiac valve repair. James always played the most active role in his father’s hospitalisations and he had face to face contact with his father for all his hospitalisations, and telephone and face to face contact with staff in some instances. He did not mention any siblings or whether his father had a spouse at the time. James found it demanding on his family’s time because the hospital was a fair distance from home, and they visited often. As a RN he understood the pre-operative tests and procedures and knew exactly what was involved in the operation. He was able to gauge that his father was too frightened to want to know what was occurring.

James chose not to disclose his RN status to staff because they treat him differently. Specifically that medical staff treat him with some disdain and nursing staff tread warily, along the lines of “he knows it all”, and he would be considered a threat or they would suspect that he had a motive for disclosing. Although James did not intentionally disclose his status, it was easy to work out when he asked questions using the correct terms or jargon.

[15 Questionnaire] Jane is 42 years old and has worked as a RN for 21 years. Her 45 year old mother [perhaps this is her step mother] was hospitalised three weeks ago, and had had multiple brief hospitalisations over 4 years and her 70 year old father had one long hospitalisation 18 months ago. Jane had face to face and telephone contact with her father and with staff during his hospitalisation and on some occasions with her mother and staff during her hospitalisations.

Jane’s preference is to disclose her RN status when dealing with medical staff as she finds they have a tendency to “talk down” to a patient’s lay relatives in many cases. Jane did not mention whether she has siblings, but said she always played the most active role in her parents’ hospitalisations, and stated she had two very stressful experiences. Jane believes that being a RN can make the experience a lot worse in some ways because: RNs know too much – all the complications what to expect and so on; RNs tend to want to get in and do the nursing care themselves; RNs can be overly critical of the care given; and it can be a very humbling experience to be “on the other side”.

[16 Questionnaire + Interview] Kate is a 42 year old married woman and had a seven-week old baby and a toddler when her father had a heart attack 10 years ago. She has worked as a RN in mental health for 22 years, and also holds a general nursing qualification. Her then 63 year old father had coronary artery bypass surgery 12 months after he had a heart attack. He had multiple long hospitalisations over a 2 year period.
Kate usually played the most active role in her father’s hospitalisations, he had congenital deafness and she facilitated communication for him. Her mother and her younger sister (by 12 years) played the most active role on a minority of occasions. Kate had face to face and telephone contact with her father and with staff during all his hospitalisations.

Kate learned to use disclosure to suit her. She feared she would be treated differently or ignored if she disclosed. Kate chose not to disclose her RN status when her father was in the intensive care unit but she did disclose whenever she wanted detailed answers. It was a no-win outcome when staff felt threatened but by telling them her father’s illness was outside her area of nursing expertise it sometimes became a win-win.

When Kate’s father was having a heart attack her mother asked her to phone the ambulance, and whilst waiting for it to arrive, Kate was preparing for him to arrest and was not thinking like a daughter. Kate copes better in an emergency by being the nurse: she was detached without any feeling whatsoever, and thinking and talking like a nurse because she needed to gain some control over the situation. Six months later it hit Kate what an awful position for an offspring to be in to have to make a decision on whether to resuscitate her father because either way it could have been a no win situation: he could have died and she would have felt awful; he could have lived and suffered a lot of brain damage. Kate finds the responsibility and expectations are greater as a nurse than as a daughter because of the family repercussions (blame was assigned to her for perceived deficiencies). During her father’s illness Kate did not know who she was and what to be: there was the role of the daughter but she was not allowed that role - she had to be the strong one and was imposed upon because she was the nurse, and also for her own benefit to get a good outcome for her father. It was frightening and she was confused between being a daughter and a nurse. Kate had experienced similar confusion when her son was hospitalised. On both occasions she did not know who to be – the relative or the nurse. Nursing staff effected a re-definition of boundaries by saying: ‘you be the mother/daughter I’ll be the nurse’. When Kate saw her father helpless post-operatively she fell apart because she sees her father as someone stronger than herself.

There was no down time for Kate: she was so busy being the nurse there was no time to look at the situation as a child. She would say to her very supportive husband it would be a relief if she was not a nurse, but then she would think ‘no’ because she would not be able to get what she wanted. Her mother was very demanding and hysterical (she became like a second patient for Kate) and put pressure on Kate to stay in Sydney with her father so that she could attend to her husband’s business (Kate lived 90 minutes away). However Kate’s own family responsibilities were the priority (including breastfeeding at the time) and prevented her from visiting her father daily (though she kept in contact with the hospital). Her mother attacked Kate, criticised her as heartless and stupid and blamed Kate for her father’s heart attack. Kate stopped talking to her parents for 4 years. Kate was exasperated because it seemed she was the only one who always dealt with the crises and reality and thought that perhaps relatives look to you because you are a RN for that function, or perhaps because you are a nurse you take on that role. In a crisis Kate is typically the strong one in the family, and she has been put upon over the years by her mother seeking advice about her illnesses, and when the crisis is over Kate is no longer needed as the nurse-daughter and gets dumped.
[17 Questionnaire + Interview] Lara is 41 years old and has worked as a RN for 21 years. Twenty five years ago Lara’s then 49 year old mother was diagnosed with cancer of the breast and had a modified radical mastectomy, lymph node dissection and radiotherapy. The cancer re-occurred 2 years later and although she had a bilateral salpingo-oophrectomy chemotherapy and radiotherapy for bony metastases and treatment with Tamoxifen, she died in hospital about 12 months later (21 years ago). She had multiple long hospitalisations over a 4 year period. Lara was doing her matriculation (HSC) when her mother had the mastectomy and then commenced nursing interstate. Lara’s father played the most active role in her mother’s hospitalisations. Lara had face to face and telephone contact with her mother and with staff during all her mother’s hospitalisations. Lara was quite young when her mother was hospitalised. She thinks her father did not know what to do and was trying to shield Lara, her older brother and younger sister.

Lara knew the hospital staff as her mother was in a local hospital. At one stage after having a bout of septicaemia and bony metastases about 9 months before she died, Lara spoke to the oncologist alone (unbeknown to her father) about quality and quantity of life because she happened to be at the hospital visiting. Lara knew all the terms but not really. She did not seek clarification – she was upset and also not wanting to show ignorance. She gained insights because she was privileged to more information than her father and non-medical siblings and she knew the outcome. She would never have said anything to them or anyone else about that conversation. Lara returned home to be with her mother in the last month and her sister was put out and resentful of her RN kudos because it was as though ‘Lara’s home now and she knows what to do’.

Lara regrets bringing her mother back to the harsh reality regarding her limited lifespan. Lara now thinks it was dreadful to shatter her mother’s hopes and dreams for the future. Her mother talked about doing this and that in the future to which Lara responded – “but Mum you won’t” – her mother’s justification was that she was allowed to have a dream and wanted something to look forward to. Lara was a first year registered nurse, so inexperienced and in retrospect quite immature, so less hands-on than she would be now. She regrets not being there at the bedside more for her mother, and recalls being told afterwards of a time when her mother was quite distressed and a close friend stayed at the hospital with her – it should have been a member of the family. Even these days Lara’s experience is a constant reminder during her work as a RN. She reflects on the patients she has nursed and sees that worse things happen to other people. Lara has a great deal of empathy for families dealing with a dying loved one, and sees her work with dying patients as returning the good deed that others did for her.

The nurses were kind to Lara, and it was a reasonably happy experience for Lara despite the inevitable outcome. However Lara’s father remained quite bitter and Lara never felt all that comfortable with the surgeon and his treatment. The surgeon was very arrogant and Lara did not think her mother received her treatment quickly enough.
[18 Questionnaire]  Lucy is 44 years old and has worked as a RN for 23 years. Nine years ago her then 82 year old father had two brief hospitalisations over a three year period. His first hospitalisation was for micro surgery to his finger (sliced by a circular saw) and his second admission was for pneumonia requiring intravenous (IV) medications. Lucy mentioned that on a minority of occasions another family member (she has a sister) had a more active role in her father’s hospitalisations. Lucy had face to face contact with her father and with staff during all his hospitalisations.

Lucy’s experience of her father’s first hospitalisation 9 years ago was a good one as it was very obvious what treatment he needed, and she felt all the necessary care was given. Her experience of the second hospitalisation was frustrating because the registrar had pre judged the situation as an admission due to social reasons and was not convinced that there was a medical need for her father to be hospitalised. Lucy’s father was treated for pneumonia by the local General Practitioner (GP) at home. The GP wrote a referral letter suggesting IV medication was needed, and observation due to his related heart conditions. On admission to casualty, the registrar pulled Lucy aside and accused her of ‘granny dumping’. Lucy had to justify the need for her father’s admission. Lucy’s father was disorientated, had difficulties with hearing and mobility as well as language difficulties (English is his second language). Once past the admission stage, the nursing staff were very helpful although most of her father’s needs were taken care of by Lucy and her sister. Because of her RN expertise she knew signs, symptoms and other relevant information, she could suggest follow-up care, organise processes for admission, and provide orientation for her father (about meals, location of the toilets and so on).

[19 Questionnaire + Interview]  Madeline is 45 years old and has worked as a RN for 25 years. Five years ago her then 77 year old father was diagnosed with cancer and died following one brief hospitalisation. Madeline had the most active role in her father’s hospitalisation. She mentioned her mother and sister were involved in her father’s care. Madeline had face to face and telephone contact with her father and with staff during his hospitalisation.

Madeline had worked at the hospital previously and therefore staff knew she was a RN. RN colleagues she had previously worked with were quite good towards her but other nursing staff members were standoffish and passive aggressive towards her and would leave the nursing care to her and the family, and required her to move out of her father’s shared room all the time when they were attending to other patients. She thought she would be better supported by the nursing staff because she had worked there previously thinking caring nurses would stick together in times of crisis. Her close RN friends did provide that kind of support.

Madeline tends not to disclose her RN status as RNs are scared of you. On the other hand the doctors gave more information to her and were very supportive. When she accompanied her father to the oncologist she did not disclose her RN status as she just wanted to see what information he gave her father. The implication being that abbreviated or excessively detailed information may have been given if the oncologist had known she was a RN and presumably leave her to fill in the gaps (which she still did to some extent).
Madeline experienced some conflict with her mother concerning the necessity to keep up the pain relief for her father. Her mother was in denial for some time and would not believe Madeline. Her mother withheld information about her father’s fall in the hospital bathroom (due to staff negligence) until he was being discharged. This was because she was scared Madeline would “have a go” at the hospital and because she was being protective of Madeline’s father (in case of repercussions) but she too was angry about the neglect. Asking RNs for information about her father’s fall was like trying to get blood out of a stone. Madeline’s experience of her father’s hospitalisation was very distressing as she knew the kind of care her father could have been getting. At times she thought ignorance would be bliss and wished she did not have the nursing knowledge as you don’t know what you’re missing out on and muddle along. She was in the role of RN (rather than daughter) most of the time but that’s just the way she is. She was in auto-pilot mode: working as well as performing carer duties.

Madeline held back and did not draw staff’s attention to deficiencies in care because of being a RN. She believes this is partly because RNs will resent you trying to run their job. She finds hospital staff are more sympathetic to lay relatives than to RN relatives. The charge nurse in Madeline’s current workplace was not sympathetic when her father died and would not give her time off to attend the funeral. Madeline was expected to work, and found that really hard, but the doctors were lovely and extremely sympathetic. Madeline needed someone to talk to about her difficulties, and her family are not good at this.

Madeline found the care in the hospital to patients generally was poor and realises these things can happen but when her father also got the same poor care she concluded that the RNs were too complacent with all elderly patients. She would feed him and do everything for him. She was assertive and successful in convincing a doctor to use his influence to arrange a single room for her dying father, however the nurses moved him back into a shared room when she went back to work. Her father usually relied on her to instigate things and they discussed options. Madeline’s father was scared and pleaded with her to take him home, even though there were obstacles because the physical environment in the home was not ideal but she made it work by re-arranging rooms and so on. She nursed him at home which was satisfying but her ”sister was cranky” about it as her father put all his trust in Madeline and said the others did not know what they were doing and pulled him about too much.

Madeline found the experience frightening and was very protective – saying : no-one cares as much as we do ourselves. Her father was well known and did things for the community but this worked against him, leading to less attention by RNs and this resulted in increased protective ness by Madeline. She was protective by being at the hospital constantly, even though the RNs were not that keen on her being there and she accompanied her father to doctor’s appointments and so on.
Appendix A  Participant Stories in Summary

[20 Questionnaire]  Matthew is 45 years old and has worked as a RN for 13 years. Some years ago his 78 year old father suffered a heart attack and had one long hospitalisation for triple coronary artery bypass surgery. Matthew’s father had not been hospitalised before and it was a shock to his father that he was hospitalised. He had been fit and healthy all his life and there had not been any family history of heart disease. Matthew played the most active role, and had face to face and telephone contact with his father and with staff during his father’s hospitalisation. Matthew did not mention any siblings or whether his father had a spouse at the time.

Disclosure of RN status did not appear to be an issue for Matthew: he did not opt to remain undisclosed, nor were there situations in which he did mention his RN status, and he was not recognised as a RN by staff.

Matthew found the experience very nerve wracking as a result of being a RN because he was aware of his father’s diagnosis, treatments and expected outcomes of the treatments. He felt helpless and would have liked to be more active in his father’s treatment, but knew that the people treating him were the best qualified to treat him. Matthew respected their judgement in treating his father. Matthew believes that the experience would have been different if he was not a RN because he would not have known what treatments were used, what procedures done, his questioning of medical and nursing staff would have been much different and he would have had different expectations regarding his father’s recovery.

His father’s lack of mobility and freedom affected him the most, and he asked Matthew to explain all hospital procedures and all treatment. It seemed to Matthew that he was needed at his father’s bedside at all times. At times Matthew felt that he was intruding on his colleagues’ territory.

[21 Questionnaire]  Max is 43 years old and has been a RN for 21 years, but has not worked in the health industry for the past 13 years. Max always played the most active role in both his parents’ hospitalisations even though he has an older brother. Max always had face to face and telephone contact with staff and his hospitalised parents. Max’s 75 year old mother who is overweight with thyroid problems, chronic obstructive airways disease and cardiac arrhythmias had multiple brief hospitalisations 2 months ago over a 3 week period. His 75 year old father had multiple hospitalisations (of varied duration) over a 15 year period for cardiac by-pass surgery, gall stones and finally following a motor vehicle accident four years ago which proved fatal.

Max found the experience a little worrying and of some concern due to the very obviously overworked staff due to staff shortage and the rundown environment in which staff must operate daily. Max firmly believes that the university education system is helping to maintain staff shortages, and produces many graduates who are qualified but lack the skills of inter-patient interaction. The problems Max identified were highlighted because of his past nursing experience and the experience of operating and training in a very different set of circumstances.
Max chose not to disclose his RN status to staff as he believes it is not his place or necessary to highlight his past nursing experience except when he had doubts or misgivings regarding treatment, medication or surroundings. Staff detected Max’s RN status when he expressed informed views on his father’s general care or highlighted some shortcomings.

[22 Questionnaire + Interview]  Oliver is a 44 year old bachelor who has worked as a RN for 14 years. He lived with his parents (who had been gymnasts) and they were very close: he included them in all of his activities like friends. He looked after his mother at home for about 5 years (on a carer’s pension) and towards the end this included tending to her needs several times during the night. He always played the most active role in his parents’ hospitalisations. They trusted his judgement but were actively involved in decision-making and told Oliver they were concerned that being their carer was ruining his life. He has an older brother (by 10 years) who hardly came near them (which upset his father) and had declined Oliver’s request for financial assistance (despite spending money on overseas holidays).

Two and a half years ago Oliver’s 81 year old mother died following multiple hospitalisations for varied periods over 3 months. She had been very active, quite well for her age and always lucid. She had congestive cardiac failure and ischaemic heart disease 3 years prior to her death, with bouts of hospitalisation within that period (mostly for pulmonary oedema). Three months before she died she deteriorated very quickly, fractured her femur and was diagnosed with non-Hodgkinsons’ lymphoma. She responded to physiotherapy (after Oliver urged them to treat her. They had incorrectly dismissed her as unsuitable for rehabilitation due to dementia and being unable to follow instructions). When she was sent for a psychiatric assessment because the staff complained she was aggressive and uncooperative Oliver accompanied her. Oliver could hardly control himself when the psychiatrist concluded she was not really sick and just pretending so Oliver said if that was the case he would take her home. Oliver then called in her local doctor who discovered that his mother had another painful fracture of her lower leg which prevented her from walking. This made Oliver very angry especially as he had been pushing his mother to try harder: saying to his father (who supported Oliver’s strategy) that he would live to regret it – which he has. Eight days before she died, Oliver was concerned that his mother was not improving so he complained to the hospital and asked to see the reports, and only then discovered she had been diagnosed with lymphoma. The doctors thought she would have had another year or two to live if she had not been dragged and pushed into trying to mobilise. Because of this Oliver felt very guilty that he had hastened his mother’s death because of the poor medical advice he had initially been given. He would have taken a palliative care approach if he had known of the lymphoma diagnosis.

Oliver suffered accusations from his brother, social workers, nurses and the police. Two weeks before she died his mother fell out of bed twice and Oliver blamed the community nurses, who had also sent a social worker to the house to say Oliver was not looking after her properly. At Oliver’s request his mother was discharged because she was being treated badly and neglected. She died at home in Oliver’s arms. Oliver called an ambulance and they resuscitated her. She said ‘let me die’ and although they tried a second time she died. The police were called (she was a coroner’s case) and investigated in case Oliver had caused her death.
Oliver was always present by her bedside at the hospital and also had telephone contact with his mother. Oliver just wanted to be a fly on the wall and not intervene, but he found he had to intervene. If he was not present his mother did not receive the proper care. He made a conscious effort to keep calm and polite but assertive and forceful to get staff to address care deficits. During his mother’s hospitalisation he witnessed substandard care, so he became more vigilant and began challenging the RNs, questioning them and giving them feedback if he detected mistakes or when the care fell short of good quality. When he asked questions: the response was: “well you should know!” He felt like an instructor. When his mother was in the Coronary Care Unit he would get personal handovers from the nurses. The RNs did not like Oliver coming in early and at irregular times. They thought he was checking up on them, which he admits he was forced to do for his mother’s sake. The cruelty of nursing staff resulted in Oliver lodging an official complaint which was poorly dealt with and lacked a positive outcome.

One week ago Oliver’s father became ill suddenly, lapsed into a coma, was hospitalised for a week and died in hospital (diagnosis uncertain). His father had a history of slight aortic stenosis and had been fit, active and mentally alert prior to this. Oliver called an ambulance when his father became very hot and tired. He was not considered urgent. For the next 3 days he was unwell, in no pain, still conscious and able to talk but with a fever. Then his temperature spiked, he lost consciousness, was intubated and transferred to the Intensive Care Unit at a larger hospital, but did not regain consciousness. Oliver would sit by the bedside all day watching helplessly, unable to do anything which he found difficult. The hospital called Oliver at 2am as they expected his father to die within hours. The doctors suggested Morphine to “ease any pain”. Oliver agreed. It was very sad; and totally unexpected even by doctors. Oliver visited his father and had face to face and telephone contact with staff during his father’s hospitalisation.

Oliver worked at the same hospital for some of his parents’ hospitalisations. The nurse manager was annoyed with Oliver because he resigned to look after his mother which impacted on staffing her ward. Prior to disclosing his RN status, Oliver was treated like a child. Each doctor and nurse would say stupid things that really told him nothing. Sometimes one doctor would contradict another doctor. It became confusing. When Oliver disclosed his status to the doctors they opened up like a book: presented Oliver with all test results, clinical observations and so on. The doctors were rejecting their own conclusions; asking for evidence from Oliver to back up their assessment to justify their treatment decisions. Oliver was frightened and worried and he questioned his own judgement and observations. He did not wish to risk the possibility that his own errors could impact on the doctor’s diagnosis and assessment of the situation and possibly lead to mismanagement of his father. Oliver felt very guilty that he missed something during the early stages of his father’s mysterious illness which may have helped. Oliver’s guilt was amplified when his brother also blamed him for not picking up signs of their father’s illness earlier.

Junior nurses were nervous or petrified when Oliver was present – fearing he might be watching them too closely. He says disclosure causes RNs to leave the care to you. Sometimes he was recognised by doctors and nurses with whom he had worked. His line of asking specific questions also prompted staff to assume and ask was he a RN.
Oliver found the experience extremely upsetting and he lost respect for the hospital. What was of greatest concern was that doctors and nurses held back information when he knew there was more available. There was antagonism between Oliver and the RNs. He was angry they withheld important information regarding his mother. Oliver feels that understanding and knowing what is happening is better than not being informed. Even if it is bad news – he would rather know. Especially regarding his father, he was totally informed, shown all test results and so on. Oliver thinks it was easier for the doctors and nurses in that they did not have to explain everything; just show him. – and when he asked a question the answer was very detailed. He was appreciative of that.

For Oliver nothing can change the guilt and disappointment he continues to experience regarding his parents’ hospitalisations.

**[23 Questionnaire + Interview]** Olivia is 41 years old and has worked as a RN for 16 years. Four years ago her then 62 year old father had one hospitalisation which lasted a week. Emma’s father had a stroke and remained unconscious throughout the hospitalisation. He died when Olivia requested that life support be withdrawn despite the neurosurgeon’s urging to continue active treatment. Olivia played the most active role in her father’s hospitalisation. She stayed at the hospital for the week accompanied by her mother older sister and younger brother, and she had close and ongoing face to face interaction with staff.

Olivia would have chosen not to disclose her RN status because actions can be easily misinterpreted; however this was not an option as she was known to staff. She is very thankful that she was well liked. Staff were incredibly supportive and once the fright of her being there was over, and after an ice-breaking episode of black humour (he needs aperients like a hole in the head - not that he hasn’t already got one!!) the staff fought to look after him and the staff became part of the loving family and treated Olivia with an increased level of privileged intimacy. Off the record they said they disagreed with the neurosurgeon’s recommendations. Olivia noticed instances of incorrect care but did not mention these to staff. She knows that misinterpretations can easily occur when such comments are made by a RN-relative, and she was careful to avoid this. When the nurses were trying to get a response from her father to painful stimuli she reassured them by saying: “don’t worry about it” (it’s not happening) and tried to dissuade their repeated attempts.

It was a vigil. Basically Olivia and her family stayed at the hospital and spent most of the time with her father (including sleeping at the bed-side). She did her own nursing assessments on her father. Nursing staff were initially very worried that she was watching things and they watched her watching. It was all a bit too tense so she told them not to worry about it. She was conscious of the impact that being a RN could have on the staff and said I’m actually a daughter at the moment that’s all I can be. Olivia found comfort at times in moving to her nursing role (which was devoid of daughter emotions) and found that intellectualising helped her cope. Olivia’s family kept her in touch with the sadness of the situation which was part of being a daughter and kept her in touch with reality as a family member. She did not think it was appropriate to provide personal care for her father as she respected his privacy (he would have wanted that).
There were times when she flip-flopped from being the emotionally distraught daughter to being the RN negotiator: she said she wanted to be included when the doctors did their rounds and invited the RNs to join in. She was also quite assertive: she insisted on seeing her father pre-operatively so they sent out the Clinical Nurse Consultant (CNC) to deal with her. They then agreed to her request.

Olivia found it really difficult being responsible for the life and death decision-making. Her mother, sister and brother looked to her for guidance continually during her father’s hospitalisation. In Olivia’s family males make the decisions, so this was a significant departure. Olivia had been called on to give advice to family members about health matters previously and she had been very comfortable in playing this type of caring and useful role, and it made sense as she was the one with the power and language. Initially she agreed to give her father a go, but he became decerebrate so it was then clear that they needed to change their focus. She had to interpret the signs of her father’s deteriorating condition for her family as they initially thought it was a good sign when her father’s foot moved until she told them it was a bad sign. The hardest thing in her life was responding frankly to her mother when she asked Olivia whether he was ever going to be OK. Olivia did not want to but she had to be really honest, because they trusted her completely and if she persisted with any glimmer of hope of recovery they would naturally want to hold on to the hope and the segue of events would have been completely different.

Olivia realised that if her belief system about the value of life had been different, her father could now be in a nursing home and not dead. Olivia felt instrumental in the decision to withdraw life-support from her father, and she fought the neurosurgeon who was trying to convince her to continue active treatment. She told him that her father would not want to live in that condition, and would literally shoot a dog under similar circumstances. She was also being very protective of her mother: thinking the neurosurgeon’s recommendation was not going to be pushed onto her mother. Olivia has no regrets and believes it was the best outcome for her father, but she felt heavily burdened about being responsible for the decision. She and her family sat with her father and he died and that was a very difficult experience. Two years after the event she realised that she still felt very troubled by being responsible for her father’s death, so she contacted her mother and siblings to share her feelings with them and achieved some closure when they confirmed that they fully supported the decision.

[24 Questionnaire] Patrick is 53 years old and has worked as a RN for 14 years and is separated from his wife and 9 year old daughter. His brother and sister always played the most active role in his parents’ hospitalisations because they live interstate near his parents and because his sister holds higher status in the family. His parents are very country, very stoic and stubborn, and either alarmed by or indifferent to new ideas and approaches.

Two years ago Patrick’s then 75 year old mother had multiple brief hospitalisations over several weeks because she had a fall at home and suffered serious fracturing of her arm. All went routinely and she made a good recovery. Five years ago, Patrick’s then 72 year old father had multiple hospitalisations (of varied duration) over a two year period. He contracted pneumonia following thoracic surgery and suffered damage to his larynx while being resuscitated and he also almost choked to death during one of Patrick’s visits.
Appendix A  
Participant Stories in Summary

Patrick always had face to face contact with his father and the staff during his father’s hospitalisations and sometimes telephone contact during both parents’ hospitalisations. Patrick chose not to disclose his RN status because staff members in attendance were doing their job (although not to his satisfaction) but he believed it was not his situation to control or interfere with. Patrick was patently aware of the short-comings of the health care system and therefore had a number of concerns even before visiting his parent in hospital. He does not want to sound like the picky know-all RN, but observed some glaring and startling mismanagement practices on every visit and said he was in no position to do something about it. Patrick was not only concerned for his parent but also had to contend with his own upsetting anger.

[25 Questionnaire]  Rachel is a 41 year old woman who has worked as a RN for 20 years. Fifteen years ago her then 54 year old mother had multiple hospitalisations (of varied duration) over a 5 year period and died in hospital from breast cancer. Rachel worked at the same hospital for most of her mother’s admissions and always played the most active role. There was no mention of siblings or whether her mother had a spouse at the time. Rachel had face to face contact with her mother and with staff during all her hospitalisations, and sometimes telephone contact.

The experience was very traumatic – Rachel felt like she had no say in what happened – in fact that she was caught up in medical politics. The ward nursing staff did not want to get involved with Rachel or the family situation. She worked in the hospital in which her mother was managed, so it was a lonely experience.

Rachel thinks she would have been none the wiser to many things but because she was a RN she had expectations of people and she thinks this frightened staff. The fact that her mother had breast cancer and was going to die did not help. She thinks they may have felt helpless, but there was a barrier. No one connected with Rachel as a daughter/relative.

Rachel did not have a choice regarding disclosure of her RN status because she worked in the hospital and was well known there. There was one time that her mother went to another hospital because she had pathological fractures of her femur and humerus and went in as an emergency. Rachel was prepared not to tell but things were so bad that she had to challenge and question the junior medical staff’s management of her mother and so she had to disclose her professional status when asked a direct question “ what are you a doctor or something”.

[26 Questionnaire + Interview]  Ryan is 47 years old who has worked as a RN for 20 years and has current experience in medical surgical and emergency care. He has a very large extended family and five siblings (a younger brother is a RN who lectures in a nursing program and an older sister who qualified as a RN but is now a psychologist) and he encourages his family to use him or his RN brother as a source of information. He is married with a family and lives in a country town about 5 hours away from his parents so he leaves it to his siblings to have close involvement in his parents’ hospitalisations.

Ryan’s mother (who was a RN) had multiple hospitalisations for varied periods over 20 years, and was last hospitalised 5 years ago at the age of 70 years. She suffered a punctured aorta during surgery on her vertebra, and her sciatic nerve was damaged which resulted in prolonged ICU stay and a long rehabilitation stay.
Ryan had face to face and telephone contact with his mother and with staff during some of her hospitalisations. He found the telephone contact with staff unproductive: he was asked to ring back later to speak to his mother’s nurse and then at a later time the nurse was too busy to talk. He had mixed feelings about this but understands it and accepts it is “par for the course” and knew he could phone his brother later for information. Ryan had low expectations and low involvement.

His 75 year old father had multiple brief hospitalisations over 20 years, and was last hospitalised 5 weeks ago. He has been hospitalised for minor procedures, has had surgery for bowel obstruction, and has a primary liver tumour. Ryan did not have face to face or telephone contact with his father or with staff during any of his hospitalisations. Instead of contacting hospital staff he often obtained detailed information and discussed his parents’ hospitalisations with his RN brother who played the most active role as he lives near his parents. Information obtained from his parents is often difficult to work out. Knowing about confidentiality, and available time that hospital staff have, has made Ryan less inclined to make direct inquiries about his parents. He believes RNs are more likely to ask their RN relatives questions than to ask hospital staff. In his nursing practice he encourages relatives to use one relative as a contact or source of information, rather than each family member continuing to inquire by telephone. His mother and brother were unhappy with the standard of care given to his father.

His parents have been in hospital sometimes for emergency treatment, sometimes for minor procedures. Ryan’s response has varied. Sometimes he was not aware that they had gone to hospital, sometimes he was worried that they would die. He believes his experiences are influenced by his RN background because he has knowledge of pathology and treatment, is familiar with organisational processes of hospitals and has experience of relatives’ responses to a family member’s hospitalisation. Ryan felt comfortable in the hospital setting and knew what to expect. He thinks there is an advantage in being a RN as the staff can give RNs more detailed information and better explanations. Ryan assessed his father clinically during visits, asked him questions and looked at his legs, charts and so on: “it’s routine”.

When visiting, he felt he had no reason to inform staff of his RN status. With telephone inquiries he did disclose this because he felt it easier for staff to provide information if they knew. There were times that staff found out about Ryan’s RN status (he couldn’t care) either because his parents told them, or when he made inquiries (staff asked if he was a nurse probably because of the information requested, terms used, and so on). Ryan perceived that staff trod fairly softly due to there being four RNs in the family, and the power differential may have been a factor for his brother (a staff member was one of his brother’s ex-students).
Appendix A  Participant Stories in Summary

[27 Questionnaire]  Sam is 47 years old and has worked as a RN for 22 years. Fifteen years ago Sam’s then 58 year old father had multiple brief hospitalisations over a 3 year period. Sam always played the most active role in his father’s hospitalisations. Sam did not mention siblings or whether his father had a spouse at the time. Sam had face to face contact with his father and with staff for some of the hospitalisations. Sam disclosed his RN status when he asked questions so that hospital staff could give him more details than a layman. He thought the experience was less scary as a RN because he does not tend to dwell on the “what ifs” unless they actually happen and because he knew what was going on. Sam described his experience as having no problems and he was quite happy with the care and teaching in general.

[28 Questionnaire]  Sarah is 42 years old and has worked as a RN for 22 years. Two years ago her then 67 year old mother was hospitalised. Her mother had been hospitalised for long periods on more than one occasion over a six year period. Sarah’s mother was dying from cancer and recently had surgery (palliative ileostomy). Sarah played the most active role in her mother’s hospitalisations. There was no mention of siblings or whether her mother had a spouse at the time. She had face to face contact with her mother and with staff during all of her hospitalisations.

As Sarah’s mother was dying from cancer it was a horrible experience. Sarah wanted her mother home as soon as possible after the operation. Post-operative care was ordinary and at one stage staff taped on the ileostomy bag using Elastoplast. Every lunch time and tea-time Sarah would arrive and her mother’s very swollen legs would be dangling in a recliner and her bag would have leaked all over her. Sarah would change her and clean her up and elevate her legs. After two days of this Sarah said it was time to let staff know.

When nursing staff were aware of Sarah’s RN status they even referred her mother to the stomal therapist who ordered appropriate bags that didn’t leak and her mother’s legs were always elevated. Until they found out that Sarah was a RN the staff had told her Aunt that it was normal for stoma bags to leak.

Sarah chose not to disclose her RN status as staff tend to act differently and it makes it uncomfortable for them if they know you are a RN. In her mother’s case Sarah felt she needed to let them know so her mother would not be left in an undignified way. There was an occasion when Sarah did not disclose her status but was recognised by a nurse that Sarah had trained with.

[29 Questionnaire + Interview]  Sophie is 45 years old and has worked as a RN for 26 years. Her 65 year old mother had multiple long hospitalisations over 7 years and recently died (cerebral bleed 7 years ago and then had a massive stroke having lost speech and limb movements 8 months ago). Sophie’s stepfather was next of kin and therefore he played the most active role as he was always the one to be consulted first but then he would discuss her mother’s condition with the siblings and always ask Sophie’s advice. She is the second eldest with four siblings (three brothers and a sister). Sophie’s 72 year old father had multiple brief hospitalisations over 3 months, and died in hospital 6 months ago. He was diagnosed with cancer of the lung and secondaries. Her father’s wife (not her mother) was next of kin and was consulted first but she asked Sophie for guidance.
Sophie had face to face contact with her parents and contact with staff during their hospitalisations and also had telephone contact with the staff.

Sophie found her mother’s hospitalisation terrifying because her mother had had a massive stroke, was on life support and the family were all called together to make a decision regarding turning off the life support. Her family were preparing for her to die but Sophie knew she would not because she was only receiving 30 percent support and her E.C.G. reading showed a very strong heart beat. Sophie found it devastating and so terribly hard as she could tell by the look in her mother’s eyes that she was suffering.

The experience would have been more distressing if Sophie had not been able to understand the ‘hospital talk’. Sophie would have been very distressed by all the tubes coming out of her mother and would have found it difficult to offer a lot of support to the rest of her family if she did not feel so comfortable with all the apparatus. Sophie has usually been happy to be in the leadership role for her family. At the same time she felt really uncomfortable and felt intimidated by being a RN. As a RN knowing the whole process was terrifying.

Sophie felt it unnecessary to disclose her RN status when staff spoke in clear simple terms when describing her mother’s condition. Sometimes staff would start to describe a complicated procedure. She then felt it polite to inform the staff that she was familiar with what was happening. The specialist doctor was wonderful and gave very detailed information which would not have been given to a lay person. Other family members would inform staff that she was a RN as they found that staff members were able to relate in an easier way when describing complicated procedures. Sophie is mindful of the way she interacts with nursing staff: she is an up-front person but has a non-judgemental approach.

In playing the leadership role for the family she ensured that they were in touch with the reality of her mother’s condition, and gently advised them not to get their hopes up high. She knew that if she said her mother would be OK the family would take her word for it. They trusted her word so much that she could not pretend, but she tried to soften it. Initially it was agonising visiting her mother: she put on a happy face during the visit, and then howled all the way home. She later found it was good to be able to do something to improve her mother’s comfort during the visit using aromatherapy.

Sophie is a Clinical Nurse Specialist working in an acute hospital unit. She believes that having worked in such a demanding environment prepared her for providing the support her family needed after her mother collapsed 7 years ago. On the other hand it created a lot of stress for her. At times she wished she was not so aware of all the things that can go wrong, thinking that perhaps it is better to be a bit ignorant of the consequences of major trauma.

When Sophie’s father was unwell and undergoing investigations, she thought: he’s got cancer (prior to diagnosis) – which later proved to be the case. She had long discussions with her father about his health but did not reveal her suspicions regarding his diagnosis. Her father preferred her to just be the daughter. He was embarrassed about toileting assistance and Sophie was very happy to just be the daughter and not get involved in his nursing care. Her father died in hospital a few months later. Sophie was relieved and grateful as she could not have coped with another long illness process.
Sophie and her father’s wife were at his bedside every day supporting him and observing his needs and treatment. It was very difficult for Sophie to explain to his wife that her father was beyond treatment: she couldn’t comprehend it at all. She looked to Sophie for that knowledge and support and Sophie stayed with her for the period of her father’s hospitalisation. Sophie kept trying to explain it gently to her.

Sophie had to be strong for everybody, and put her own emotions on hold (unconsciously). Sophie felt robbed of being a daughter, and that was why she had to take time off when it was all over as she suffered a major depression and was not functioning. She was appreciative of having a close family and a very supportive husband to lean on when she did fall apart. Sophie stated she really needed to allow herself those feelings as the child of the parent sooner to prevent falling apart so badly. As a result of experiencing the deaths of three close family members within a 2 year period, her mother, her father and the unexpected death of her son, she cannot now take on emotional stress.

[30 Questionnaire + Interview] William is a 49 year old man who has worked as a RN for 25 years and is currently working in palliative care as a deputy director of nursing (DDON). William is single and lived hours away from his parent’s home. He has a younger brother who is married and lives interstate. William always played the most active role in his parents’ hospitalisations. Seven years ago William’s then 70 year old mother had multiple brief hospitalisations over a 12 month period. She had chest pain, was admitted to hospital for investigation, found an arterial occlusion and was for angioplasty. He requested detailed information from her doctor about this but only received a very general reply which made him wonder whether it was more serious or perhaps that the doctor did not wish to give him the details. The procedure worked well then she had a myocardial infarct which was devastating but she made a full recovery. Going through his mother’s recovery was stressful. During the first 24 hours he was watching her ECG, waiting to see if she would have another infarct and so on, whilst pretending everything is OK. A little knowledge is frightening. William had face to face and telephone contact with his parents and with staff during all their hospitalisations.

William’s then 66 year old father became ill and was hospitalised at the same time as his mother to have cardiac surgery (parents were in different hospitals a few hours’ drive apart). His father was diagnosed with cancer and liver secondaries, which led to multiple brief hospitalisations over a 12 month period. His father died about 12 months later having been admitted to hospital for the last 3 days of his life. When his father became ill and William read the referral letter he knew exactly what was wrong although he withheld this information from his parents partly because he wondered whether he might be wrong and because he wanted to minimise his parents’ fear and stress. He did not tell his parents though they asked – he felt stuck in the middle with a whole day of waiting for the doctor to talk to his parents. William thought he would lose both parents at once. William’s brother wept and was devastated by his father’s news (which William had to convey over the phone as the brother lived interstate) and William felt inadequate as he was unable to do anything to comfort him.
Non-disclosure was not an option because William was well known to staff, however in other settings he is usually quite guarded about disclosing because you are treated differently and given less care. William was advantaged in some ways because of his RN status and when he struck problems trying to get information he was given direct phone numbers to hospital wards (which are not normally given to the public) and because he was the DDON staff were pretty careful and tended to jump a bit, which was an advantage in relation to the parent’s care. William was very conscious of not abusing the status and power of his nursing position and he never corrected staff in relation to his parents’ care.

As a RN, William knew when to push for better care or treatment. At times he stepped in to get his father urgent medical attention, and on one occasion he agreed to assist a nurse in giving his father personal care. He immediately regretted this as it impinged on his father’s privacy and modesty, and he knew his father would not have liked that. At a different hospital William did not disclose his RN status but staff found out (his mother probably told them). The most significant thing was having both parents seriously ill together. It was all consuming: organising other family members, getting help, home care and so on, trying to be positive and not falling in a heap, remaining positive for them. He was too busy being the RN to deal with the sadness and tragedy of it himself. There was no release, no time for just himself. Towards the end he was exhausted and wished things would hurry and take their course. Months after it was all over he burst into tears one day in the car and cried all the way home. William believes it would have helped to talk to others about what he was going through to unburden himself but he did not consider this at the time.

[31 Questionnaire] Zac is 45 years old and has worked as a RN for 18 years. His 54 year old mother [perhaps stepmother given she is only nine years older than Zac] was hospitalised eight days ago. She had been hospitalised on more than one occasion over a two week period (reason for hospitalisations not provided). He had face to face contact with his mother and with staff during some of her hospitalisations.

Zac’s 78 year old dying father had multiple hospitalisations (varied periods) over the past 5 years. The most recent hospitalisation was 11 days ago. Zac had telephone contact with his father and staff during some of his hospitalisations. Zac mentioned that his sister played the most active role in his parents’ hospitalisations as she was not working and had more time.

Zac’s experience was not as harrowing as he imagined it might be and he was a lot calmer for his parents’ hospitalisations then for his own. Zac was disappointed that staff were not telling them much. During Zac’s three initial visits he chose not to disclose his status until he discovered they were not providing enough information, so he “pulled out the big guns”.
Appendix B

University Human Research Ethics Committee Approval p239

Information Sheet for participants p240-241

Consent for Interview Form p242-243

Questionnaire p244-249

Pilot Questionnaire p250-255

Letters (proforma) to participants p256-257
UNIVERSITY OF WESTERN SYDNEY
Locked Bag 1797
PENRITH SOUTH, NSW 1797
26 November 2001

Helen Ledwidge
29 Eltham Street
Gladstone NSW 2111

Dear Helen,

Re: Research Project: The experiences of NSW registered nurses in attempting to get the best care possible for their parent in hospital Registration Number HEC 01/188

Your Application has been reviewed and you are advised that your project has been granted a full ethics approval.

You are advised that the Committee should be notified of any further changes to the research methodology should there be any in the future. You will be required to provide a report on the ethical aspects of your project at the conclusion of this project. The form is attached and also located on the Research Services Web Page.

The Protocol No. HEC 01/188 should be quoted in all future correspondence about this project. Your approval will expire 30 December 2004. Please contact the Human Ethics Officer, Kay Buckley on tel: 4570 1136 if you require any further information.

The Committee wishes you well with your research.

Yours sincerely

[Signature]

Professor Elizabeth Deane
Chairperson
UWS Human Research Ethics Committee
Appendix B

INFORMATION SHEET

Research Topic: The experiences of registered nurses with a parent in hospital

Researcher: Helen Ledwidge  Supervisors: Prof L.Wilkes, Dr A.Fleming

(Contact details overleaf)

Dear Registered Nurse,

Have you had a parent in hospital?

If you have had a parent in hospital I invite you to share your experiences by completing the enclosed questionnaire, and/or by being interviewed. Please select Option 1, or Option 2, or Option 3. These options are described below.

Your assistance will be greatly appreciated, as the information you provide will help us to identify and address important issues or difficulties that RNs have faced in this situation, and the ways in which they have responded to them.

Option 1 involves completing the enclosed questionnaire.

If you decide to participate, please complete the questionnaire and mail it to me in the postage-free envelope enclosed by 22nd November 2002.

Option 2 involves completing the enclosed questionnaire and being interviewed by me for about 1hr. The interview (to be conducted either in person or on the phone) will be audiotaped, and provides you with an opportunity to share (in greater depth) your experiences about having a parent in hospital. If you decide to participate, please mail me the questionnaire PLUS your contact details on a signed copy of the 'Consent for Interview' form in the postage-free envelope enclosed by 22nd November 2002.

Option 3 involves being interviewed by me for about 1hr. The interview (to be conducted either in person or on the phone) will be audiotaped and provides you with an opportunity to share your experiences about having a parent in hospital.

If you are willing to be interviewed, please provide your contact details on a signed copy of the enclosed 'Consent for Interview' form, and mail it to me in the postage-free envelope enclosed by 22nd November 2002.

Please turn over
Appendix B

INFORMATION SHEET (Continued)

Research Topic: The experiences of registered nurses with a parent in hospital

Please note: I do not have access to the names and addresses of RNs on the Board’s Register and I am grateful to the Nurses’ Registration Board for forwarding this invitation to you on my behalf. I will only know your name and address if you choose to provide these details to me.

If you participate in the project, any identifying information that you provide to me will remain confidential. There are no adverse consequences if you decide to withdraw from the project at any time, or if you choose not to participate.

If you experience any distress as a result of participating in the project counselling can be arranged.

If you would like to be advised of where to access the results of this research project, please complete the Research Results Notification Slip enclosed, and return it together with your Questionnaire and/or your signed ‘Consent for Interview’ Form in the postage-free envelope provided.

This project is part of a doctoral degree program at the University of Western Sydney. If you have any queries, please do not hesitate to contact me:

Helen Ledwidge Phone (02) 9685 9032; or 0407 702 827 (Mobile);

or by email h.ledwidge@uws.edu.au. Alternatively you may contact

Professor Wilkes, (Principal Supervisor):Phone 02 47 343182; or by email l.wilkes@uws.edu.au

Thank you very much for your time.

NOTE: This study has been approved by the University of Western Sydney, Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research Ethics Officers (Tel: 02 4570 1136). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Are you consenting to be interviewed? If so, please complete this form and post it to me in the enclosed envelope by 22 November 2002.

University of Western Sydney
Locked Bag 1797, PENRITH SOUTH DC NSW 1797
School of Nursing, Family & Community Health

CONSENT FOR INTERVIEW FORM

Research topic: The experiences of registered nurses with a parent in hospital

This form is to indicate your consent to be interviewed in person or on the telephone, and to have the information from the audio-taped interview included anonymously in the project: ‘The experiences of registered nurses with a parent in hospital’, as outlined in the enclosed Information Sheet.

The information obtained from the interview may be included in various publications or conference presentations. Your name will not be used. Pseudonyms will be used when discussing or writing up the information you provide.

STATEMENT OF CONSENT

I, the undersigned, have read my copy of the Information Sheet, and have had the opportunity to contact the researcher to discuss any queries. I hereby consent to be interviewed, and to have my taped interview used as outlined above, as part of this research project. I understand that I may withdraw from the project at any time without question or adverse consequences. I have retained my copy of the Consent form.

Name: ........................................................................
Address (optional): ..............................................................
Phone (work, home, or mobile): ..........................................
e-mail: ..........................................................................
Signature: ........................................................................
Date: .............................................................................

Please note: You may withdraw from the project at any time, and you may also withdraw your permission to have your material used in the project. You are not required to give any reasons if you withdraw from the project. Your decision will be respected. If you experience distress during the interview, the interview will be terminated, and counselling can be arranged.

NOTE: This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research Ethics Officers (Tel: 02 4570 1136). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix B

University of Western Sydney
Locked Bag 1797, PENRITH SOUTH DC NSW 1797
School of Nursing, Family & Community Health

CONSENT FOR INTERVIEW FORM
PARTICIPANT’S COPY

Research topic: The experiences of registered nurses with a parent in hospital

This form is to indicate your consent to be interviewed in person or on the telephone, and to have the information from the audio-taped interview included anonymously in the project: ‘The experiences of registered nurses with a parent in hospital’, as outlined in the enclosed Information Sheet.

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Name: .......................... Address (optional): ..........................
Phone (work, home, or mobile): ..........................
e-mail : ..........................

Signature: ..........................
Date: ..........................

Please note: You may withdraw from the project at any time, and you may also withdraw your permission to have your material used in the project. You are not required to give any reasons if you withdraw from the project. Your decision will be respected. If you experience distress during the interview, the interview will be terminated, and counselling can be arranged.

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University of Western Sydney

Locked Bag 1797, PENRITH SOUTH DC NSW 1797

School of Nursing, Family & Community Health

QUESTIONNAIRE

Research Topic: The experiences of registered nurses with a parent/s in hospital

This part of the questionnaire asks about your experiences of having a parent/s in hospital.

1. What was the experience like for you, of having a parent/s in hospital?
   Attach extra pages if necessary

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

2. In what ways, if any, did you think that because you are a registered nurse the experience may have been different to that of a non-registered nurse?

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Please continue to the next page
Appendix B

3. In relation to your experiences of having a parent/s in hospital, were there times when you chose not to disclose your RN status? That is, were there times when you decided not to let hospital staff know that you are an RN?

☐ 1 Yes  ☐ 2 No

If you answered Yes to Question 3 above, please tell me about those circumstances or situations. **Attach extra pages if necessary**

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

4. In relation to your experiences of having a parent/s in hospital, were there times when you did disclose your RN status? That is, were there times when you chose to let hospital staff know that you are an RN?

☐ 1 Yes  ☐ 2 No

If you answered Yes to Question 4 above, please tell me about those circumstances or situations. **Attach extra pages if necessary**

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

5. In relation to your experiences of having a parent/s in hospital, were there times when you did not disclose you are an RN, but the hospital staff found out or knew that you were an RN anyway?

☐ 1 Yes  ☐ 2 No

If you answered Yes to Question 5 above, please comment about this. **Attach extra pages if necessary**

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

Please continue to the next page
Appendix B

This part of the questionnaire seeks background information about you and your parents.

6. How old are you? _________ Years

7. Are you □₁ Female □₂ Male

8. How long have you been an RN? _________ Years

9. What is the highest educational qualification you have completed? Tick one box only.

□₁ School certificate or equivalent □₄ Bachelor degree from university
□₂ HSC or equivalent □₅ Postgraduate diploma or certificate
□₃ Technical or trade certificate or □₆ Postgraduate degree, e.g., Masters
diploma, other than nursing certificate or PhD

10. In relation to your experiences of having a parent/s in hospital, were you working at the same hospital/s to which your parent/s had been admitted? Please tick any statements below that apply to your circumstances.

□₁ Yes, I worked at the same hospital for all my mother’s admissions
□₂ No, I did not work at the same hospital for any of my mother’s admissions
□₃ Yes, I worked at the same hospital for some of my mother’s admissions

□₁ Yes, I worked at the same hospital for all my father’s admissions
□₂ No, I did not work at the same hospital for any of my father’s admissions
□₃ Yes, I worked at the same hospital for some of my father’s admissions

11. Did any member of your family have a more active role than you had concerning your parent/s in hospital?

□₁ Yes □₂ No □₃ On a minority of occasions

11(a) If you answered Yes to Question 11 above, please comment.

_____________________________________________________________________________
_____________________________________________________________________________

12. Do the experiences you have described relate to:

□₁ the Hospitalisation of both your parents
□₂ your Mother’s hospitalisation
□₃ your Father’s hospitalisation

Please continue to the next page
Appendix B

If any of the experiences you have described were related to your mother’s hospitalisation/s, or to both your parents’ hospitalisations, please answer the questions below.

If your experiences related only to your father’s hospitalisation/s, please go to Question 19.

13. How long ago was your mother’s hospitalisation/s to which your experiences relate?

_________ days/weeks/months/years (Please circle)

14. How old was your mother at that time?

_________ Years

15. Did your mother have more than one hospitalisation?  □  Yes  □  No

15(a) If you answered Yes to Question 15 above, over what period of time did your mother’s hospitalisations occur?

_________ weeks/months/years (Please circle)

16. What was the duration of your mother’s hospitalisation/s?

□  Brief period/s (days rather than weeks)
□  Long period/s (weeks or months)
□  Varied periods of hospitalisation

17. Indicate the type of contact you had with your mother and with hospital staff during your mother’s hospitalisation/s, by ticking any statements below that apply to your circumstances.

□  I did not have any face-to-face contact with my mother for any of her admissions.
□  I had face-to-face contact with my mother for some of her admissions.
□  I had some face-to-face contact with my mother during all her admissions.
□  I did not have telephone contact with my mother for any of her admissions.
□  I had telephone contact with my mother for some of her admissions.
□  I had some telephone contact with my mother during all her admissions.
□  I did not have any face-to-face contact with hospital staff for any of her admissions.
□  I had face-to-face contact with hospital staff for some of my mother’s admissions.
□  I had some face-to-face contact with hospital staff during all my mother’s admissions.
□  I did not have telephone contact with hospital staff for any of my mother’s admissions.
□  I had telephone contact with hospital staff for some of my mother’s admissions.
□  I had some telephone contact with hospital staff during all my mother’s admissions.

17(a) Please comment re the above, or specify if you had other types of contact

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

18. Please add any information about your mother that you believe is relevant background and could help me to gain a better understanding of the experiences you have described concerning your mother’s hospitalisation/s. (OPTIONAL) Attach extra pages if required

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

Please continue to the next page
Appendix B

If any of the experiences you have described related to your father’s hospitalisation/s, or to both your parents’ hospitalisations, please answer the questions below. If your experiences related only to your mother’s hospitalisation/s, please go to Question 25.

19. How long ago was your father’s hospitalisation/s to which your experiences relate?
   __________ days/weeks/months/years (Please circle)

20. How old was your father at that time?
   __________ Years

21. Did your father have more than one hospitalisation?
   □ Yes  □ No
   21(a) If you answered Yes to Question 21 above, over what period of time did your father’s hospitalisations occur?
      __________ weeks/months/years (Please circle)

22. What was the duration of your father’s hospitalisation/s?
   □ 1 Brief period/s (days rather than weeks)
   □ 2 Long period/s (weeks or months)
   □ 3 Varied periods of hospitalisation

23. Indicate the type of contact you had with your father and with hospital staff during your father’s hospitalisation/s, by ticking any statements below that apply to your circumstances.
   □ 1 I did not have any face-to-face contact with my father for any of his admissions.
   □ 2 I had face-to-face contact with my father for some of his admissions.
   □ 3 I had some face-to-face contact with my father during all his admissions.
   □ 1 I did not have telephone contact with my father for any of his admissions.
   □ 2 I had telephone contact with my father for some of his admissions.
   □ 3 I had some telephone contact with my father during all his admissions.
   □ 1 I did not have any face-to-face contact with hospital staff for any of his admissions.
   □ 2 I had face-to-face contact with hospital staff for some of my father’s admissions.
   □ 3 I had some face-to-face contact with hospital staff during all my father’s admissions.
   □ 1 I did not have telephone contact with hospital staff for any of my father’s admissions.
   □ 2 I had telephone contact with hospital staff for some of my father’s admissions.
   □ 3 I had some telephone contact with hospital staff during all my father’s admissions.

23 (a) Please comment re the above, or specify if you had other types of contact
   ______________________________________________________________________________
   ______________________________________________________________________________
   ______________________________________________________________________________

24. Please add any information about your father that you believe is relevant background and could help me to gain a better understanding of the experiences you described concerning your father’s hospitalisation. (OPTIONAL) Attach extra pages if required
   ______________________________________________________________________________
   ______________________________________________________________________________

Please continue to the next page
Appendix B

25. Please add any background information about yourself or your situation that you believe could help me to gain a better understanding of your experiences of having a parent/s in hospital. (OPTIONAL)

Attach extra pages if necessary

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________ 

• Please return the completed questionnaire by 22nd November 2002 in the postage-free envelope provided.

• Please also enclose the ‘Consent for Interview’ form if you are willing to be interviewed about your experiences regarding this research topic.

• If you have lost the free-postage envelope provided, just address a plain envelope with the address shown below, so that you won’t need to attach a postage stamp.

  Write the following words on the (front) top left-hand side of the envelope:

  Delivery Address: 29 Eltham Street, Gladesville NSW  2111

  Write the following in the centre of the envelope:

  Helen Ledwidge

  Reply Paid 76397

  Gladesville NSW  2111

  Thank you very much for your assistance.

  The information you provide will help to identify and address important issues or difficulties that RNs face when they have a parent in hospital.
Research Topic: The experiences of registered nurses with a parent/s in hospital
This part of the questionnaire asks about your experiences of having a parent/s in hospital.

1. What was the experience like for you of having a parent/s in hospital? 
   Attach extra pages if necessary

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

2. In what ways, if any, did you think the experience may have been different because you are a registered nurse? (That is, different to the experience of having a parent in hospital if you had not been a registered nurse). Attach extra pages if necessary

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
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_____________________________________________________________________________
_____________________________________________________________________________

Please continue to the next page

Comment [HL1]: Page 1
Do I need to specify the type of hospital to which I am referring? Does it really matter whether it's an acute care hospital or some other? I don't really think it matters, as the RNs can tell me in questions 18 & 25 if there is extra info I need to know to.
Appendix

3. Were there times when you chose not to disclose your RN status? That is, were there times when you decided not to let hospital staff know that you are an RN?

   o1 Yes       o2 No

If you answered Yes to Question 3 above, please tell me about those circumstances or situations. Attach extra pages if necessary

____________________________________________________________________________________________
____________________________________________________________________________________________
____________________________________________________________________________________________
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____________________________________________________________________________________________
____________________________________________________________________________________________

4. Were there times when you did disclose your RN status? That is, were there times when you chose to let hospital staff know that you are an RN?

   o1 Yes       o2 No

If you answered Yes to Question 4 above, please tell me about those circumstances or situations. Attach extra pages if necessary

____________________________________________________________________________________________
____________________________________________________________________________________________
____________________________________________________________________________________________
____________________________________________________________________________________________

4 (a) Were times when you did not disclose you are an RN, but the hospital staff found out or knew you were an RN anyway (For example you might have worked at the hospital previously, or be well known within the profession, or have taught the staff RNs or students at some stage, or your parent may have told them etc).

   Yes       No

If you answered Yes to Question 4(a) above, please comment about this. Attach extra pages if necessary

____________________________________________________________________________________________
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Comment [HL2]: Page: 3
This extra question would cover the only other possibility regarding disclosure – it might make the RN feel angry/resentful/betrayed if her cover has been blown, particularly if she had not wanted her RN status to be known to hospital staff.
Appendix B

This part of the questionnaire seeks background information about you and your parents.

5. How old are you?
   o1  40-54 years
   o2  55-65 years

6. Are you o1 Female  o2 Male

7. How long have you been an RN? _________ Years

8. What is the highest educational qualification you have completed? Tick one box only.
   o1  School certificate or equivalent
   o2  HSC or equivalent
   o3  Technical or trade certificate or diploma, other than nursing certificate
   o4  Bachelor degree from university
   o5  Postgraduate diploma or certificate
   o6  Postgraduate degree, e.g., Masters or PhD

9. Do the experiences you have described relate to your mother’s hospitalisation, your father’s hospitalisation, or to both?
   o1  Mother’s hospitalisation
   o2  Father’s hospitalisation
   o3  Hospitalisation of both parents

10. For the experiences you have described, were you working at the same hospital/s to which your parent/s had been admitted?
    o1  Yes, for every hospital admission
    o2  No
    o3  Yes, for some admissions

11. For the experiences you have described, did any member of your family have a more active role than you had concerning your parent/s in hospital? o1  Yes  o2  No  o3  On a minority of occasions

11(a) If you answered Yes to Question 10 above, please comment.

Please continue to the next page
Appendix B

If any of your experiences relate to your mother’s hospitalisation/s, please answer these questions about your mother. If your experiences relate only to your father’s hospitalisation/s, please go to Question 19 on the next page. If your experiences relate to both parents please complete this page and the next page.

12. How long ago was your mother’s hospitalisation/s to which your experiences relate?

__________ days/weeks/months/years (Please circle)

13. How old was your mother at that time?  __________ Years

14. Did your mother have more than one hospitalisation?

 1 Yes   2 No

14(a) If you answered Yes to Question 14 above, over what period of time did these hospitalisations occur?

__________ weeks/months/years (Please circle)

15. What was the duration of your mother’s hospitalisation/s?

 1 Brief period/s (days rather than weeks)
 2 Long period/s (weeks or months)
 3 Varied periods of hospitalisation

16. For the experiences you have described, did you visit your mother on at least one occasion during that/those hospitalisations?

 1 No   2 Sometimes   3 Yes

16(a) Please comment:

______________________________________________________________________________

17. Did your mother live with you?

 1 Yes   2 No

If Yes, go to Question 18 below.

17(a) How far away from you did your mother live?  ________ minutes/hours/ or km

(Please circle)

18. Please add any information about your mother that you believe is relevant background to understanding the experiences you had concerning your mother’s hospitalisation. (OPTIONAL)

Attach extra pages if necessary

______________________________________________________________________________

Please continue to the next page
Appendix B

If any of your experiences relate to your father's hospitalisation/s, please answer these questions about your father. If your experiences relate only to your mother's hospitalisation/s, please go to Question 26 on the next page.

19. How long ago was your father’s hospitalisation/s to which your experiences relate?
   __________ days/weeks/months/years (Please circle)

20. How old was your father at that time?  __________ Years

21. Did your father have more than one hospitalisation?
    o1 Yes  o2 No

14(a) If you answered Yes to Question 21 above, over what period of time did these hospitalisations occur?
   __________ weeks/months/years (Please circle)

22. What was the duration of your father’s hospitalisation/s?

    o1 Brief period/s (days rather than weeks)
    o2 Long period/s (weeks or months)
    o3 Varied periods of hospitalisation

23. For the experiences you have described about having a parent in hospital, did you visit your father on at least one occasion during that/those hospitalisations?
    o1 No  o2 Sometimes  o3 Yes

23(a) Please comment:
_____________________________________________________________________________________
_____________________________________________________________________________________

24. Did your father live with you?  o1 Yes  o2 No
   If Yes, go to Question 25 below.

24(a) How far away from you did your father live? __________ minutes/hours/ or km
      (Please circle)

25. Please add any information about your father that you believe is relevant background to understanding the experiences you had concerning your father’s hospitalisation. (OPTIONAL) Attach extra pages if necessary
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Please continue to the next page
Appendix B

26. Please add any background information about yourself or your situation, which you believe would help me to gain a better understanding of your experiences of having a parent/s in hospital.

(OPTIONAL) Attach extra pages if necessary

_____________________________________________________________________________________
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_____________________________________________________________________________________
_____________________________________________________________________________________
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_____________________________________________________________________________________
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_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Please return the completed questionnaire in the reply-paid envelope provided by (insert date here).

Please also enclose the ‘Consent for Interview’ form if you are willing to be interviewed by me about your experiences regarding this research topic.

If you have lost the reply-paid envelope provided, just address a plain envelope with the address shown below, so that you won’t need to attach a postage stamp.

<Insert return postal address here>

Thank you very much for your assistance.

The information you provide will help to identify and address important issues or difficulties that RNs face when they have a parent in hospital.
Appendix B

Helen Ledwidge
NSW 2111

PRIVATE & CONFIDENTIAL

Mr xxxx
xxxxxxx
xxxNSW

Dear xxxx,

Subject: The experiences of registered nurses with a parent in hospital

Thank you for taking the time to share personal information about your experiences with me about your (insert: father’s/mother’s/parents’) hospitalisation. It’s greatly appreciated.

Thank you for also agreeing to talk with me. I will phone you soon on the phone number you provided (xxxx xxxx) to ask whether you would prefer to be interviewed on the phone or in person, and to arrange a suitable date for the interview to occur.

I have recorded your contact details for future reference so that I can advise you of where to access the results of the project upon its completion (probably in 2004).

Yours sincerely,

Helen Ledwidge

Email address: h.ledwidge@uws.edu.au

Phone: 02 9685 9032 (W); 0407 702 827 (Mobile)
PRIVATE & CONFIDENTIAL

Mr xxxxxxxxx
xxxxxxxxxxxx
xxxxxxx NSW

Dear xxxxx,

Subject: The experiences of registered nurses with a parent in hospital

Sorry for the delay in contacting you to arrange a suitable date for the interview to occur. I’ll phone you this week to see about a date for the telephone interview to take place (within the next few weeks if possible).

Thanks again for being prepared to share your experiences with me about your parent/s hospitalisation.

Yours sincerely,

Helen Ledwidge

Email address: h.ledwidge@uws.edu.au
Phone: 02 9685 9032 (W); 0407 702 827 (Mobile)
Appendix C

Table C1: Parent's Age, Presence of Spouse when Parent Hospitalised, Medical Condition, Number and Duration of Hospitalisation/s  p259

Table C2: Siblings, Workplace, and Playing an active role  p260

Table C3: Disclosure of RN status to Hospital Staff: Participants Preference and Outcomes  p261
### Table C1
Parent's Age, Presence of Spouse when Parent Hospitalised, Medical Condition, Number and Duration of Hospitalisation/s

<table>
<thead>
<tr>
<th>Participants</th>
<th>Mother</th>
<th>Father</th>
<th>Father's condition</th>
<th>Mother's condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>60</td>
<td>Spouse?</td>
<td>Elective surgery (not life threatening); One brief hospitalisation 5 years ago</td>
<td>2 cervical fusions; 2 knee replacements; Multiple long hospitalisations over 3 years</td>
</tr>
<tr>
<td>Amelia</td>
<td>61</td>
<td>Spouse?</td>
<td>2 Hospitalisations; Aortic aneurism repair 6 yrs ago; Cardiac arrest; died</td>
<td>Diabetic (Insulin dependent) with complications 2 yrs ago (Multi Long Hosps over 3 years)</td>
</tr>
<tr>
<td>Andrew</td>
<td>82 RN</td>
<td>Spouse</td>
<td>Cancer (Liver and Lungs); one long Hosp 17 yrs ago (died)</td>
<td>Cardiac Surgery died post-op 3 yrs ago (Multi brief hosps over 3 yrs)</td>
</tr>
<tr>
<td>Ben</td>
<td>69</td>
<td>Spouse?</td>
<td>2 Hospitalisations; Aortic aneurism repair 6 yrs ago; Cardiac arrest; died</td>
<td>Diabetic (Insulin dependent) with complications 2 yrs ago (Multi Long Hosps over 3 years)</td>
</tr>
<tr>
<td>Cameron</td>
<td>Spouse</td>
<td>82</td>
<td>2 Hospitalisations; Aortic aneurism repair 6 yrs ago; Cardiac arrest; died</td>
<td>2 Hospitalisations; Aortic aneurism repair 6 yrs ago; Cardiac arrest; died</td>
</tr>
<tr>
<td>Claire</td>
<td>Spouse AN</td>
<td>66</td>
<td>Endstage Cancer (Lung): died; one brief hospitalisation</td>
<td>Endstage Cancer (Lung): died; one brief hospitalisation</td>
</tr>
<tr>
<td>Daniel</td>
<td>Spouse</td>
<td>78</td>
<td>No information provided (brief hospitalisations over 10 years)</td>
<td>No information provided (brief hospitalisations over 10 years)</td>
</tr>
<tr>
<td>Eliza</td>
<td>69 Div</td>
<td>Spouse</td>
<td>Cancer (pancreas)/diabetes/alcoholism/depression died a yr ago (Multi Hosps over 4 yrs)</td>
<td>Cancer (pancreas)/diabetes/alcoholism/depression died a yr ago (Multi Hosps over 4 yrs)</td>
</tr>
<tr>
<td>Emma</td>
<td>Spouse RN</td>
<td>69 Dr</td>
<td>Cardiac surgery: 6 months ago (Multi brief hosps over 7 yrs)</td>
<td>Cardiac surgery: 6 months ago (Multi brief hosps over 7 yrs)</td>
</tr>
<tr>
<td>Eva</td>
<td>Spouse</td>
<td>69</td>
<td>Cancer (Bowel) diagnosed inoperable died 2 yrs ago one long hospitalisation</td>
<td>Cancer (Bowel) diagnosed inoperable died 2 yrs ago one long hospitalisation</td>
</tr>
<tr>
<td>Gil</td>
<td>69</td>
<td>75</td>
<td>Medulla tumour 16 yrs ago (Multi long hosps over 1 yr)</td>
<td>Medulla tumour 16 yrs ago (Multi long hosps over 1 yr)</td>
</tr>
<tr>
<td>Harry</td>
<td>73</td>
<td>Spouse</td>
<td>Mentally ill (incarcerated for life); 10 yrs ago (Multi hosps over 44 yrs)</td>
<td>Mentally ill (incarcerated for life); 10 yrs ago (Multi hosps over 44 yrs)</td>
</tr>
<tr>
<td>Jack</td>
<td>87 Widow</td>
<td>59</td>
<td>Cardiac valve repair; Multiple hospitalisations over a 2 month period</td>
<td>Knee replacement critically ill post-op 6 weeks ago Multi long hosps over 15 months</td>
</tr>
<tr>
<td>James</td>
<td>Spouse</td>
<td>45</td>
<td>No information provided; One long hospitalisation</td>
<td>No information provided: Multiple brief hospitalisations over 4 years</td>
</tr>
<tr>
<td>Jane</td>
<td>Spouse</td>
<td>70</td>
<td>No information provided; One long hospitalisation</td>
<td>No information provided; One long hospitalisation</td>
</tr>
<tr>
<td>Kate</td>
<td>Spouse</td>
<td>63</td>
<td>Heart attack + Bypass surgery 9 yrs ago (Multi Long Hosps over 2 yrs)</td>
<td>Heart attack + Bypass surgery 9 yrs ago (Multi Long Hosps over 2 yrs)</td>
</tr>
<tr>
<td>Lara</td>
<td>Spouse</td>
<td>49</td>
<td>Cancer (breast): died 21 yrs ago (Multi Long Hosps over 4 yrs)</td>
<td>Cancer (breast): died 21 yrs ago (Multi Long Hosps over 4 yrs)</td>
</tr>
<tr>
<td>Lucy</td>
<td>Spouse?</td>
<td>82</td>
<td>Pneumonia; hearing &amp; mobility, problems, ESL, disorientated 9 yrs ago (Multi brief hosps over 3 yrs)</td>
<td>Pneumonia; hearing &amp; mobility, problems, ESL, disorientated 9 yrs ago (Multi brief hosps over 3 yrs)</td>
</tr>
<tr>
<td>Madeline</td>
<td>Spouse</td>
<td>77</td>
<td>Cancer died 5 yrs ago one brief hospitalisation</td>
<td>Cancer died 5 yrs ago one brief hospitalisation</td>
</tr>
<tr>
<td>Matthew</td>
<td>Spouse?</td>
<td>78</td>
<td>Cardiac bypass surgery one long hospitalisation years ago</td>
<td>Cardiac bypass surgery one long hospitalisation years ago</td>
</tr>
<tr>
<td>Max</td>
<td>75</td>
<td>75</td>
<td>Chronic Obstructive Airways Disease/ arrythmias/ overweight/ thyroid (Multi brief hosps over2 weeks</td>
<td>Chronic Obstructive Airways Disease/ arrythmias/ overweight/ thyroid (Multi brief hosps over2 weeks</td>
</tr>
<tr>
<td>Oliver</td>
<td>81</td>
<td>83 Widfr</td>
<td>Sudden coma (Uncertain diagnosis) died (one brief hospitalisation one week ago)</td>
<td>Fractured femur + Non-Hodgkin’s Lymphoma Died 2.5 yrs ago (Multi varied hosps over 3 months)</td>
</tr>
<tr>
<td>Olivia</td>
<td>Spouse</td>
<td>62</td>
<td>Stroke (life support) died 4 years ago one brief hospitalisation</td>
<td>Stroke (life support) died 4 years ago one brief hospitalisation</td>
</tr>
<tr>
<td>Patrick</td>
<td>75</td>
<td>72</td>
<td>Serious fracturing of arm. Made good recovery 2 yrs ago (Multi brief hosps over 2 weeks)</td>
<td>Serious fracturing of arm. Made good recovery 2 yrs ago (Multi brief hosps over 2 weeks)</td>
</tr>
<tr>
<td>Rachel</td>
<td>54</td>
<td>Spouse?</td>
<td>Cancer (breast); died 15 yrs ago (Multi varied hosps over 5 yrs)</td>
<td>Cancer (breast); died 15 yrs ago (Multi varied hosps over 5 yrs)</td>
</tr>
<tr>
<td>Ryan</td>
<td>70 (RN)</td>
<td>75</td>
<td>Cardiac bypass surgery, Gallstones, Fatal Motor Vehicle Accident (Multi Varied Hosps over 15 yrs)</td>
<td>Cardiac bypass surgery, Gallstones, Fatal Motor Vehicle Accident (Multi Varied Hosps over 15 yrs)</td>
</tr>
<tr>
<td>Sam</td>
<td>Spouse?</td>
<td>58</td>
<td>No information provided; Multiple brief hospitalisations over 3 years</td>
<td>No information provided; Multiple brief hospitalisations over 3 years</td>
</tr>
<tr>
<td>Sarah</td>
<td>67</td>
<td>Spouse?</td>
<td>Cancer (bowel), palliative ileostomy, dying 2 yrs ago (Multi long hosps over 6 yrs)</td>
<td>Cancer (bowel), palliative ileostomy, dying 2 yrs ago (Multi long hosps over 6 yrs)</td>
</tr>
<tr>
<td>Sophie</td>
<td>65</td>
<td>72</td>
<td>Cancer (Lung); died 6 months ago (Multi brief hosps over 3 months)</td>
<td>Cancer (Lung); died 6 months ago (Multi brief hosps over 3 months)</td>
</tr>
<tr>
<td>William</td>
<td>70</td>
<td>66</td>
<td>Cancer (Liver secondaries) died at home 7 yrs ago (Multi brief hosps over 1 yr)</td>
<td>Cancer (Liver secondaries) died at home 7 yrs ago (Multi brief hosps over 1 yr)</td>
</tr>
<tr>
<td>Zac</td>
<td>54</td>
<td>78</td>
<td>Cardiac surgery 7yrs ago (Multi brief hosps over 1 yr)</td>
<td>Cardiac surgery 7yrs ago (Multi brief hosps over 1 yr)</td>
</tr>
<tr>
<td>Mean</td>
<td>64.00</td>
<td>71</td>
<td>Chest pain then Cardiac surgery 7yrs ago (Multi brief hosps over 1 yr)</td>
<td>Chest pain then Cardiac surgery 7yrs ago (Multi brief hosps over 1 yr)</td>
</tr>
<tr>
<td>Median</td>
<td>69.00</td>
<td>72</td>
<td>No information provided: Multiple brief hospitalisations over 2 weeks</td>
<td>No information provided: Multiple brief hospitalisations over 2 weeks</td>
</tr>
</tbody>
</table>

| Mean | 64.00 | 71 |
| Median | 69.00 | 72 |
| SD  | 11.00 | 7.00 |
# Appendix C

## Table C2
**Siblings, Workplace, and Playing an active role**

<table>
<thead>
<tr>
<th>Participants</th>
<th>Siblings (RN or medical status as indicated)</th>
<th>Working at same Hospital</th>
<th>More active role by others?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Adam</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>2 Amelia</td>
<td>Yes some of Mother's hosps</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>3 Andrew</td>
<td>4 (2 Older Brothers &amp; 2 Older Sisters RNs)</td>
<td>No</td>
<td>Minority of occasions Eldest Brother</td>
</tr>
<tr>
<td>4 Ben</td>
<td>3 Brothers</td>
<td>No</td>
<td>Minority of occasions</td>
</tr>
<tr>
<td>5 Cameron</td>
<td>7 (3 Brothers &amp; 4 Sisters)</td>
<td>No</td>
<td>Minority of occasions</td>
</tr>
<tr>
<td>6 Claire</td>
<td>Younger Brother</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>7 Daniel</td>
<td>2 or more</td>
<td>No</td>
<td>Minority of occasions</td>
</tr>
<tr>
<td>8 Eliza</td>
<td>Sister (EN)</td>
<td>No</td>
<td>Minority of occasions EN Sister</td>
</tr>
<tr>
<td>9 Emma</td>
<td>5 (3 Younger Brothers one is a surgeon &amp; 2 Younger Sisters)</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>10 Eva</td>
<td>Spouse (Female - not mother)</td>
<td>No</td>
<td>RN Sister</td>
</tr>
<tr>
<td>11 Gail</td>
<td>Older Sister RN</td>
<td>Yes some of Mother's Hosps</td>
<td>Minor of occasions RN Sister</td>
</tr>
<tr>
<td>12 Harry</td>
<td>No</td>
<td>No</td>
<td>Minority of occasions</td>
</tr>
<tr>
<td>13 Jack</td>
<td>6 (2 Brothers &amp; 4 RN Sisters)</td>
<td>No</td>
<td>4 RN Sisters</td>
</tr>
<tr>
<td>14 James</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>15 Jane</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>16 Kate</td>
<td>Younger Sister</td>
<td>Yes some of Father's hosps</td>
<td>Minority of occasions Sister &amp; Spouse (Mother)</td>
</tr>
<tr>
<td>17 Lara</td>
<td>2 (Brother &amp; Younger Sister)</td>
<td>No</td>
<td>Spouse (Father)</td>
</tr>
<tr>
<td>18 Lucy</td>
<td>Sister</td>
<td>No</td>
<td>Minority of occasions</td>
</tr>
<tr>
<td>19 Madeline</td>
<td>Younger Sister</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>20 Matthew</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>21 Max</td>
<td>Older Brother</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>22 Oliver</td>
<td>Older Brother</td>
<td>Yes some of both parents' hosps</td>
<td>No</td>
</tr>
<tr>
<td>23 Olivia</td>
<td>Younger Brother &amp; Older sister</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>24 Patrick</td>
<td>2 (Brother &amp; Sister)</td>
<td>No</td>
<td>Brother and Sister proximal</td>
</tr>
<tr>
<td>25 Rachel</td>
<td>Yes most of Mother's hosps</td>
<td>No</td>
<td>RN Brother proximal</td>
</tr>
<tr>
<td>26 Ryan</td>
<td>5 (Younger Brother RN &amp; Older Sister RN/Psychologist)</td>
<td>No</td>
<td>Spouse Stepfather; Spouse (Female - not mother)</td>
</tr>
<tr>
<td>27 Sam</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>28 Sarah</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>29 Sophie</td>
<td>4 (3 Brothers &amp; Sister)</td>
<td>No</td>
<td>Spouse Stepfather; Spouse (Female - not mother)</td>
</tr>
<tr>
<td>30 William</td>
<td>Younger Brother</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>31 Zac</td>
<td>Younger Sister</td>
<td>No</td>
<td>Sister not working</td>
</tr>
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</table>
### Table C3. Disclosure of RN status to Hospital Staff: Participants Preference and Outcomes

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<tr>
<th>RN</th>
<th>Prefer to remain undisclosed</th>
<th>Disclosure Necessary</th>
<th>Recognised</th>
<th>Family revealed</th>
<th>Detected by staff</th>
<th>Remained Undisclosed</th>
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<tbody>
<tr>
<td>1</td>
<td>Adam</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Mother</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Amelia</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Andrew</td>
<td>Yes</td>
<td></td>
<td>Yes RN-Sisters</td>
<td></td>
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</tr>
<tr>
<td>4</td>
<td>Ben</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Mother</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Cameron</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>6</td>
<td>Claire</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
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<tr>
<td>7</td>
<td>Daniel</td>
<td>Yes</td>
<td></td>
<td>Yes Father</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Eliza</td>
<td>Yes*</td>
<td>Yes</td>
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<td>Emma</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Father</td>
<td></td>
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<td>Yes</td>
<td>Yes Father</td>
<td></td>
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</tr>
<tr>
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<td>Gail</td>
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<td>Yes</td>
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<td>Harry</td>
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</tr>
<tr>
<td>13</td>
<td>Jack</td>
<td>Yes</td>
<td></td>
<td>Yes Mother</td>
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<td>James</td>
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<td>Jane</td>
<td>Yes*</td>
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<td>Kate</td>
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<td>Yes</td>
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<tr>
<td>17</td>
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<tr>
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<tr>
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<td></td>
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</tr>
<tr>
<td>21</td>
<td>Max</td>
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<td></td>
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<td>Oliver</td>
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<td></td>
<td>Yes</td>
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<tr>
<td>23</td>
<td>Olivia</td>
<td>Yes</td>
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<td></td>
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</tr>
<tr>
<td>24</td>
<td>Patrick</td>
<td>Yes</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>25</td>
<td>Rachel</td>
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<td></td>
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</tr>
<tr>
<td>26</td>
<td>Ryan</td>
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<td></td>
<td>Yes Parents</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>27</td>
<td>Sam</td>
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<td>28</td>
<td>Sarah</td>
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<tr>
<td>29</td>
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</tr>
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</tr>
<tr>
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<td>Zac</td>
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<tr>
<td>Totals</td>
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<td>Yes = 15</td>
<td>Yes = 10</td>
<td>Yes = 7</td>
</tr>
</tbody>
</table>

* Disclosed only to Drs

Males 15/16; Females 15/15; Males = 7; Females = 12; Males = 4; Females = 11; Males = 6; Females = 4; Males = 6; Females = 1; Males = 3
Appendix

End of document.