

The meaning of the experience for ICU nurses when a family
member is critically ill: A hermeneutic phenomenological study

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2007

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Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signature

Acknowledgements

I wish to dedicate this dissertation to my brother Glen, without whom the study would not have occurred.

To my husband and best friend: thank you Graeme; without your love, support and encouragement I could not have completed this dissertation.

To my four beautiful children: thank you so much Fleur, Crystal, Daniel and Aaron for your patience, help and understanding.

To my mother, Dorothy: thank you Mum for being my transcriber, and for your love, support and encouragement.

To my supervisor, Dr Deb Spence: thank you Deb for always being there for me and for the patient and caring way in which you have guided me through this study.

To my friend, and mentor, Christine Payne: your passion for nursing has always inspired me Christine; thank you for being such a wonderful mentor.

To my editor, Heather Moodie: thank you Heather for your caring support and the wonderful job editing this dissertation.

To my research participants: thank you for selflessly sharing your time and experiences as ICU nurse/relatives with me for this study.

To the New Zealand Education and Research Foundation (NERF) and the Greta and Hamblin Trust: I sincerely thank you for your kind letter of approval and for funding this research.

Ethics Approval

Ethical Approval received on the 31/03/07

Approval number: 07/01

Abstract

The meaning of the experience for ICU nurses when a family member is critically ill: A hermeneutic phenomenological study.

This study provides insight into the experience of 'being' an ICU nurse and relative of a critically ill patient. Current research focuses mainly on the needs of family members of critically ill patients, with several qualitative studies describing the experience. The specific experience of ICU nurses as relatives is absent in current research.

This is a New Zealand based phenomenological study informed by the work of Gadamer and van Manen. Data from interviews of four ICU nurses who had experienced having a family member admitted to ICU was analysed using van Manen's framework.

The experience of being an ICU nurse when a family member is admitted to ICU is described in the following themes: A nurse's nightmare; knowing and not knowing; feeling torn; and gaining deeper insight and new meaning. van Manen's lifeworld existentials assist in gaining a deeper understanding of the findings.

New and deeper understanding provides a rationale for ICU nurses from which to improve nursing practice. Recommendations for organisational support for ICU nurse/relatives, education for staff and further research are made based on the findings of this study.

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Chapter One

Introduction

An intensive care unit (ICU) is a dynamic, unpredictable environment where families experience either the slow and unsure process of recovery, or the inevitable passing of a loved one. As an ICU nurse it is important to support and care for families through this critical experience. This study provides insight into the meaning of the experience when ICU nurses have a member of their own family become critically ill. Nurses are forced to live with the worry of a critically ill family member as they are simultaneously the providers and the recipients of nursing care.

1.1 *Motivation for the study*

As an intensive care nurse I believed I had a reasonable understanding of the experience of critical illness for family members. However, I was poorly prepared for my own family crisis. Approximately three years ago I found myself in the very painful position of 'being' the family of the critically ill.

I came to realise that my experience was very different from that experienced by other members of my family. This was further highlighted when my family and I participated in another Masters student's study which used a phenomenological approach (Lyford, 2006). Our experiences were presented diagrammatically in a way that showed links between family members. My part showed the fewest links. I searched nursing literature to no avail in an attempt to understand how other ICU nurses experienced a family member's critical illness because I was particularly interested in the emotional, psychological and social effects of the experience on nurses.

1.2 *Study purpose*

This research study sought to gain insight into the meanings derived by intensive care nurses when a family member was critically ill. A number of studies have explored the experience of critical illness for families but none have explored the meaning of the experience or the specific impact on ICU nurses.

1.3 *The research approach*

Nursing is a situated, dynamic and inter-subjective phenomenon (Spence, 2001). As such, and because the following study focuses on the meaning of the experience, an inductive research design is most appropriate.

Qualitative research is both inductive and subjective and seeks understanding beyond numbers. It seeks deeper and context specific understanding rather than a universal truth as sought by quantitative research. The following hermeneutic phenomenological study is interpretive, informed by the work of Hans Gadamer (1976) and Max van Manen (1990).

Hermeneutic phenomenology explores the individual's understanding of a phenomenon and seeks to identify the 'essence' of the lived experience (van Manen, 1997). Research carried out in the Gadamerian tradition comes from a desire to develop a deep understanding (Gadamer, 1976). This research design allows participants to freely describe their experiences.

1.4 *Definition of key terms*

The terms 'intensive' and 'critical care' are often used synonymously in the literature when referring to service delivery units. For the purposes of this study, the definition of intensive care as outlined by the Joint Faculty of Intensive Care Medicine (1997) is appropriate. An intensive care unit is a

"specially staffed and equipped separate and self contained unit in the hospital for the management of patients with life threatening or potentially life threatening conditions. Such conditions should be compatible with recovery and have the potential for an acceptable future quality of life. An ICU provides special expertise and facilities for the support of vital functions, and utilises the skills of medical nursing and other staff experienced in the management of these problems". (p. 5)

The intensive care unit is part of the hospital's critical care complex which is the range of critical care services offered at each hospital. These ICUs may include general or specialty ICUs, combined ICU and coronary care units (ICU/CCUs), pediatric ICUs (PICUs), high dependency units (HDUs) combined with ICUs or a combination of the above (Higlett, Bishop, Hart & Hicks, 2005).

Use of the term ‘family’ is congruent with that articulated by the National Consensus Project for Quality Palliative Care (2004) which stated that ‘family’ is defined by the patient or their surrogates. Family may be persons related or unrelated who provide support and with whom the patient has a significant relationship.

The definition of critical care nurses in New Zealand aligns with the Critical Care Nurses’ Section (CCNS) of the New Zealand Nurses Organisation (NZNO), (2002) who state that

“Critical care nurses provide care for patients and their families who require intensive medical and nursing care. These services may include haemodynamic and respiratory support and monitoring which may be provided in critical care, intensive care, coronary care or high dependency units” (p. 4).

In this study I have used the feminine pronouns ‘she’ and ‘her’ when referring to the ICU nurse/relative.

1.5 Context of the study

Describing the Intensive care environment will assist the reader to appreciate the working world of the ICU nurse. Considering this environment from the perspective of a family member will also assist the reader to understand what it is like to be an ICU visitor rather than a staff member.

Intensive care units in New Zealand

There are 25 public sector and two private sector ICUs in New Zealand. Fourteen of these units are combined medical/ surgical units, while nine are combinations of intensive/coronary care and high dependency units. One is a pediatric ICU, and three are cardiothoracic intensive care units (Higlett, Bishop, Hart & Hicks, 2005).

The number of ICUs in New Zealand has increased since 1997 when there were no private sector ICUs and only 21 in the public sector. The number of available beds in the public sector however, has decreased since 2000/2001 from 228 beds, (6 per 100,000 of population), of which 173 (4.5%) were ventilator beds, to 214 beds, (5.3 per 100,000 of population), of which 149 (3.7 per 100,000 of population) were ventilator beds. These statistics are comparable with overseas trends. The changes are thought to

be the result of an increasing population and decreasing number of physical beds. (Higlett, et al. 2005).

Intensive care nursing

ICU nurses are an essential and vital part of the ICU care team (Miracle, 1994). The Critical Care Nurses' Section (CCNS) of the New Zealand Nurses Organisation (NZNO) (2002), provide guidelines for scope and five standards for professional practice. These state that nurses

- are accountable for their practice, within their scope of practice;
- are responsible for the safety and well-being of their patient group;
- are responsible for entering into and maintaining a partnership with patients and colleagues and employers;
- are committed to nursing professional development;
- manage resources efficiently and effectively to meet patient health care needs.

In 2004, throughout New Zealand, 1,441 nurses were employed in ICU/CCUs. This was 4.2% of the national number of active nurses and midwives registered in New Zealand (New Zealand Workforce Statistics, 2004). Supply and demand statistics for 2002/2003, based on nurses' full time equivalent (FTE) hours, showed a shortage of 108.3 FTE hours (Higlett, et al. 2005). These statistics are similar to overseas trends which reflect a serious global shortage of nurses.

According to the American study *Projected Supply, Demand and Shortages of Registered Nurses: 2000-2020* released by the Health Resources and Service Administration, Bureau of Health Professionals and the National Centre for Health Workforce Analysis (2002), if current trends in America continue, the shortage of registered nurses (RNs) will rise from a six percent shortage in 2000 to 29% by 2020.

Nursing shortages have a profound effect on how nurses experience the quality of their professional work and their ability to provide care for patients (Buerhaus, Donelan & Ulrich, Norman & Dittus, 2005). A study by All, Mannahan, Cuaderes, Wallace and Hays (2006) of 135 ICU nurses from seven metropolitan hospitals in the USA, reported that nurses perceived shortage of staff to be their greatest stressor.

An earlier study by Hurst & Koplin-Baucum (2005) had shown that the daily challenges of caring for critically ill patients and their families, combined with role expectations and frequent exposure to pain, death and sorrow mean that intensive care units are complex and stressful environments.

The critical care environment through the eyes of the family

An ICU admission may be a family's first encounter with the hospital environment and although there is some understanding that the technologies help to preserve and save lives, ICU is a formidable place for families (McNamara, 2005).

The doors are usually locked. Staff enter using electronic keys or an intercom while family and visitors sit in a separate room and wait to be invited in. The ICU is clearly labelled with signs and red lines which help to maintain its 'boundaries'. Coming through the doors can be a huge step for families as they enter the world of the critically ill (Turnball, Flabouris & Iedema, 2005).

Harsh bright lights and constant noise from monitor alarms, telephones, ventilators, staff and family add to the intensity of the environment (Turnball, Flabouris & Iedema 2005). I clearly remember my first visit to ICU as a student nurse:

The small ward was brightly lit. The white light seemed to cover everything in its path – the linen, the beds, even the walls and ceilings. The nurses seemed to quietly blend in to the surroundings as they went about their tasks. A strong smell of disinfectant permeated the ward and I wondered if the people in this environment ever smelt any different.

Lined up along one wall were five small television screens, each with their own squiggly lines and tiny beeping sounds. I smiled as I imagined them all beeping in unison or making a tune.

The ventilators joined in as they forcefully channeled air through their tubes. Hearing the body sounds magnified in this way made me realise how rhythmic the human body is. I was literally hearing the rhythm of life.

Each small space in front of the television screens housed a bed and a very still body, surrounded by bags of liquid and tubes. The tubes were all dated and marked with tape and they looked like they came from everywhere and went everywhere. I stopped to look at one of the hosts. I saw no sign of pain or human emotion: it was as if the machine that bridged the gap between this life and the unknown had engulfed him (McNamara, 2002).

1.6 *Families in ICU*

Admission to ICU may happen suddenly causing a crisis and leaving families no time to mobilize adequate coping resources (Dyer, 1991, and Jones, Skirrow & Griffiths, et. al., 2004). When the hospitalisation of a relative involves a threat to life with little or no warning, post traumatic stress disorder (PTSD), a common psychological sequelae of critical illness, may develop in both family members and patients (American Psychiatric Association, 1997). PTSD most often develops in family members who live with persistent multiple stressors or tensions and have ongoing feelings of profound anxiety (Hughes, Bryan & Robbins, 2005).

1.7 *Conclusion*

In this chapter I have provided an overview of ICU nurses, NZ ICUs, and the environment from the perspectives of ICU nurses and families. Chapter two will review the literature relating to stress in ICU nurses; the needs and experiences of families of critically ill patients; and the experience of nurses as family members.

Chapter Two

Literature Review

2.1 *Introduction*

In this chapter I will review the most recently published literature in order to provide a background for the proposed study. Literature printed in English was selected chronologically from 1990 onwards with a focus on stress in ICU nurses and the needs and experiences of relatives of adult critically ill patients and ICU nurses. The earlier work of Motler (1979) and Leske (1986) is included in the review because it has great significance for later studies. Literature pertaining to paediatric patients and their family members was not included due to length and time restraints in this study.

2.2 *Search Strategy*

The databases MEDLINE, Cinahl, ProQuest Nursing Journals and Blackwell Synergy were searched using the MeSH headings: 'intensive care', 'critical care', 'critically ill patients', 'own family', 'nursing', 'lived experience', 'stress' and 'family needs'. The National Bibliographic and the Australasian Digital Theses (ADT) databases were also searched using the headings 'intensive care' and 'critical care' to identify unpublished New Zealand theses and dissertations relating to the research topic.

The search revealed numerous studies documenting the perspectives, experiences and perceived needs of the families of critically ill patients (Walters, 1995; Alvarez and Kirby, 2006; Verhaeghe, Defloor, Van Zuuren, Duijnste & Grypdonck 2005; Lee and Lau, 2003; Molter, 1979; Al Hassan & Hweidi, 2004; Medonca & Warren, 1998; Lyford, 2006). Several studies focussed on family needs and compared the perspectives of family members and ICU nurses (Miracle, 1994, 2006; Forrester, Murphy, Price & Monaghan, 1990). Further studies discussed the effect of stress on nurses in the ICU environment (Sawatzky, 1996; Cronqvist, Lutzen and Nystrom, 2006).

The search for unpublished theses in New Zealand revealed several studies related to adult intensive care nursing (Blanchard, 2006; Fogerty, 2005; Hall, 2000; Patel, 2006;

Vandergoot, 2005; Fielding, 2006; Cook, 2006; Turner, 2001; Rummel, 2001; Evans, 2006; Pirett, 2005; Hardcastle, 2003; Soh, 2003; Williams, 2006; MacGeorge, 2000; Lyford, 2006).

Of the available literature there were no studies relating specifically to the experience of ICU nurses as relatives. However, two anecdotal accounts of ICU nurse's experiences as relatives (the first in three parts) were found (Fulbrook, Allen, Carroll & Dawson, 1999; Fulbrook, Buckley, Mills & Smith, 1999; Fulbrook, Creasy, Langford & Manley, 1999, and Feeg, 2006. A study by Mills & Aubeeluck (2006) explored the experience of nurses as carers of relatives. An article by Olivet and Harris (1991) discusses nurse/relatives. Review of the literature will be presented thematically under the following headings:

- stress in ICU nurses
- the needs of families of critically ill patients
- the experiences of families of critically ill patients.
- the experiences of nurses as family

2.3 *Stress in ICU nurses*

A number of authors, such as All, Mannahan, Cuaderes, Wallace & Hays (2006); Sawatzky (1996) and Cronqvist & Nystrom (2006) have discussed the effect of stress on nurses in the ICU environment. Stress has a major impact on the health and well-being of ICU nurses and may lead to absenteeism, staff conflicts, lowered morale and ultimately burnout.

A survey by All, Mannahan, Cuaderes, Wallace & Hays (2006) of 135 ICU nurses in America, identified stressors such as unnecessary prolongation of life, apathetic and incompetent nursing and medical staff, critically unstable patients, a noisy work environment and exposure to death and dying. The nurses, however, perceived their greatest stressors to be the nursing shortage (49.5%) followed by issues concerning patients' families (30.3%).

Sawatzky's (1996) descriptive, correlational approach with 96 ICU nurses in Canada, echoed these findings, with the greatest overall stressor relating to patient care.

Stayt (2007) used a phenomenological approach to explore the experiences of 12 ICU nurses in the United Kingdom caring for families with relatives in intensive care. The nurses reported feeling high stress levels as they experienced conflict between role expectations and the reality of their everyday work. The lack of role definition resulted in the nurses referring to their own impossibly high standards of care which they expected to be able to fulfil. The study addressed a fundamental conflict that ICU nurses face when balancing their professional ideals with “being human” in the world.

2.4 *The needs of families of critically ill patients:*

Hammond (1995) and Higlett, et al. (2005) describe family members as an extension of the patient arguing that nowhere is family involvement more crucial than in ICU where it has a profound influence on clinical decision making and patient outcomes. Gonzalez, Carroll, Elliot, Fitzgerald & Vallent (2004) agree, stating that family members provide reassurance, help the patient to interpret information and reinforce treatments. They also assist in keeping patients, especially older adults orientated, which may in some cases avoid the onset of delirium (McNamara, 2005).

The importance of caring for family members was also recognised by the Institute of Medicine (2001) and the American College of Critical Care Medicine (2004-2005) who developed clinical guidelines which advocate for flexible visiting and patient-centred care, to support family members in ICU.

The guidelines were based on a systematic review of over 300 related studies (Davidson, Powers, Hedayat, Tieszen, Kon, Shepard, Spuhler, Todres, Levy, Bar, Ghandi, Hirsh, & Armstrong, 2004-2005) and are divided into the sub-headings: decision making; family coping; stress related to family interactions; cultural support; spiritual/religious support; family visitation; family presence on rounds; family presence at resuscitation; family environment of care and palliative care.

The first study to identify the needs of the families of critically ill patients was a descriptive study by Motler (1979) in which forty-five ‘need’ statements were identified (Miracle 2006). The following ten were ranked as the most important: the need to

- believe there was hope
- believe hospital personnel cared about the patient

- have a waiting room near the patient
- be called at home about changes in the patient's condition
- know the prognosis
- have questions answered honestly
- know specific facts about the patient's prognosis
- receive information about the patient once a day
- have explanations given in understandable terms
- be allowed to see the patient frequently (Motler, 1979).

The need statements were then divided into five categories: information, assurance and proximity, support and comfort. In 1986 Leske reordered the need statements adding an open-ended component. This resulted in the development of the Critical Care Family Needs Inventory (CCFNI).

The tool has been extensively used in the literature ever since. Authors such as Price, Forrester, Murphy & Monaghan (1991, 1990); Miracle, (1994); Medonca & Warren, (1998); Leung, Chien & McKenzie, (2000); Lee & Lau, (2003); Redley, La Vasseur, Peters & Bethune, (2003) and Al Hussan & Hweidi, (2004), consistently report that the need for information, assurance and proximity rank highly. The need for information has been shown to be the greatest need (Verhaeghe, De floor & Van Zuuren, et al., 2005; Alvarez & Kirby 2006 and Kleinpell & Powers, 1992).

Although general consensus has been reached about the needs that families prioritise, studies by Forrester, Murphy, Price and Monaghan (1990); Kosco and Warren (2000) and Miracle (1991), using the CCNNI shows that nurses differ from family members when they prioritise care.

Forrester, Murphy, Price and Monaghan (1990) gathered data from 92 family members of critically ill patients and 49 ICU nurses providing direct care for the patients. Significant differences were found in the following items:

- feeling accepted by hospital staff
- knowing the types of staff providing care
- helping with the patients' care
- talking about death and knowing the facts about the condition.

Kosco and Warren (2000) reported similar findings but noted that only four of the top ten needs were perceived to be consistently met by both parties.

Miracle's (1994) descriptive study focussed on the perceptions of families of critically ill patients and ICU nurses as they related to the informational needs. The needs that were significantly different were:

- the need to know specific facts about the patient's progress
- to know exactly what is being done
- to know which medications are being given to the patient
- to know more about the specific illness
- to be able to visit at any time and to know where the restrooms are.

The prescriptive nature of tools such as the CCFNI allows families to express needs included in the list but family members themselves did not assist with the compilation of this list. Such tools therefore only identify and rank needs. They do not uncover the experience or the meaning of the experience, nor do they allow for the impact of the experience on family members.

Recognising the limitations of quantitative research instruments, Burr (1998) used triangulated methods to illicit both the needs and the experience of family members in an American study. The CCFNI was used to establish 105 family members' needs and 26 semi-structured interviews were used with other family members to bring out elements the inventory missed. Five major themes emerged: 'maintaining the vigil', (the need to be near the patient, the need to maintain contact and the need for hope), 'patient takes precedence', (the need for families to direct all their energy and attention toward the patient), 'not knowing was the worst part', (a need to know), 'network rallies', (the need for support for family) and 'protecting', (the need to protect certain family members from anxiety-provoking information). This method generated a more comprehensive view of the needs and experiences of the families.

Wilkinson (1995) used grounded theory research to identify family needs in the intensive care environment and reported similar findings to Burr (1998). The categories were identified as shock of admission, coming to terms with the illness, the need for access, the need for a positive environment, social support, information and hope.

Over the last two decades, researchers have become more aware of the value of qualitative research and a small number of qualitative studies focussing on the experience of families of critically ill patients have been undertaken..

2.5 *The experiences of family members of critically ill patients*

The following studies by Walters (1995), Lam & Beaulieu (2004); Fontana (2006); Jamerson, Scheibmeir, Bott, Crighton & Cobb (1996); Lyford (2006) and Williams (1996) highlight the terrifying experience families endure when a family member is critically ill. Although the studies highlight different aspects of the experience, the central concepts of proximity, assurance and information appear to be consistent findings.

The two themes used to describe participants' experiences in an Australian hermeneutic study by Walters (1995) were 'being-with' and 'seeing'. 'Being-with' described the participants' desire to physically and emotionally be with their relatives and 'seeing' highlighted the importance for relatives to physically 'see' family members.

Research by Lam & Beaulieu (2004) revealed similar findings. A descriptive, exploratory multiple-case design study involving 13 family members in a neurological ICU, used participant observation and semi-structured interviews to capture the family's experiences. A two-fold phenomenon called the 'bedside phenomenon' became the major finding. The bedside phenomenon showed that the two main goals for families at the bedside were firstly to ensure that their loved one was receiving the best possible care and secondly to maintain a connection with them.

Proximity to the patient was also a key finding in Fontana's (2006) phenomenological study in the USA. Her study explored the experiences of ten family members of patients who suffered a sudden life-threatening medical crisis. Ten themes evolved from their experiences. The themes describing their experiences included the inability to feel, terrified waiting, understanding the unspoken, controlled information speaking, protecting others, isolated and alone, the busy mode, fighting the system, the saturation point and a new normal.

Jamerson, Scheibmeir, Bott, Crighton, Hinton, & Cobb's (1996) research used a qualitative, descriptive, retrospective design to describe the experiences of families with

a relative in a surgical-trauma ICU in the USA. This study is the largest qualitative study involving 20 participants. Data from 18 women and 2 men assisted identification of four categories of experiences: hovering, information seeking tracking and the garnering of resources.

Hovering, which described the initial sense of confusion, stress and uncertainty was a common experience for family members in all of the studies. Information seeking, echoes the findings of previous qualitative and quantitative studies. Tracking, which described the process of observing, analysing and evaluating patient care and the family's satisfaction with the environment and caregivers, is congruent with findings in studies by Levy, (2006); Lyford, (2006) and Feeg, (2006). The garnering of resources, which is the acquisition of what family members believe they needed for their family member is similar to Fontana's (2006) theme 'fighting the system'.

The following studies by Lyford (2006), and Williams (2006), take place within the New Zealand context as this study does.

Lyford's (2006) phenomenological study explored the psychosocial impact of liver transplant on recipient families. The findings presented a "passage of rite" and introduced the concept of "journeying" through four stages: 'realisation', which is the initial phase when families are informed about their relative's liver disease; 'readying', describing the family's social, emotional and financial preparation; 'reality', showing how the family comes to terms with the new chronic condition and 'renaissance', which describes a reintegration back into mainstream life with new understanding and meaning.

The journey through Lyford's (2006) passage of rite quite clearly describes the experiences of many of the participants in these studies. As families come to terms with the critical nature of the illness they experience many of the same emotions and coping strategies and eventually experience a "new normal" as Fontana (2006) so aptly put it

Williams' (2006) small study, which involved two participants, echoed the findings of previous studies with the themes: seeing and being terrified; wanting and needing to be there; lack of information gives rise to mistrust; needing support in order to cope; feeling out of control and acknowledging "humanness".

Another important contribution to the literature was provided by Dr Levy (2007) who, after twenty years working in an ICU in America, became the relative of a critically ill family member when his sister-in-law was admitted. The anecdotal account of his experience reveals the enormous impact that visitation policies and ICU staff methods of communication have on the families of critically ill patients.

Dr Levy speaks vividly of his experience of being separated from his family member. Being on “the other side” provided a very different view of such things as locked doors and inconsistent visitation policies. It also provided a different view of the attitude from some of the nurses, that requesting information was taking them away from the bedside and therefore compromising the care they could deliver to his relative.

Dr Levy’s description of his experience reveals how the quality of care he received as the relative of a family member did not meet his expectations. Dr Levy had been, for many years instrumental in developing many of the ICU policies (such as visiting policies) to which he was now subjected to as a relative. In the following studies, nurses as family members gain similar insight to Dr Levy as they experience being on the other side.

2.6 *The experiences of nurses as family*

I found four published articles which focussed on the experiences of nurses as family.

Mills & Aubeeluck (2006) studied six UK nurses’ experiences of caring for their own family members. Four themes emerged from the interviews: quality of life (which describes the negative impact on their quality of life that the nurses’ experienced while caring for family members); personal and professional boundaries (which describes how the nurses were unable to separate their professional and personal identities); disempowerment (which related to the feeling of disappointment as the nurses experienced dissatisfaction with care delivery) and the positive aspects of the role (which related to the fact that their nursing skills helped them to provide comfort for their relatives).

This study did not involve ICU nurses, and the family members were terminally rather than critically ill; however, the nurses experienced feelings of “confusion” regarding

their professional and personal roles and boundaries similar to the findings of Stayt (2007) and Olivet & Harris, (1991).

Olivet & Harris, (1991) are authors of an article called “Expectation versus realization: The family member who is a nurse” which was not based on the nurse’s experience as the relative of a critically ill patient, but rather discusses the nurse’s understanding of the phenomenon. This article also echoes the findings of Stayt’s (2007) research as she discusses “role uncertainty” in nurse/relatives and “knowing too much”. The authors attempt to describe and explain the behaviour of the nurse/relative.

The following articles relate more closely to my research topic as they were written by ICU nurses describing their experiences as family members. However, both are anecdotal accounts and take place in the context of the USA.

A series of studies by Fulbrook, Allen, Carroll & Dawson (1999); Fulbrook, Buckley, Mills & Smith (1999), and Fulbrook, Creasy, Langford & Manley (1999) describe the experience of an ICU nurse whose husband was admitted to an ICU and neurological unit in the same hospital in which she worked. The findings showed dissatisfaction with the capacity of ICU staff to provide honest information, provide a private space for grieving and consider the relative’s dignity. The ICU nurse felt a strong need to stay at the bedside in order to ensure the adequacy of care delivery. Moreover, despite numerous attempts to cope by becoming involved in practical tasks like feeding and changing linen, feelings of uselessness persisted. Similar feelings of helplessness were also reported by Feeg, (2006) whose father was admitted to a cardiothoracic ICU.

Feeg (2006), similar to Levy (2007) and Fulbrook, et al. (1999) was dissatisfied with restricted and inconsistent visiting policies, the inability of staff to provide continuity of care and provide honest and timely information. Communication with ICU staff was poor and responses to questions were often patronising or incorrect.

Inherent in these publications is a strong sense of dissatisfaction by ICU nurses of professional care delivery and the policies and practices in ICU to which they were subjected. The ICU nurses as relatives in these studies were clearly dissatisfied with the way in which medical and other nursing staff treated them.

The lack of available research and the inability of professional staff to meet the needs of ICU nurse/relatives, shows that most health professionals have little empathy and insight into the experience of ICU nurse/relatives. This clearly indicates a need for further research. This study therefore aims to

- provide useful insights which may be used to develop more appropriate family policies
- help fill a gap in current literature and more clearly identify the specific needs of ICU nurse/relatives
- provide an opportunity to critique professional care delivery, potentially improving care delivery
- assist ICU nurses to support one another more effectively
- allow the professional organisation to more effectively assist ICU staff during their family crisis, thereby reducing stress for ICU nurse/relatives. This may reduce possible absenteeism, burnout and the development of PTSD or other psychological disorders.

2.7 Conclusion

In this chapter I have discussed current literature and established a need for research that focuses on the phenomenon of the ICU nurse as relative of a critically ill patient. I have argued that this study will add to current literature and help provide insights that will benefit nurses, nursing and add to the delivery of services to ICU patients and their families. Chapter three will outline the philosophical basis, methodology, method, and ethical considerations which will guide my research.

Chapter Three

Methodology and methods

3.1 *Introduction*

In this chapter I will outline the philosophical basis for this study, discussing hermeneutic phenomenology and the work of Gadamer (1976) and van Manen (1990) whose philosophies have guided data collection and analysis. My own pre-understandings will be identified as they relate to the phenomenon and ethical considerations will be discussed.

Interpretivism, the theoretical perspective or philosophical stance behind the selected methodology, emerged in direct contradiction to positivism in an attempt to understand and explain human and social reality (Crotty, 1998). “The interpretivist researcher looks for culturally derived and historically situated interpretations of the social life world” (Crotty, 1998, p.67). The epistemology inherent in interpretivism is constructionism which is the view that all knowledge and meaningful reality, is contingent upon human practices and human beings’ interaction with their world (Crotty, 1998). The epistemological assumptions in this study were guided by principles of openness and pliability to meaning in data (Dahlberg, Drew & Nystrom, 2001).

Hermeneutic phenomenology, based on the work of Heidegger and Gadamer, interprets the meaning of the “lived experience” through a dialogical process (Gadamer, 1996). Hermeneutics developed in order to clarify the conditions in which understanding occurs (Dowling, 2004). This gave understanding an ontological orientation, interpreting it as ‘existential’ (Taylor, 1994). Gadamer continued Heidegger’s work, arguing that use of the scientific method was not necessarily the way to truth and understanding.

Understanding is derived, in hermeneutical research, from personal involvement by the researcher and participants in reciprocal processes of interpretation that are inextricably related to one's being in the world (Spence, 2001). The terms ‘fusion of horizons’ and the ‘hermeneutic circle’ describe these processes; both are metaphors for understanding.

The fusion of horizons occurs when the perspectives or world views of the participants and the researcher join to create new understanding. Gadamer (1976) argues that human understanding is based on prejudgements and prejudices and embedded within a historical community. Understanding occurs within a range of vision which includes everything that can be seen from a particular vantage point. The horizon is never fixed but continually forms with ongoing dialogue and with our traditions and other forms of life. Developing new or shared understandings means that our former understanding of what life means becomes only one possibility among others.

The hermeneutic circle is a process described by van Manen (1990) as the reciprocal movement between the whole and the parts. Both Gadamer (1976) and van Manen (1990) share the belief that in philosophical hermeneutics there is no method, only tradition, i.e:

...a body of knowledge and insights, a history of lives of thinkers and authors, which constitutes both a source and a methodological ground for present human science research practices... (van Manen, 1990).

In relation to human science research, van Manen, (1990) described a methodological structure showing the dynamic interplay between six research activities: “turning with commitment to an abiding concern; investigating the experience as it was lived; reflecting on the essential themes; describing the phenomenon through writing and rewriting; maintaining a strong, oriented stance toward the question; and balancing the research context by considering parts and whole” (pp. 31-33).

Thus in order to begin the research process it was essential for me as an intensive care nurse and also as a family member who had experienced the phenomenon to identify my own assumptions and pre understandings.

3.2 Pre-understandings

My supervisor interviewed me prior to data collection in order to help make visible the assumptions that I held in relation to the research topic. The following assumptions will be revisited throughout the study:

- ICU nurses share a slightly different personal experience of critical illness from other family members who are not nurses.

- Each ICU nurse will respond differently to a personal crisis depending on his or her unique circumstances.
- The role of support person in a professional sense is different from that in a personal sense.
- Certain expectations are placed upon an ICU nurse who has a critically ill family member, both by staff and by other members of the family.
- Providing support for colleagues during the ICU admission of a relative is beneficial and welcome.

In order to answer my research question: “What is meaning of the experience for ICU nurses when a family member was critically ill? it is necessary to address ethical concerns and gain ethical consent.

3.3 *Ethical considerations*

Ethical consent was obtained on 7th February, 2007, subject to some minor changes in the proposal. The proposal was altered accordingly and final ethical approval was granted on 31 March, 2007. The research also required endorsement by the Auckland District Health Board Research Review Committee (ADHBRRRC) before nurse managers could display my advertisement. Management approval was gained on 7th May, 2007.

The ethical principles of informed consent, anonymity and confidentiality, non-maleficence, beneficence and justice were acknowledged and addressed in this study.

Burns and Grove (1995) state that informed consent must contain four critical elements: information, comprehension, competency and voluntary consent. To ensure that participants were informed prior to interviewing, they were given an information sheet (see Appendix B) and ample opportunity to ask questions. All questions were answered honestly and openly.

Voluntary consent was obtained from all participants. Burns & Grove (1995) argue that voluntary consent entails ensuring that participants have freely consented without coercion or undue influence. All participants were self-selecting having responded to my advertisement, and understood that they could withdraw at any time without giving

reasons. The participants' consent form (see Appendix C) was signed before interviewing commenced.

To address issues of confidentiality, participants chose a pseudonym which was used on all transcripts throughout the research. Participants were told before interviewing that due to the in-depth accounts of participants' experiences, it was possible that colleagues or friends may identify them from the data and that anonymity could not be guaranteed.

All study data was kept in a locked cabinet at the researcher's home. A confidentiality declaration (see Appendix D) was signed by the audiotape transcriber. Pseudonyms were used on all research data and reported findings.

It is also essential no harm come to participants (LoBiondo-Wood & Haber, 1996) Due to the sensitive and personal nature of the interviews, I allowed for the possibility of participants becoming distressed about unsolved issues related to their experience. I had pre-arranged up to three free counselling sessions through AUT if necessary. However, because the research participants did not come from Auckland I undertook to arrange for two sessions with a local professional counsellor if necessary. I contacted each of the participants 15-24 hours after the interview to check how they were feeling. None required counselling.

My own position in relation to the topic was also considered because of my previous experiences. Debriefing by a colleague followed all interviews and regular contact with my research supervisor was maintained. If required I could have accessed AUT counselling also. However, I did not feel that this was necessary during the course of the study.

Research should also promote social good and be shown to be worthwhile (LoBiondo-Wood & Haber, 1996). This study will, I believe allow ICU nurses to have their stories and experiences recognised. I am also hopeful, as noted earlier, that health institutions may benefit by being able to offer nurses more appropriate support during these critical times. The insights gained as a result of this research may also enable nurses to better support their colleagues and ICU nurses from other units. With a view to justice, everyone has the right to be treated fairly. To some extent the approach used in this study views the researcher as co-constructing the interpretations. Participants were

asked to delete or alter transcript data as they saw fit. They were also offered access to a copy of the completed dissertation.

3.4 *Te Tiriti O Waitangi*

In New Zealand, research must uphold principles relating to Te Tiriti O Waitangi. The Kawa Whakaruruhau Komiti, within the Division of Health Care Practice at AUT, assisted me with the development of my research proposal. Kai Awhina support was also available through AUT for Maori participants during and after interviews although no Maori ICU nurses volunteered to take part in the study. Consultation with the National Council of Maori Nurses resulted in further suggestions for the dissemination of my research results.

3.5 *Participants*

To recruit participants I visited nursing managers in ICUs in the greater Auckland area and asked that advertisements be placed on their notice boards. I then contacted the critical care nurses' section (CCNS) of the New Zealand Nurses' Organisation (NZNO) who suggested I place an advertisement in the *Kai Tiaki Nursing Journal*.

Participants needed to meet the following inclusion criteria:

- be registered nurses working in a New Zealand ICU
- have experienced a critically ill adult family member
- be at least 12 months past or beyond the family member's discharge from ICU
- be able to speak English sufficiently to have their stories understood
- be either male or female, Maori or Pakeha

Participants were excluded if their family member

- was under the age of 20
- died in ICU
- died within 12 months following discharge from hospital.

The first four participants to meet the inclusion criteria were selected. The number of participants was limited to four because of the constraints imposed by a 60 point dissertation. Each participant was given an information sheet (see Appendix B) which explained the purpose and process of the study as well as ways of ensuring

confidentiality and anonymity. All participants were asked to sign a consent form prior to interviewing (see Appendix C). Interview times were discussed via telephone and commenced at a time and place convenient for the participant. No payment was made for participation in the study. The participants included four female ICU nurses who identified themselves as NZ Europeans. None of the participants withdrew from the study.

3.6 Interviews

The audio taped interviews took place over a six week period. The interviews lasted between 45 and 90 minutes.

van Manen (1997) states that in hermeneutic phenomenological human science the interview serves two very specific purposes. The first is for the purpose of exploring and gathering experiential narrative material as a resource for developing a deeper and richer understanding of the phenomenon. The second is to develop a conversational relationship with a partner about the meaning of an experience.

The art of the researcher in the hermeneutic interview is to keep the questions open and to remain focussed on the substance of the phenomenon (Gadamer, 1976). The interview questions in my study were non-directive to enable the participants to tell their stories in the way they wished. I started by asking participants to tell me the story about when their family member was critically ill. Questions such as “would you please tell me more about that?” or “how was that important?” helped me to gather rich data and keep the participants focussed on the original research question. Throughout the interview I was mindful of my body language and attentiveness and the need to remain open to the stories (Koch, 1996). This served as a means of tracking and helped alert me to my own prejudices. Directly following the interviews, impressions, reflections and observations were written down in order to identify non verbal communication which could help to depict the meaning of participants’ experiences.

The interviews were transcribed verbatim by a transcriber as soon as possible and returned to participants to confirm or alter as they so wished. None of the participants changed their transcripts.

3.7 *Data Analysis*

Phenomenological research explores the structure of the human lifeworld and the meanings we ascribe to everyday situations. van Manen (1990) argues that the true reflection of lived experience is a thoughtful grasping of that which renders an experience its special significance. He suggests that in order to identify the structure of meaning within the text it is helpful to think of the phenomenon in terms of units of meaning or themes. He suggests that three different approaches that may be used to uncover or isolate these essential themes.

The first is the holistic or sententious approach whereby the researcher attempts to capture the fundamental meaning of the text as a whole and formulates a phrase to capture the meaning therein.

The second is the selective or highlighting approach in which the researcher listens to and reads the text several times before highlighting particularly essential or revealing statements about the phenomenon. In the third detailed or line-by-line approach, every single sentence is examined for essential meanings.

From participants' transcripts I drew out essential themes using van Manen's (1990) holistic and selective approaches. These preliminary themes were then discussed further with the participants to ensure that they represented an accurate account of the meaning of their personal experience.

Four lifeworld existentials: lived body (corporeality), lived space (spatiality), lived time (temporality) and lived other (relationality) (van Manen, 1990) were then used to deepen understanding of the findings and strengthen the phenomenological nature of the study findings.

3.8 *Rigour*

For some writers, research credibility of qualitative studies is established by adopting the concepts and terminology of positivist research. Sandelowski (1993), however, states that issues of validity in qualitative studies should be linked not to 'truth' or 'value' but to 'trustworthiness'.

Lincoln and Guba (1985) identified criteria in dealing with the trustworthiness of qualitative research. They divided trustworthiness into four separate criteria: credibility, fittingness, auditability and confirmability.

Credibility relates to faithful descriptions or interpretations of the human experience so that people having the experience would immediately recognise it. Fittingness refers to the degree to which the findings of the inquiry 'fit' with contexts outside the study situation. Auditability allows another to clearly follow the decision trail used by the investigator. One must arrive at a comparable but not contradictory conclusion given the researcher's data, perspective and situation. Confirmability relates to the relationship between the researcher and the participant and measures how well the inquiry's findings are supported by the data collected (Lincoln & Guba, 1985).

Hermeneutic research is a rigorous process and, when well implemented, many of the criteria to achieve trustworthiness as described above are inherent in van Manen's (1990) methodological structure. The idea that understanding is achieved through consensus of the whole and the parts of the text, for example, offers a standard for trustworthiness that relates to the processes rather than the conclusions of the research alone.

Moreover, Gadamer (1976) argues that the fusion of horizons can only be experienced if one's preconceptions and prejudices are brought to consciousness. I was particularly mindful of the fact I had personally experienced the phenomenon and that my own personal bias could influence the process. In addition to being interviewed to uncover my pre-understandings, I also kept a reflective journal throughout the research project to track my evolving interpretations. This is how I constantly revised my position in the hermeneutic circle of developing understanding in relation to the findings. I have also used participant quotes to support the study findings. This will help readers to judge the credibility and transferability of the research to other settings.

3.9 Conclusion

In this chapter I have provided an outline of how the research proceeded and the philosophies used to guide the process. In the following chapter I will present the thematic findings of the study.

Chapter Four

Findings

4.1 *Introduction*

In this chapter, thematic description of the findings will precede discussion and integration of van Manen's (1997) lifeworld existentials. Four themes: a nurses' nightmare, knowing and not knowing, feeling torn, gaining deeper insight and new meaning, will depict the meaning of the experience for the ICU nurse/relatives.

4.2 *The ICU nurse as relative of a critically ill patient*

The ICU nurse/relative experiences a horrific reality as she lives through her own nightmare. While struggling with the many tensions of being an ICU nurse/relative, she encounters numerous paradoxes. The experience provides new and deeper understanding of the meaning of being an ICU nurse/relative and can enable the nurse to provide higher quality care in their own professional practice.

4.3 *A nurse's nightmare*

A nurse's nightmare describes unexpected intense emotions experienced by ICU nurses when a family member is admitted, critically ill, to an ICU. Nurses would not normally allow themselves to develop personal feelings for a patient. As a relative, however feelings of connection, fear and uncertainty are experienced simultaneously. The nurse feels vulnerable and overwhelmed.

Sarah, Lily, Kay and Anna recall the shock and horror they felt when they first realised that someone they loved was critically ill in ICU. Their own brothers, sisters, mothers and fathers required their comfort and reassurance. None of the participants had experienced feelings like this when caring for people in ICU to whom they were not related. The personal connection to the ill person significantly altered the nurses' experience of critical illness.

It's not any other 80-yr-old it's my Dad and it was this personal involvement that overwhelmed everything. Because this was my Dad ... (Sarah)

Feeling disconnected was simultaneously experienced as the ICU became a different and frightening place. What was normally acceptable suddenly became frighteningly abnormal. The lifeworld of the ICU nurse became a place of uncertainty, one in which she felt vulnerable and powerless. It became a place where the unthinkable might happen. Questions such as: Will my relative die? What will the future hold? Will my family be alright? How well will my relative be cared for could not be answered with any degree of certainty, and the nurses had no way of knowing how or when the nightmare would end. Kay describes her thoughts when her brother in law was admitted to the ICU:

... what are we going to be left with and how is it going to be? and then that whole rehab stage after that and the uncertainty lasts for years ... I mean without thinking of all the things that could be going wrong ... (Kay)

The nurse/relatives also felt helpless and powerless. There was nothing they could do to change the clinical course of their relative's critical condition. Sarah remembers the helplessness associated with her feelings of fear:

... I know that feeling of utter helplessness, it's that fear, it's that fear that is so persuasive... I think you underestimate the absolute fear that you're actually related to everything ... (Sarah)

The participants tried valiantly to find ways of avoiding their fears and concerns and efforts were made to keep busy as a means of distraction. Sarah wanted to leave the hospital rather than sit in the waiting room worrying, so she took her mother shopping. She remembers purchasing an item of clothing that she would not normally have chosen. Reflecting on this behaviour, Sarah knew her thoughts had been at the hospital with her father.

... Mum and I went shopping which was just bizarre because I bought this red jersey it was like a flaming vermillion red which, in my right mind, I would never have done ... I must have been just out of it ... (Sarah)

Anna talked about things that she had said and done that she could not recall.

... staff have told me things that I did, I don't remember doing, the poor girl I bollocked because she hadn't replaced the potassium unit. I don't remember doing it at the time ... (Anna)

Lily had chosen to stay at work to keep busy. She asked to nurse a particularly time consuming patient, but still worried about what would happen if the emergency bell went off for her brother-in-law while she was on duty.

... What if I hear an emergency bell go from that bed space, what would happen? ... so I just tried to, there was an element of trying to switch off, I think I just had so much to do when I think back ... I really kept away, and I tried not to sort of focus too much ... (Lily)

The nurse's nightmare is an overwhelming myriad of fears. Past knowledge of what can go wrong combines with seeing the ill relative's present circumstances and worrying about future outcomes.

4.4 *Knowing and not knowing*

The nurse as relative of a critically ill patient knows how important the person is to family and friends. She knows the person's past, his or her special attributes and something of the person's future potential.

... you know their family background, and you know all the people that love him, and they're going to be really worried about him, and you know how hard that's going to be on them you know ... So you feel anxiety about knowing all that ... (Lily)

As a highly trained professional, the ICU nurse also knows the broader implications of critical illness for patients and their families. The nurses in this study had had many years of ICU experience. Their memories of previous patients and families reminded them of the fragility of life and thus exacerbated their fears.

I have nursed patients in acute renal failure who just never get their kidneys working again ... (Lily)

The nurse/relatives had expectations about the normal clinical progression of events based on previous experiences. Anna knew, for example, approximately how long her relative should be in theatre and felt anxious when he was much longer than she had envisaged.

... Normally about 4 hrs later you sort of start to think ... Oh yeah, they'll be back (from theatre) soon ... because of the knowledge I have when an Aorta dissects ... I would know that he had quite a poor outcome ... you're just sitting there waiting for the phone

to ring and I just felt dreadful, I kept thinking the longer he's away, the worse it is ... (Anna)

Knowing signs of deterioration and improvement meant that the nurses felt compelled to watch their relative's recordings, yet the 'numbers' communicating the vitals signs provided both relief and fear.

Kay's statement shows an understanding of how knowing can exacerbate anxiety, and how not knowing may provide some relief:

... it's good that he didn't have an ICP monitor in because I would have been fixated sitting there thinking Oh its going over 30 or you know something like that ... (Kay)

Anna, on the other hand, felt a strong need to see the numbers to reassure her that her relative's vital signs were within what she knew to be normal limits.

... I wanted to see what his numbers were doing ... (Anna)

Sarah explains:

... you are on tenderhooks the whole time ... he had low MAPS all the way through ... you just look at these numbers and you think, I know what that means ... (Sarah)

When Anna's brother in law dissected his aorta after cardiac surgery and was taken back to the operating theatre to have it repaired, she knew how ill he was and tried to warn her family. However, despite the surgeon telling the family that their relative had only a 50/50 chance of survival, the family went home for dinner convinced that all would be well. Anna was terrified that her brother in law would not survive surgery and felt concerned that the family was not adequately prepared for the worst. She worried, knowing that if she emphasised the critical nature of his condition, her family would think she was being pessimistic.

... Underlying knowledge made me fear the worst ... it was a struggle for me ... if I hadn't been an ICU nurse I wouldn't have been quite so pessimistic that first 24 hrs after his second operation ... the family were saying, "Oh he'll pull through it" dreadful ... I was like doom and gloom, and they were all extremely positive, but you know I've seen it before, and I just wanted them to be realistic and be prepared ... (Anna)

On other occasions, professional knowledge helped to ease feelings of fear. There was something reassuring about knowing the norm in the clinical environment. Anna specifically recalls making sure that her brother in law's pupils 'were equal and reacting' after his critical cardiac surgery. Sarah, speaking more generally remembers:

I was scared ... it was just that there was that nurse part of me that maybe added to that personal role that actually kept me from panic ... I'd be panicking about something and thinking ... Don't be ridiculous this is how it would normally go ... (Sarah)

Alongside knowing, not knowing also caused feelings of anxiety and stress. Not knowing what was happening while sitting in the waiting room and not having answers for relatives created feelings of frustration and powerlessness. The ICU nurse feels many frustrations and tensions as the relative of a critically ill patient.

4.5 *Feeling torn*

The ICU nurse/relative bears a double burden as she experiences the clinical worry alongside the embodied concern for her relative. The ICU nurse is simultaneously a wife, mother and daughter and daughter-in-law. She wants and needs to be there for the ill person and to comfort and support the rest of the family. As a nurse and relative, she also feels drawn to advocating and being spokesperson so that her relative and family will receive the best possible care.

... I went backwards and forwards very much backwards and forwards ... I don't think I was ever comfortable in a personal role. I was too ... I was scared it was just there was that nurse part of me that kept, that maybe kept me from panic, but the panic was also because I was a nurse. I knew what was happening ... so it's not from one to another to another to another, it's just a big mish mash you're nurse and personal ... (Sarah)

The nurse as relative cannot simply switch off the nurse in her being. Inextricable connections mean that she cannot act as a detached family member. Anna recalls her actions when at her relative's bedside:

... when I kissed him in the morning, I looked at the urine in his bag and felt how warm his skin was and all of those things and checked his heart rate, and probably I didn't even do it consciously, it was more of a subconscious thing I think ... (Anna)

Anna cannot help being a nurse as she greets her ill relative. Without thinking she finds herself assessing his output and checking vital signs. She also struggles to combat the

urge to stay at the hospital and watch her relative's surgery knowing that she should go home with the rest of her family.

... I wanted to be watching his monitor because we can watch the monitors from theatre, and then part of me said: "Look, I might even go and sit in the gallery"... I mean totally illogical sort of things you wouldn't allow family members to do normally. Part of me wanted to do that but the family side of me said I had to go home and be with my family ... (Anna)

The ICU nurse/relative becomes the family educator and the one to whom questions and concerns are directed. She explains treatments, medications and procedures. She disseminates important information to members of the family unable to be present and must constantly maintain contact with them. Kay and Lily explain:

... I was the only member of my family, who was able to go down there and be with her at that time. So I felt like I was representing my other sisters and my parents for her ... (Kay)

... he was like "Oh thank goodness you're here, can you help ... [his wife] can you help her and make sure that everyone knows"?... (Lily)

Kay also describes having to resist contributing her professional knowledge, so that her sister could experience, in her own way, what was happening to her husband.

I had to restrain myself because I was thinking ahead all the time. I had to restrain myself and let my sister experience things as they evolved. In family meetings I wanted the attention to be on my sister so I didn't ask the professional questions I would have liked to ask ... (Kay)

In her normal professional life, an ICU nurse is a teacher, patient advocate, preceptor, team leader and member of a multidisciplinary team. Responsibilities include establishing and maintaining relationships with patients, families, medical staff and nursing colleagues. She coordinates nursing staff in the ICU to ensure that patients receive optimal care. The participants in this study were aware that their units were busy and needed their experience and skills. They felt an obligation toward their colleagues, and worried that if the ICU was short staffed, their relative might not receive the appropriate care.

I was worried that if the unit was short staffed or if the skill mix wasn't right then he wouldn't get the care he should get ... (Lily)

Kay had returned to work out of a sense of professional duty but knew that she belonged at her sister's side and hated feeling that she had abandoned her sister.

... when I left her there I felt really bad as if I was abandoning her ... (Kay)

Sarah also felt a strong obligation to work, but medical staff told the charge nurse that this was out of the question. She was grateful that the decision was taken out of her hands because she felt torn between her desire to be with her father and her professional obligation to her colleagues.

... I didn't want to work but I felt kind of obliged to work, and one of the charge nurses said to me ... Well you can work down the other end no big deal really and I just didn't know what to do, it was almost like a little bit of pressure there. You know they really need you to work...So I was torn between being a nurse and being a relative ... (Sarah)

In some ways being an ICU nurse and being familiar with the staff and the clinical environment provides a sense of security and comfort. Three of the four participants had had family members admitted to their own workplace. The staff tried to allocate the most experienced nurses to care for their colleague's ill relative. Anna and Lily explain:

... staff would say to me you know "Are you happy with so and so looking after him today? And that gave me a little bit of control as well, I didn't want any new or junior staff looking after him ... (Anna)

...My colleagues thought I might mind who was looking after him, and put nurses of seniority in there. So actually it wasn't so much my response, but their response ... (Lily)

Being consulted and informed was reassuring and the participants enjoyed feeling respected professionally.

... I didn't have one person who didn't treat me as a professional. It was good ... I'd go up and give him a hug, and they would go up and tell me all his vital signs, and they would go up and tell me what his BP was, and his hemoglobin, and things like that ... (Anna)

... they treated me more as a colleague. It would have been very difficult for them to adjust to as well because as I was a senior colleague I'd been there for years ... in some ways I was grateful for that because I found out far more than I would have normally ... (Sarah)

Since Kay's relative was not admitted to her workplace, the environment was less familiar and she was not known by the staff. Her feelings of comfort were different and she seemed happy not to be known professionally.

... I think what settled me down straight away was that I could see that my sister was being looked after ... I tried to be a relative and not to interfere in any way ... (Kay)

There were times for Sarah, however, in her own workplace, when feelings of resentment and even anger contributed to significant discomfort. She recalls feeling resentful when she was expected to watch her father, and frustrated that the nurse had not recognized her as the patient's daughter.

... I was sitting there one day and the nurse just said to me ... "keep an eye on his MAP, I'm going round the corner", and I was looking at the MAP and it was dropping down towards 50 and I knew it was too low and this feeling of paralysis because I know that needs turning up, but I can't do that because I'm not a nurse here I'm a relative and I just couldn't ... there's boundaries there ... I felt really resentful ... Don't you dare leave me here that's not fair ... (Sarah)

Lily too, was frustrated when staff expected her to contribute professionally while sitting by her relative's bedside. In the following excerpt she has been asked to check medications for other patients:

... some of the medical staff were still asking me for things like, "Can you check me out some medicines for this gentleman"? and I was, "Oh please, hang on a minute" ... (Lily)

Kay remembers trying to fit in with staff and be seen as a good relative. She remembers feeling sorry for staff when a family member who was also a doctor demanded blood results and detailed information and constantly criticised her relative's treatment. Kay understands how hard it is when family members behave in this way.

... I mean the staff dealt very well with this kind of demanding attitude from [Dr relative] because I've been on the other side, I didn't want to be rocking anyone's boat ... (Kay)

Sarah also tried to behave the same as other members of her family when her father arrived back from theatre. She no longer felt comfortable entering her workplace and

instead had to ring the bell. Something she had previously taken for granted seemed alien and required substantial effort.

... Why haven't they called us in? They know we're here, and, in the end I plucked up courage and I went and knocked on the door which was really weird. I had to knock to go into my own unit and that felt really strange because possibly if I'd just walked in nobody would have turned a hair but I just felt that I just could not walk in ... (Sarah)

Being an ICU nurse/relative means trying to meet the needs of an ill relative and family member while also trying to meet professional obligations. The nurses in this study felt torn between their responsibilities as ICU nurses and their desire to be there for their family.

4.6 Gaining deeper insight and new meaning

Each of the nurses in this study previously believed that they understood families' experiences as relatives of critically ill patients. Becoming the relative of a critically ill patient, however, provided new and deeper insights.

... I always thought I did know families really well, but actually it showed me that perhaps I didn't know them as well as I thought ... (Lily)

The way nursing and medical staff communicated with the nurse/relatives had a huge influence on their experience. Anna remembers feeling physically sick when a member of the cardiac team told her that her brother in law had arrested. After hearing the first sentence she immediately assumed the worst. She thought her relative had died. The experience emphasized, for Anna, the importance of relaying information carefully. The order of what is said and the words that are used or not used, are significant. Being a health professional delivering information is very different from being a relative receiving the same information.

... she just walked up and said "I'm sorry Anna it's [relative] ..." and my heart, I just... the whole bottom of my stomach just wanted to fall out, and I felt physically like I wanted to be sick, and then she said "He's off down for angiography, we think he's dissected his aorta." But she didn't tell me that to start with, she let it sink in, and I actually thought he'd died ... (Anna)

Sarah recalls how she felt when staff failed to deliver a promise they had made to telephone if and when her father's condition changed. Sarah was reminded of how

relatives rely on staff members to be honest and how important it is develop a nurse-patient relationship based on mutual trust and respect.

... I knew he wasn't well and it was difficult getting the ward staff to listen and understand that I was concerned for a reason ... things seemed absolutely devastating when I was basically told to go home ... I rang an hour later and found that they had rung the registrar 30 minutes after I left, I was annoyed that they had not rung me and that I was fobbed off ... I thought about what it must be like for other families... (Sarah)

Anna was also reminded of how important it is to keep family members informed when she realized what her sister-in-law was experiencing in the waiting room one day.

... I know my sister-in-law had to wait one day for probably 45 minutes, and she had terrible visions of dreadful things happening to [family member] when really there had been an emergency in another part of the unit ... nobody had actually explained that to her, and she was out in the waiting room, pacing up and down. I found her in a terrible state ... it's made me understand more of what it's like for them to have to wait 10 minutes if we're changing his linen, or getting him out of bed ... Sort of explaining actually what we're doing ... (Anna)

Sarah had a similar personal experience and describes her thoughts and fears as she waited:

... if you are out in the waiting room and you hear people running or any of those things that indicate trouble, there's always that slight panic and that just cold feeling ... and hearing little excerpts of things and thinking. Now are they talking about Dad or somebody else ... little things make a huge difference you know just little things that you hear and suddenly they kinda haunt you ... So it also gave me that understanding of how horrible it is for the families ... (Sarah)

Another insight gained related to the way families responded to information. The ICU nurse/relatives who participated in this study were surprised by how little information their families retained. Lily provides an example:

... my family are intelligent, they are articulate, they understand. At the same time they just didn't grasp stuff. It took them so long ... (Lily)

Sarah understands how difficult it is for families to retain information as she recalls repeatedly asking staff the same questions:

... when you are told things when you are so frightened um you don't actually hear what they are saying... You hear it but it doesn't sink in and then what you do is you think that maybe that's not what they meant ... maybe denial or just deep shock that something could ... and also you don't want to think about the unthinkable so you kind of shut yourself out in case you hear something that's actually going to make it reality ... (Sarah)

Being with her sister-in-law helped Lily understand how daily tasks such as cooking, shopping and cleaning were no longer priorities in the lives of her family. Life revolved instead around what was happening in the ICU.

... you realise what grinds to a halt outside of the ICU ... and we don't realise that they're not cooking at home, they're not grocery shopping at home, they're not heating their home ... I called round to pick up my sister in law one day ... and she was having a terrible day, she had been in tears all morning, the house was very cold ... there was no milk, and you know, realising people actually just go home, and they just don't know what to do ... (Lily).

All of the participants changed aspects of their clinical practice as a result of being the relative of a critically ill patient. By reflecting back on aspects of their experience that caused undue anxiety or distress they were able to identify steps they could take to care more effectively for their patients' families. The participants identified that providing more information, being more honest with families, providing a more detailed family handover to a nurse and sharing their own experience to establish a connection with families would assist them in providing a higher quality of care to families in the future.

... I'll give more detail of why they have to wait now. I'm quite honest with them, probably more honest with them now than I was ... (Anna)

... I would regard it as probably quite a pivotal turning point for me. I have started to maybe question things a lot more ... I do a far better family handover ... I have a deeper understanding of relatives and it has changed my reaction to them quite a bit. It was a huge eye opener to me just ... seeing the way things happened and seeing it from the other side ... (Sarah).

New and deeper insight has provided the nurse/relative with a greater appreciation for the importance of some of the more taken for granted aspects of daily ICU nursing.

The insights have also provided their practice with new meaning.

Sarah, Anna, Kay and Lily remembered the colleagues who were caring and supportive during their family crisis and gained new respect for them.

... I've always valued the people I work with but for me it just became so much clearer, that they were really good people ... they also do that every day, with everybody, and they didn't do it just because it was my family and me they do it for everybody. And I think you know for me, I sort of am really fortunate that I work in a great place, and that I work with nice people ... even though I've worked there a long time, I think it changed ... (Anna)

... I feel very close to my team members now ... and I do trust them. I have an immense respect for them, and I have immense respect for the way they managed it ... (Lily)

Using phenomenological notions to further describe lived experience will assist understanding of being an ICU nurse/relative.

4.06 *Bringing van Manen's existentials to the findings*

van Manen (1997) suggests that four (and maybe more) existentials: "lived body", "lived time", "lived space" and "lived other" describe the fundamental nature of being human. These existentials can be distinguished from each other in writing but, in everyday life they overlap and cannot be separated.

van Manen's existential, lived body or corporality reminds us phenomenologically that we are always bodily in the world (1997 p.2). These embodied feelings help to characterize the phenomenon of being an ICU nurse/relative.

The ICU nurses as relatives described their experience as a "nightmare" in which they felt strong personal emotions. Yet rather than these emotions showing in a physical way such as crying, becoming unwell or not sleeping, they showed more often as a change in usual behavior. In feeling torn the nurses were less focussed on their work and were quieter and less patient than usual. They worked particularly hard, keeping themselves busy and increasing their usual physical activity as a way of distraction. As relatives were admitted to their work environment, the ICU environment also acquired a deep personal significance.

van Manen's (1997) existential lived space or spatiality describes the integral relationship human beings have with their environment and how they feel in the spaces they inhabit. The ICU nurses as relatives described the workplace as changing from a comfortable familiar environment where they would normally feel at home, to an unfamiliar, uncomfortable place where they felt fearful and vulnerable.

Furthermore, the ICU environment changed for the nurses as relatives of critically ill patients, so did the relationships they shared in the workplace. van Manen (1997) refers to these relationships as lived other or relationality.

Relationships with colleagues changed because many found it difficult to understand and respond to the ICU nurse/ relatives personal circumstances. They were used to sharing a professional relationship rather than a personal one. These altered relationships caused many tensions and discomforts for the ICU nurse/relatives.

The relationship with family members also changed as they became patient and family advocates, family spokespeople and responsible for passing on information to absent relatives and friends. The ICU nurse/relatives were expected by family members to provide information and rationale for treatments and answer questions.

The prior knowing and experiences of the ICU nurse/relatives in this study impacted significantly on the ways they interpreted their present situation and their anticipation of outcomes. van Manen (1997) calls this lived time or temporality. It describes the subjective nature of time which is lived simultaneously through the past, the present and the future. At times knowledge from the past triggers positive feelings of hope but it also engenders feelings of fear and helplessness.

Time as lived was experienced as longer than clock time when nurses/relatives and their families sat in the waited while important procedures were being carried out. The days and weeks seemed to drag as they waited for their relatives to recover. Yet, there were also times when distance interacted with time and seemed to shorten or contract. The time that Kay was able to spend with her sister went surprisingly quickly when she knew she had to return to work a long distance away.

Lived time also impacted on the nurse/relatives professionally. Being nurse as relative of an ICU patient changes the way in which nurses perceive and relate to relatives in the workplace. As the ICU nurse/relatives reflected on their experience and past communications with family members they were able make changes to daily practice and anticipate how those changes could better meet the needs of the relatives of their critically ill patients in the future.

4.07 Conclusion

In this chapter I have presented the findings of this study under specific themes: a nurse's nightmare, knowing and not knowing, feeling torn, and gaining new insight and new meaning. van Manen's (1997) lifeworld existentials have provided a deeper insight into the phenomenon of being an ICU/nurse relative.

In the following chapter I will discuss these findings in relation to current literature and make recommendations for education, practice and further research.

Chapter Five

Discussion

5.1 *Introduction*

In this chapter I will discuss the study findings under the headings; the tensions inherent in the phenomenon and the paradoxical nature of the phenomenon linking themes to current literature. I will then identify the limitations of this study and provide recommendations for education, practice and further research. The chapter will conclude with a summary that addresses the research question.

5.2 *The tensions inherent in the phenomenon*

A number of tensions were identified in the findings of this study. ‘A nurse’s nightmare’ describes the horror and shock of being family and feeling connected when a critically ill relative is admitted to the ICU. My findings suggest that nurses feel the same initial feelings of shock, fear, uncertainty, helplessness and anxiety as other family members. Taylor (1994), who describes family as the sense of home within ourselves, believes that family is central to the theme of “being with”. He suggests that it is our sense of family that urges us to be present when a relative is critically ill. Tracey (2001) claims that having a family member admitted to ICU constitutes a crisis which affects family functioning and the ability of family members to communicate and understand complex information.

The findings of this study are also congruent with those of Fontana (2006), who likens the experience of critical illness for families to a roller coaster ride, full of emotional ups and downs. The ‘nurse’s nightmare’ describes experiences of shock, continual uncertainty, overwhelming fear and profound helplessness and powerlessness (Keung-Sum & Twain, 2007). Being “in a state of shock” was reported by Fontana (2006) and Lam & Beaulieu (2004) who stated that their participants felt “tattered” as a result of the ongoing uncertainty.

Fear was an integral part of the ‘nurses nightmare’ as participants described feeling terrified or overwhelmed by their fear. Several studies support these findings (Fontana, 2006; Fulbrook, 1999 and Lam & Beaulieu, 2004). Walters (1995) suggests that fear

may arise partly from the notion of self likedness in which one is prompted to consider their mortality. Although none of the participants talked specifically of their own mortality, being a nurse and relative in the context of ICU certainly challenged and changed the values and priorities of the participants in this study.

The findings in this study revealed that ‘keeping busy’ was a strategy used by the nurse/relatives to combat feelings of helplessness and powerlessness. Keeping busy helped to distract them from their anxiety and fears. Fontana (2006) similarly described the “busy mode” as a strategy adopted by family members to cope with their terror and stress. The need to “do something” was further echoed by Fulbrook (1999) and Feeg (2006) as a coping strategy for nurse relatives while their family members were in the ICU.

The theme ‘knowing and not knowing’ revealed how professional knowing became a constant source of anxiety. This supports the findings of Olivet & Harris (1991) who found that professional knowledge provided frightening insight into potentially fatal complications. Such knowledge was, for the most part, inescapable in this study.

With knowing came several responsibilities. The findings showed that the nurse/relatives felt responsible for educating family members and disseminating information. In many cases they felt that family members expected them to give direct care at the bedside, be support people, decision makers and resident experts. Olivet & Harris (1991; Feeg (2006); Mills & Aubeeluck (2006), confirm that family expectations place considerable responsibility on the nurse/family member.

Providing information, however, caused a dilemma for the ICU nurse/relatives. They were forced at times to choose between being honest and providing hope. Congruent with the findings of Mills (2006) and Mills & Aubeeluck (2006), they wanted to protect their family from the worry and fear that they were experiencing and knew that expressing their real feelings would impact adversely on family members.

The findings also showed the positive contribution of knowing. There were times when it fostered a sense of familiarity and security. Being an ICU nurse/relative enabled them to utilise professionally acquired skills to comfort and support their own families (Mills & Aubeeluck, 2006).

Not knowing was another essential part of the phenomenon. Being unable to reassure their families that their loved one would survive, or provide information about their anticipated level of functioning or recovery, meant that despite their professional knowledge, the ICU nurse as relative could not offer the required reassurance. Olivet & Harris (1991) and Mills & Aubeeluck (2006) reported that being unable to offer reassurance to relatives made nurses feel professionally and personally inadequate.

5.3 *The paradoxical nature of the phenomenon*

The theme ‘feeling torn’ describes the paradoxical nature of being an ICU nurse/relative. In the context of this study, paradox describes the many contradictions and ironies that pervade human experience. Spence (2004) uses paradox to describe situations “that initially seem to be incongruent but prove on closer examination to be connected” (p. 163), arguing that such contradictions are part of being human and are not to be solved but rather to be understood.

ICU nurse/relatives simultaneously feel connected and disconnected. Knowing coexists with not knowing and nurse/relatives are both grateful and resentful of their knowledge. The experience is familiar professionally but unfamiliar personally, and being a nurse simultaneously makes things easier and more difficult for them. Being treated by some staff as professionals, and by others as family members can be both affirming and disconnecting.

Experiencing strong personal connections with patients is not a familiar feeling for ICU nurses. As powerful personal emotions and strong family obligations dominated their lives, they experienced a sense of disconnection from their professional responsibilities. Nursing and medical staff however continued to view the ICU nurse/relatives primarily as colleagues.

In the theme ‘feeling torn’ the nurses were happy to be treated as professionals when they needed special access or clinical information. As echoed by Mills & Aubeeluck (2006), the nurses enjoyed being confident and respected advocates for their families and their ill relative. Yet with the tensions experienced as relatives, the nurses often wished they could discard their professional identity. Feeg (2006) aptly described this as “just wanting to be a daughter” and in the study this was exemplified by Sarah who recalled feeling upset with colleagues.

The theme of feeling torn described how the ICU nurses as family members and professionals were uncertain how to behave and what to expect from colleagues during the time their family member was in ICU. Mills & Aubeeluck (2006) reveal similar findings in their research which discusses the expectations of nurses and “role boundaries” (p 163). The nurses struggled with the many demands of their professional responsibilities.

Professional boundaries, as discussed by authors such as Peternelj-Taylor & Yonge (2003) and Sheets, (2000), provide a line or a limit for something abstract; they mark territory. Feeling torn describes the tensions experienced as the ICU nurse/relative tries to maintain what she considers to be professional behaviour. This finding is similar to that which Olivet and Harris (1991) have described as “role uncertainty” (p. 248). Mills & Aubeeluck (2006) also discuss balancing professional and personal roles to ensure that they are working ethically and in line with the system.

Human beings live with many responsibilities. In the absence of crisis we emphasise one and downplay another without thinking. In our everyday lives, there is a certain level of predictability and agreement. In sudden unforeseen situations such as a family crisis, we no longer feel certain. Powerful emotions affect our behaviour and we try to cling to whatever we can to retain some sense of order among the chaos. These experiences are similar to the findings of Hurst & Koplin-Baucum (2005) who suggest that nurses need to feel control over their environment, their patients and their personal issues. Nurses strive to regain a sense of security and calmness (Johannson, Bengt, Fridlund & Hildingh, 2005).

Contemporary ICU nursing takes place in a highly technological environment requiring the ICU nurse to carefully manage time to meet the psychological needs of patients and families. Time is prioritised according to biomedical and physiological acuity and family needs are secondary to the physical needs of the patients.

Nursing shortages contribute further to the difficult climate as nurses juggle staff rosters in an attempt to maximise the efficiency of the ICU. National and international trends indicate a decline in the number of ICU nurses and, as was discussed in chapter one, pressures and tensions within the ICU environment are commonly identified as

contributing factors. The participants in this study in the theme feeling torn described feeling guilty about taking time off work and felt torn between their obligations as nurses and their desire to be with their family and the critically ill relative. Mills and Aubeeluck (2006) support these findings noting the stressful situation this put nurses in.

Gasquoin (1996) emphasises the meaning of 'stress-full' through using altered spelling to more accurately portray the feelings of being emotionally overwhelmed. Being an ICU nurse/relative is a similarly stress-full experience.

Feeling emotionally overwhelmed and consistently feeling anxious puts the nurses as relatives at risk of developing post traumatic stress disorder (PTSD), (Azoulay et al., 2005). In feeling torn the nurse relatives were reminded of events that they had no memory of. Turnball (1998) demonstrated that memory is adversely affected by psychological trauma and Hughes, Bryan & Robbins (2005), argue that traumatic events such as family crises interfere with the processing of information. The findings of this study revealed participants' surprise at how little information their family members could process or remember.

The findings of this study revealed that the participants gained a much deeper understanding of families than they had had previously. They more fully understood not only the changing emotions of relatives but also the intensity and overwhelming nature of these (Mills & Aubeeluck, 2006). The participants also verbalised a significant change in the meaning that they gave to ICU nursing and the meanings associated with the experience of being the relative of a critically ill patient.

The meaning of the experience of being an ICU nurse/relative is different from the experience of being an ICU nurse/relative.

ICU nurses live with life and death every day, and in the busyness of the ICU maintaining life becomes an embodied routine. Although ICU nurses see the devastating effect of critical illness on families, the meaning of such goes unnoticed. Heidegger's (1962) notions of, ready-to-hand, unready-to-hand and present-to-hand, help to explain this phenomenon. He explains that when everything is going as expected the phenomenon itself disappears. It becomes taken for granted (ready-to-hand). It is only when something happens to the usual way the phenomenon presents itself

(unready-to-hand) that we are forced to stop and consider the phenomenon itself (present-to-hand). A beating heart and the act of breathing go unnoticed until they become problematic.

Similarly, the meaning and value of life becomes more visible in the face of death. Walters (1995) suggests that in the face of death there is a new appreciation of the temporality of existence. Having a family and being part of a family is more visible when the fundamental structure of the family unit is threatened.

The meaning of being an ICU nurse changes through the experience of being a nurse/relative. Behind what is seen by ICU nurses in their normal professional life is a family experience, known and understood through deep personal connection.

In this context, life is not that which we take for granted, not that which we mindlessly endure, but an experience of living a nightmare, feeling torn, knowing and not knowing. The nurse as relative of a critically ill patient suddenly realises how much that life touches her own and how much of a gap there would be if the person were not there. The meaning of being an ICU nurse/relative, also shows itself through seeing another ICU nurse caring for their loved one and family. They come to realise how much it means to feel that the family member is cared for. The new insights that were integral to this phenomenon seem similar to what Fontana (2006) calls “new normal”.

5.4 *Revisiting pre-understandings*

In order to properly engage in the hermeneutic circle and to meet methodological obligations, I will revisit my pre-understandings. This paragraph will discuss how the horizon of my own understandings, past and present fused with the participants’ understandings throughout the research process to create new understanding.

The understanding that nurses share a slightly different personal experience of critical illness from family members, who are not nurses, formed the fundamental basis for my study. This understanding came from my own experience as a nurse/relative. I remember inwardly panicking and feeling terribly alone as my brother lay critically ill in ICU awaiting a liver transplant. “Death” can be an accepted and sometimes natural progression of critical illness. For me, death was not unthinkable, unacceptable, but rather, a normal occurrence in ICU. Memories of trying to comfort families whose

loved ones did not survive reminded me of the fragility of life and I had thoughts of my brother being one of the “normal occurrences” in the ICU. Although other members of my family shared the same shock, fear, uncertainty and emotional ups and downs, they could not share the in-depth understanding I had of the potential complications relating to his illness.

The participants in this study described their fear, anxiety and the burden of knowing. They discussed the dilemma they experienced as they considered sharing their misgivings. I now understand that ICU nurses cannot disregard their knowledge even if it threatens their sense of hope because being a nurse is not something one does. It is fundamentally and inescapably who one is. Being a nurse is not like wearing a uniform that one can discard at the end of the day. It is more like wearing a uniform permanently under clothing. The ICU nurse and the knowledge and understanding gained through practice become part of who she is. I recognise that this is the most significant shift in my understanding that has resulted from my participation in this research project.

I still believe that each nurse will respond differently to a personal crisis depending on his or her unique circumstances. This is based on my belief that each human being is unique. I was surprised throughout the study to find however, that all the ICU nurse/relatives purposely kept themselves busy in different ways. I now understand that despite the unique circumstances of each ICU nurse/relative there seems to be an almost universal inherent sense of connection, an embodied way of responding to anxiety.

My understanding that certain expectations are placed on the ICU nurse/relatives by staff and family arose from my own experience of staff interacting differently with me than with other members of my family. I was expected to cope well with my brother’s critical illness because I was ‘used to this’. I felt pressured to behave in a certain way. In this study, the ICU nurse/relatives described feeling expected to behave in a certain way by staff and colleagues because they were nurses. In the theme feeling torn, the participants described how they tried to behave appropriately as family members.

I believe that support from colleagues is very beneficial when a family member is critically ill. Feeling supported helped the ICU nurse/relatives in this study through their nightmare by fostering strong friendships and creating a second family atmosphere in the working environment.

My pre-understandings related to this study came primarily from my experience as an ICU nurse who became the family member of a critically ill patient. I struggled to be either an ICU nurse, or a family member. I tried to remain the strong, efficient, safely detached ICU nurse when times were particularly difficult or emotionally overwhelming, and only allowed myself to be a sister when I was on my own. However I too felt torn.

This study has significantly changed the way I understand this experience. I now know that an ICU nurse/relative is never able to be just a nurse or just a family member she is always a nurse and a relative.

5.5 *Study limitations*

Due to the limitations of a 60 point dissertation this study drew insights from only a small number of participants. However qualitative approaches, and phenomenology in particular, seek to uncover deep understanding and large numbers alone do not necessarily achieve this.

Each of the four study participants was female and all were of European descent. The study's findings do not reflect the experiences of male nurses, nor will they account for meanings derived from people from other ethnic groups.

The experience of individual nurse/relatives may also alter depending on the nature of family relationships prior to the critical illness. A mother and child relationship may, for example, differ from a sibling experience. I cannot claim therefore that the findings of this project are/or would be transferable to a wider population.

The relatives of three of the four participants in this study were admitted to the nurse's own workplace. These nurses were well-known and respected professionals within their ICUs. This is likely to have influenced their interactions with nursing colleagues and medical staff and thus to have, in turn, influenced their experience as a family member. The phenomenon as described may therefore have been different for less known or less experienced ICU nurse/relatives.

5.6 *Implications for practice*

This study has generated a number of insights related to practice. It is clear that each participant struggled to function normally as an ICU nurse during their family member's illness. Yet, some of the nurses were expected to work in the unit where their family member was critically ill. Senior staff members appear to have a poor understanding of what they are asking of nurse/relatives. Nurse/relatives must be able to take leave, so that they can be with their families, without feeling that they are letting the team down. Filling staff shortages or being asked to assist with client care at such a time places an unacceptable burden on the ICU nurse/relative.

Colleagues and medical staff also lacked understanding of the tensions experienced by the nurses. Thus there is a need to educate ICU and other staff about the tensions and challenges experienced by the ICU nurse/relative.

5.7 *Recommendations*

I recommend that ICU nurse/relatives

- Are offered unlimited leave during the time they have a critically ill family member
- Have a support person to meet with daily while the relative is in ICU
- Are encouraged to attend professional counseling for a period of up to 6 months after the event
- Contribute to reviewing the improvement of services for families within the ICU
- 5.9Provide in-service training for new and existing ICU staff members in order to increase staff understanding of families' experiences

5.8 *Suggestions for further research*

I suggest that further research be undertaken with a larger and more diverse sample with questions such as:

- “What are the needs of ICU nurses when they have a critically ill family member?”

- “What is the meaning of the experience for ICU nurses when a parent or sibling is critically ill?”
- What constitutes effective help for ICU nurse/relatives?
- How many family members of critically ill patients go on to develop PTSD?
- How is professional counseling for ICU nurse/relatives after the admission of a family member helpful?

5.9 Conclusion

The final paradox lies in the realization that this study cannot provide insight into the meaning of the experience for ICU nurses when they have a critically ill family member in a way that can ever be fully understood. Readers can only take true meaning from living the moments, enduring the days and finding their own truths. This study has however provided a window of opportunity from which to view the phenomenon and an opportunity to enhance one’s understanding.

The thematic findings: a nurses’ nightmare, knowing and not knowing, feeling torn, gaining deeper insight and new meaning have described the experience of the ICU nurse/relatives in this study. There are enormous challenges inherent in simultaneously being an ICU nurse and a relative; however, the experience also provides professional and personal enlightenment. The participants in this study gained a renewed passion for the profession and a greater admiration for their colleagues. They also developed a deeper understanding for patients’ relatives and recognised that they shared a special connection.

I have argued that senior nurses and employers must recognize the additional burdens experienced by ICU nurses when they become relatives of critically ill patients. In doing so they may help avoid the development of psychological disorders such as PTSD. Assistance and support for ICU nurse/relatives will provide a therapeutic environment where reflection and genuine concern for their well-being will help end the nurse’s nightmare.

The following poem summarises my own beliefs as an ICU nurse/relative:

*From somewhere deep inside, amid the hidden chaos, beneath the silent tears
From somewhere deep inside where hope cannot smother the stealthiest of fears
From somewhere deep inside the soul where life's meanings lie at rest
Waiting for a moment in time and a deeply personal quest
From somewhere far beyond the sadness, beyond where one can see
A window to the universe opens and offers a gift to me
A glimpse of what is truly valuable, the simple gift of seeing
A glimpse of what it means to be alive, the simplicity of "being"
What a precious gift to receive, but at such a cost
How sad that in the busyness of life, the MEANING of such, is lost*

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MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Deb Spence
From: **Madeline Banda** Executive Secretary, AUTEC
Date: 31 March 2007
Subject: Ethics Application Number 07/01 **ICU nurses' experience of a critically ill family member: a hermeneutic phenomenological study.**

Dear Deb

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 22 January 2007 and that as the Executive Secretary of AUTEC I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 16 November 2007.

Your ethics application is approved for a period of three years until 31 March 2010.

I advise that as part of the ethics approval process, you are required to submit to AUTEC the following:

- A brief annual progress report indicating compliance with the ethical approval given using form EA2, which is available online through <http://www.aut.ac.nz/research/ethics>, including when necessary a request for extension of the approval one month prior to its expiry on 31 March 2010;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/ethics>. This report is to be submitted either when the approval expires on 31 March 2010 or on completion of the project, whichever comes sooner;

It is also a condition of approval that AUTEC is notified of any adverse events or if the research does not commence and that AUTEC approval is sought for any alteration to the research, including any alteration of or addition to the participant documents involved.

You are reminded that, as applicant, you are responsible for ensuring that any research undertaken under this approval is carried out within the parameters approved for your application. Any change to the research outside the parameters of this approval must be submitted to AUTEC for approval before that change is implemented.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the Committee and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Madeline Banda', is positioned above the printed name.

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee
Cc: Nancy McNamara gandnmcn@xtra.co.nz



Participant Information Sheet

Research Title:

The experience for ICU nurses when a family member was critically ill: a hermeneutic phenomenological study.

Invitation:

I would like to take this opportunity to invite you to participate in my research project which will be part of the requirement for my Master's Degree and will focus on the above subject. Participation is entirely voluntary.

What is the purpose of the study?

The purpose of the study is to gain insight into how having critically ill family members affects intensive care nurses.

How are participants chosen?

Intensive care nurses who have had critically ill family members will choose whether or not they wish to accept my invitation to participate in the study. The first four to six nurses to accept my invitation will be included. Due to in-depth interviews and time restraints I will not be able to include more than six participants.

Nurses will be excluded from the study if they are under 20 years old or if their family member died while in ICU or in the 12 months following discharge from hospital.

What happens next?

You will choose a time and place for us to meet. The interview will take approximately 90-120 minutes and will be taped (with permission) and transcribed. You will receive a copy of the transcription.

What are the discomforts and the risks?

The interviews will include personal stories of your experiences and these recollections may prove painful or may even be overwhelming for you. I will phone you 24-48 hours after our interviews to see how you are feeling. There will be three free counselling sessions available for you with a professional counsellor through the AUT counselling service if you choose to access this service.

What are the benefits?

This study will allow ICU nurses to tell their story and allow colleagues a deeper insight into the experience so that they may be able to provide more effective support. Institutions will also gain insight so that they may intervene appropriately in times of personal crisis.

How will my privacy be protected?

You will choose a pseudonym which will be used on transcripts by myself and the transcriber. All data or anything that may identify you will be confidential and locked in a cabinet for six years before being burned. If you choose to withdraw from the study, all data will be destroyed. I cannot guarantee you anonymity because parts of the research will include your quotes which may allow other people involved in the critical event to identify you.

What will it cost me to participate in the study?

The cost involved for you is your time which I greatly appreciate. I am happy to travel anywhere you choose to go for the interviews. If you do have any costs incurred participating in the study please tell me and I will reimburse you.

Opportunity to consider the invitation

Thank you for taking the time to read this information sheet. Please do not hesitate to contact me with any further questions regarding the study. If you would like to take part in my study please contact me by phoning or emailing the address below. I will look forward to hearing from you.

What if I have concerns about the research?

Any concerns regarding the study should be notified in the first instance to the Project supervisor.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda,
Madeline.banda@aut.ac.nz, 921 9999 ext 8044.

Researcher contact details:

Nancy McNamara

Work phone: 07 5798831

Mobile: 027 480 4448

Email: gandnmcn@xtra.co.nz



Consent to Participation in Research

Project Title: The meaning for ICU nurses when a family member was critically ill:
a hermeneutic phenomenological study

Supervisor: Deb Spence

Researcher: Nancy McNamara

- I have read and understand the information provided about this research project
- I have had an opportunity to ask questions and have them answered.
- I understand that the interviews will be audio taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant tapes and transcripts or parts thereof will be destroyed.
- Anonymity cannot be guaranteed because parts of the research will include your quotes which may allow other people involved in the critical event to identify you.
- I agree to take part in this research.

Participant:

Signature:

Date:

