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**OPTIMISING THE HUMAN EXPERIENCE:
THE LIVED WORLD OF NURSING THE FAMILIES OF
PEOPLE WHO DIE IN INTENSIVE CARE**

**A thesis presented in partial fulfilment of the requirements
for the degree of Master of Arts
in Nursing
at Massey University**

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ABSTRACT

Intensive Care nurses share some of the most precious and poignant moments with people who have family members dying in ICU. This study explores the lifeworld of seven ICU nurses who describe their experiences working with these families. Data was gathered using unstructured, indepth, face-to-face interviews. These were tape-recorded and transcribed. The study uses a phenomenological approach informed by Heidegger and hermeneutics. Van Manen's methodological suggestions are followed to shape and focus the study, and provide guidelines for analysis of the data and the writing of the report. The findings reveal that ICU nurses recognise that this is a particularly tragic and difficult time in peoples' lives. The nurses are aware that the last hours or days with a dying relative may be vividly remembered for years to come. During this time nurses seek to optimise the human experience of the family members by making the time as positive, or best, as possible. This is achieved through strategies such as Being There, Supporting, Sharing, Involving, Interpreting and Advocating. These strategies are enabled by three domains: Nurse as Person, Nurse as Practitioner and Nurse as Colleague which describe a wider context to working effectively with families rather than merely looking at direct interactions between the nurse and the family. Optimising the Human Experience is proposed as the central essence or phenomenon of nursing the families of people who die in ICU.

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A handwritten signature in black ink, appearing to read 'Cathy Andrew', followed by a stylized flourish.

Cathy Andrew
Christchurch
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KEY TO ABBREVIATIONS

The following abbreviations have been used in this thesis when material has been used from transcriptions of participants' interviews:

...	Pause
..//..	Material edited out of transcript
(round bracket)	Researcher's comments or questions
[square bracket]	Clarifying or explanatory comment

CHAPTER ONE

INTRODUCTION

This thesis is a phenomenological study of seven Intensive Care Unit (ICU) nurses and how they describe their experiences of nursing the families of people who die in Intensive Care.

Many definitions, models and theories of nursing have been proposed to describe what the nurse does, identify the goals of nursing and seek to understand the complex nature of the interactions between nurse and client in a variety of health care settings. Within an acute care hospital, nursing is usually viewed as the process that occurs between nurse and client. This study, while acknowledging the importance of the client, focuses on the broader perspective of nursing the family members whose lives will be irreversibly altered as a result of a relative dying in an ICU.

Nurses see their work and relationships with the family as a vital part of ICU nursing practice. Nursing the family must be combined with their professional obligations to the patient and wider health professional team. Although communication and the provision of information to families is an aspect of work of all members of the health team, it is only the nurses who are present at the bedside, 24 hours a day, seven days a week. This close contact facilitates an environment where nurses live through the minute-by-minute, hour-by-hour experience of family members. Nurses share the good times and the bad. For the duration of the duty, or duties, the lifeworlds of family, patient and nurse are blended, sharing what will be one of the most significant journeys in the lives of those whose family's destiny will be permanently changed.

For nurses, this experience can be rewarding or devastating. It provides a huge challenge in terms of utilisation of professional nursing knowledge and expertise but also requires and demands that, on a person-to-person level, the nurse supports the family and shares the human aspects of the journey. This is the lifeworld of ICU nursing.

OVERVIEW OF THE STUDY

The aim of this study is to provide a rich, indepth description of the nurses' experiences of nursing the families of people who die in ICU. In conducting this study, the purpose has been to deepen the understanding and acknowledge the importance of the nursing role with family members. The seven participants' descriptions of their nursing practice illustrate the depth and complexity of the nature of ICU nursing and how nurses genuinely seek to optimise the human experience of the family members during a time of deep, acute personal loss and grief.

A phenomenological approach has been used to guide data collection, analysis and presentation. It is acknowledged that there is ongoing debate in nursing and wider academic circles about the philosophical underpinnings of phenomenology and the process of conducting a phenomenological study. Support for using this approach comes from Walters (1994b) who comments that as more technology is introduced in ICU settings it is important that nurses develop and use research processes that enable the experiential dimensions of their lifeworlds to be explored. The research approach chosen for this study seeks to expose and describe some of the more hidden aspects of intensive care nursing practice.

Phenomenology, in a pure sense, arises from philosophy and makes use of published fiction, art, poetry and drama to depict the lived experience of being human. This study is primarily a clinically based project rather than philosophical, therefore the findings have been generated from the transcribed interviews of the participants with nursing literature sourced to contextualise the study within broader nursing scholarship. Wider sources of literature and art have not been accessed. The importance of maintaining a meaningful clinical focus in the study has been paramount.

This study fits mostly comfortably within what Crotty (1996) describes as 'new phenomenology'. That is, it seeks to describe the subjective experience of the participants it studies. Crotty is critical that this is not the traditional phenomenology of the European phenomenological movement. However, studying the subjective experience of the participants has been used widely in nursing research circles by scholars such as Patricia Benner and Nancy

Diekelmann and has contributed significantly to the development of practice-based knowledge in nursing.

It is acknowledged that this study is a beginning exercise in phenomenological research. The design and focus of the study have been influenced by ideas attributable to the phenomenological movement. The Husserlian concepts of *intersubjectivity* and *lebenswelt* referring to plurality of subjectivities making up a community sharing a common world and lived experience are central to the study. The Heideggerian emphasis on the role of context and the notion that meanings are assigned to experience generated from ourselves and particular situations is acknowledged. Van Manen (1990) claims that understanding of phenomenology can only be gained by actively 'doing it'. He describes undertaking a phenomenological study as an interplay of six procedural activities. These procedural activities will be outlined and have been used to focus this study as phenomenological in its approach to data collection, analysis and presentation.

BACKGROUND TO THE STUDY

Interest in this study has evolved over a decade of nursing practice in a variety of ICU settings and subsequent exposure to a huge range of nursing approaches and responses to the presence and involvement of family members with the patient. The family are not acknowledged or measured by management as part of hospital admission or bedstate statistics yet can be extremely demanding of nursing time and expertise. If an institution aims for truly holistic patient care, then the nursing requirements of the family as well as the patient must be acknowledged and valued as a legitimate part of nursing work.

Since the 1970s, the ICU nursing literature contains acknowledgment of the importance of the family. Moulter (1979) presented the Critical Care Family Needs Inventory (CCFNI) which has been used extensively as a tool to rank family needs and compare families' and nurses' perceptions of family needs in a range of studies. Leske (1986) claims that the ability to assess and intervene to meet the needs of families may have a positive effect on the outcome of the critically ill patient.

The contribution of this needs based work is acknowledged, particularly with regard to recognising that the family, in its own right and independently of the patient, has a requirement for and can be assisted by nursing. Identifying family needs is an important step in determining the nature of nursing interventions required.

Needs-based research concerning families in ICU has predominantly used quantitative approaches. This has been extremely informative and undoubtedly contributed to positive changes in nursing practice including the introduction of more liberal ICU visiting policies. However, this type of research has not been designed to specifically provide a description and capture the essence and complexity of the nature of nursing practice with families.

No broad description of nursing practice with families in ICU has been found although the needs-based literature gives some insight into the importance of interactions with the family. My own experience and discussions with ICU nurses lead me to believe that nursing the family is a vital and sometimes extremely time-consuming aspect of ICU nursing practice. When a patient dies, the family's perception of those last few days or hours can impact significantly on them for a considerable time after the death. This directly influences their ability to resume their usual roles within their own family and wider society in general. Nurses are in the privileged position of working with the family during the time their relative is dying and can significantly influence how that time is perceived by each family member for the rest of their lives.

It is therefore important that the process of nursing the families is described to legitimise this aspect of ICU nursing as essential and worthwhile. Nursing the family cannot be quantified or measured. This makes justifying time to nurse the family extremely difficult in a health care world that increasingly requires measurable outputs and results. Through indepth description of the nursing role as provided by ICU nurses themselves, the human aspects of recognising and supporting others in a combined professional and personal capacity can be exposed as valuable and worthy of health care resources.

STRUCTURE OF THE THESIS

This thesis contains ten chapters. Chapter One, the Introduction, has presented

the background, purpose and justification for undertaking a study exploring nursing the families of people who die in ICU from a phenomenological perspective. The ICU environment, nursing in ICU and the human dimension of ICU are explored in Chapter Two. Narratives, the nursing literature and the writer's personal experience of nursing in ICU settings are used to set the scene and craft a contextual backdrop for the study.

Chapter Three reviews the philosophical and methodological underpinnings of phenomenology and gives an overview of the phenomenological approach taken in this study. The history of the phenomenological movement, Heideggerian phenomenology and hermeneutics are explored from a philosophical basis. The relationship between nursing and phenomenology is described. Van Manen's (1990) approach to phenomenology is outlined and new phenomenology discussed.

The specific design and features of this study are described in Chapter Four. The aim is stated and a review of literature related to the family in ICU undertaken. The purpose of the study is described. Participant procedures including recruitment of participants and the selection of sites are outlined. Methods of data collection and analysis are described along with discussion concerning the trustworthiness of the process and outcome of the study. Ethical issues and procedures are identified.

Chapters Five presents the Research Outcome – Optimising the Human Experience. The phenomenon is described and the underlying rationale of the process of optimising the human experience is discussed. Chapters Six to Nine present the key strategies and domains that enable this phenomenon to occur. In these chapters excerpts from the participants' interviews are integrated with reference to nursing and phenomenological literature to provide ongoing interpretation and discussion of the data.

Chapter Ten reviews the findings and contribution to knowledge of the study. The limitations are acknowledged and recommendations for nursing practice and further research are made.

SUMMARY

This chapter has provided a brief introduction and overview of the study. The background to the study is outlined and an introduction to the structure of the thesis provided.

CHAPTER TWO

SETTING THE SCENE - NURSING IN THE INTENSIVE CARE UNIT

Caring for Sarah was fairly routine, but caring for her family would prove to be one of my greatest professional challenges.... A searing pain gripped my heart, and I was again lost and adrift in pain and confusion. I could not speak, could not help. I could only stand behind this boy, stroking his head, feeling joined with him in his agony, one huge sadness, one huge incalculable loss. In this world of pain, we were one (Likins, 1994, p.54 - 55).

Likins (1994) in the exemplar from which this quote is taken, provides a poignant account of her interactions with the children of Sarah, a dying patient. Despite her 11 years experience as a critical care nurse, Likins finds the situation places a huge personal demand on her as she attempts to strike a balance between empathy and professional distance. She crafts a powerful narrative to tell of her experience with this family and the emotions it arouses in relation to the death of her own father in ICU when she was a child.

Johnson (1992) speaks of her experience working with the parents of a dying 11 year old girl:

So much happened that day between the parents and myself: too much to go into. I went home exhausted but happy, feeling that I had made a difference and that somehow they would see the time in ICU as positive, even in such tragic circumstances (p.42).

As the above excerpts demonstrate, ICU nurses share some of the most moving, precious and intimate moments with the families of dying patients. They are aware of the huge impact and major life changes that will be the outcome of the dying process for the family members. The nurses' own words express a feeling of something good coming out of a tragic situation for one, the shared

helplessness, suffering and pain for the other. This is their lifeworld of ICU nursing.

THE INTENSIVE CARE UNIT

ICU can be an exciting, challenging, rewarding, stimulating and rapidly changing environment in which to work. It can also be frustrating, boring, tragic, sad and physically and emotionally exhausting. Nurses working in this area often become deeply involved with patients and their families who are facing life-threatening crises. In most units, patients are nursed on a one-to-one basis and there may be policies requiring a constant nursing presence at the bedside of ventilated patients. This sharing of time and space sets a scene where personal and family intimacies that would often not be discussed with outsiders are disclosed to the nurse. A range of diverse, intense emotions such as sadness, grief, anger, relief, frustration and bitterness may all be seen in a short space of time.

Cooper (1993) describes the highly technical ICU environment as an alien world to the patients and families who face it. However, for the ICU nurse, this setting becomes the familiar reality of their lifeworld of work. Nurses must remember that their familiar, everyday work environment does not fit within the realm of ordinary experience for the people for whom they are mandated to care. Cooper (1993) states:

Nowhere is the paradoxical nature of the relationship between technology, an offshoot of science, and care more evident than in the microculture of an ICU, where the dominance of technology renders many experiences of care invisible or at best obscured. ICUs are inescapably distinguished and defined by technology (p.24).

ICU nurses are therefore challenged to amalgamate the scientifically advanced, technologically demanding environment with the need to feel and demonstrate a genuine human caring and concern for patients and families.

Most ICU nurses will have some memories of their early encounters with the environment as outsiders. They remember seeing relatives anxiously waiting

outside the unit, looking expectantly to any passing nurse in uniform who may have information about their loved one; the closed unit doors and frosted windows a reminder to all that one must have permission to enter this alien world. Even staff from other areas of the hospital may pause before entering, uncertain if the 'Staff Only' sign excludes them. The intercom or telephone on the wall provides the only link to the nurses who answer and perhaps respond that they will be out in a few minutes or "as soon as we can" to "let the family in". That few minutes so easily stretches to half-an-hour, every minute an eternity for the waiting family.

Efforts are made to disguise the clinical, sterile world - perhaps a painting of a garden scene or mountain lake, dried flower arrangements minus the potential pseudomonas of fresh flowers, brightly coloured helium balloons with "I love you" or "Get well soon" messages written on them. These attempts to humanise the environment at first go unnoticed amid the vast array of equipment, a stark reminder of the primary purpose of the unit - to save the life of a loved one facing a life-threatening event.

The sights, sounds and smells are unfamiliar. A row of beds, each containing a person, yet which person? Usually, all that can be seen is a face and head perhaps distorted by injury, but almost always lacking colour and obscured by a large tube in the mouth, a smaller tube in the nose. Each bedspace is a self-contained unit in itself. Most of the patients are not moving, each is attached to cardiac monitor - for the relatives a quick glance to check the line displayed on the monitor is not straight, provides some very temporary relief! A red glow from the finger, toe, earlobe or nose signals the presence of the pulse oximeter. Numerous intravenous lines and bags hang at the bedhead and a urinary catheter is visible below the sheet. This equipment, although familiar to a health professional, provides reinforcement for the family of the gravity of the situation.

The rhythmic psst, psst ... psst, psst of the ventilator disturbed by the shrill of an alarm causes terror in the eyes and being of the family. The nurse responds, silencing the alarm. Chances are, that like most alarms, just a small adjustment is required yet at this point for the family, any alarm signals disaster and can mean 'the end'. These are tools for the ICU nurse yet, for the relatives, they are reminders of the complete and utter lack of familiarity with the setting, and lack of control that they have over the patient and their own destiny at this point.

ICU is a highly technical, alien environment but amongst the technology is a person who is a precious and significant part of the lives of others. Whatever has happened to cause admission to ICU and whatever the outcome of treatment and intervention, the lives of all involved will be irreversibly changed.

WORKING IN ICU

ICU is one of those places where nurses choose to work. In my own experience as a student and newly registered nurse in New Zealand provincial hospitals in the early and mid-1980s, the ICU nurses were always viewed with some kind of awe. A lot of people wanted to work there but it seemed you had to prove yourself as a really 'good' nurse before you would be considered. They seemed to be quite an exclusive group. The ICU nurses were part of the Crash Team and often coordinated resuscitation on the wards even when doctors were present. Junior doctors would seek advice from the ICU nursing staff about medical matters concerning ward patients in the afternoons and weekends before they phoned the consultant. There were also delegated medical tasks that ICU nurses could do such as taking arterial blood gases and performing IV cannulations - those of us working in the wards did not have this technical expertise. Everyone knew who the ICU nurses were, failing all else you could identify them in the corridor or staff cafe by the stethoscope draped around their neck or the cardiac ruler protruding from their pocket. They were the 'hot' nurses, the ones who really 'knew their stuff'. The picture was very much that of the technical expert who possessed a huge range of skills and a vast repertoire of knowledge.

In New Zealand, most nurses applying to work in ICU have a background of some years' experience in surgical and medical settings. Although some units have employed recent graduates, this is not common practice except in unusual circumstances. The new ICU nurse is confronted with a huge challenge in terms of becoming familiar with a different working environment. New equipment, monitoring devices and alarms may be completely unfamiliar. Working with critically ill, unstable patients and the policies and procedures of the particular institution may demand a different approach to nursing than working on a general medical or surgical ward. New skills have to be learned. This will

require a period of re-adjustment for novice ICU nurses who may have been experts in their previous practice settings.

Even the most experienced ICU nurse would not attempt to predict how any person will respond to their first actual bedside encounter with their family member in ICU. The admission may have been arranged so that the family has some warning and time to prepare. Other times the admission is sudden and unexpected. Some relatives will stand and stare, paralysed, unable to speak or move. Others will want to touch or hold, maybe seeking the nurse's permission, maybe not. Some will express relief at actually seeing for themselves that their family member, no matter how ill, is still alive. Some will be frightened, some will cry, some will faint. Whatever the reaction, the nurse is party to seeing pure, raw human emotion. A person may want the nurse to support or hold them; they may want their grief, relief or whatever it is they are experiencing to be private. They may need time and space to absorb and understand the complexity of the situation and their own emotion.

Many nurses employed in ICU become extremely skilled at working with families to minimise the potential trauma of that initial encounter with the patient while also recognising the immensity of that task. Often it is a matter of living through and accepting the initial reactions. With each subsequent visit, information is repeated, and the family become accustomed to the sights, sounds and smells. The nurse can see the confidence of the family grow as the environment becomes more familiar and maybe even predictable to some degree.

Unfortunately, the confidence and ability to work with acutely distressed family members is not something that comes naturally to every nurse working in ICU. Benner (1984) identified levels of competence in nursing practice which can be easily recognised in the ICU environment. The novice ICU nurse is confronted with the need to develop technical mastery and new skills in order to maintain patient safety at a physiological level. The unfamiliar alarms and equipment take priority over the emotional needs of the patient and family. This does not mean that the nurse does not feel empathy for the family, it is just a stage on the path to competence in ICU nursing. Patient safety at a physiological level is inevitably a conscious priority initially for the novice ICU practitioner, and the nurse may not be able to cope with demands beyond that. As experience and confidence are gained, a broader perspective on the ICU environment is able to

be taken. The patient's family, other patients and the workload and demands of the rest of the unit are able to be considered to a greater degree. The rules that ensure basic safety standards are maintained are able to be viewed in a more flexible context. The nurse feels confident and comfortable with the vast range of specialised procedures and protocols. Although the significance and importance of technology in the intensive care setting is acknowledged, it tends to become to be seen as only a part of a much wider environment.

This heightened awareness leads to a reawakening of the actual human dimension of ICU nursing.

DEATH AND DYING IN ICU

As stated, admission to ICU often comes with little warning or time for preparation for either the patient and family. Patients may be admitted, because of a deteriorating physiological state or the development of complications, from a variety of areas such as other hospital wards and departments. A number are admitted via the Emergency department (or equivalent) where an acute medical crisis or accident has occurred outside the hospital setting.

The sudden, unexpected nature of admission can be perceived by the patient and family in a variety of ways. For some, it is interpreted as an indication of the seriousness and life-threatening nature of the event, leading to increased anxiety, fear and dread. For others, admission to ICU may be perceived with relief in the knowledge that all technical and medical expertise that could possibly be required is available. Feelings of guilt may be associated with the reason for admission. The immediate reactions and responses of the family will be greatly influenced by how they perceive the admission and the consequences.

From a nursing perspective, there is sometimes little warning and time for preparation for new admissions. Experienced nurses will often say they know as soon as they arrive on the unit they feel what the duty will be like before they actually see the patient, families or other staff. Other times the duty may start off quietly and orderly; in the space of an hour that situation can dramatically change due to new admissions or a sudden deterioration in the condition of a previously stable patient.

When a patient is first admitted to ICU immediate efforts are directed at life-saving interventions or establishment of some sort of physiological stability. Psychological and emotional needs of the patient, let alone the family, are often not able to be a priority at this stage.

At some point contact between the nurse and the family is made. ICU nurses see and respond to a huge range of reactions to the admission of a family member. Some relatives express strong emotions immediately. Others seem numb, unable to comprehend the dramatic, unexpected turn their lives have taken. Although it can be difficult for the nurse to know how to respond when this first contact is made, it is important that some sort of rapport is established as quickly as possible. ICU nurses do not necessarily ever get to know the person who is the patient because they may be unconscious, sedated or have suffered a cerebral event. Through stories and discussion with the family, a picture of the type of person the patient is grows and develops. The body that is the patient becomes a person, a human being.

Death in ICU, like admission, may be expected or unexpected. The dying process may take weeks or only minutes. Nurses may have had time to develop a deep, intense relationship with the family, and sometimes the patient. They may genuinely like them as people and feel a deep sense of failure or loss as it becomes evident that the patient will die. The nurse may be dealing with personal feelings of grief, loss and sadness while also having a professional responsibility to support the family and care for the patient.

In some situations, a rapport is not developed. The nurse may be left with feelings of dissatisfaction and failure to reach out to people at a time of great suffering and loss. In other circumstances, the nurse may feel that despite the tragedy of the situation, everything that could have been done was done. Despite the sadness a deep sense of satisfaction is felt.

Death fits within the range of normal outcomes of ICU admission, and nurses work with this knowledge. Death is part of the lifeworld of ICU nursing. Nurses find that, day after day, tragedy is part of their lives as they see the pain and suffering that death of a family member brings. A reminder of the fragility of human existence is ever present - that could be their mother, their father, their husband, their wife, their child, or their friend. What makes ICU nurses want to

face this sort of tragedy day-after-day, month-after-month, year after year? Perhaps it is best answered in the words of the nurses themselves:

I felt sad, tired, and child-like. With the support of good friends, I was able to finish the day. The experience left me exhausted and weak, yet cleansed and renewed as well (Likins, 1994, p.55).

We not only provide emotional support for the patient's family members during the period of hospitalisation, but also for how they are going to view the situation for the rest of their lives (Johnson, 1992, p.42).

SUMMARY

ICU nursing is not only about technical knowledge and mastery of lifesaving interventions and skills. Whatever the outcome, on the most basic human level ICU nursing is about sharing a special journey that is of deep significance in the lives of those involved.

This chapter has set the scene of ICU nursing. The environmental features and working environment have been described. Each ICU will have its own unique features. However, in every unit the stark reminders of technology and the life-threatening reason for admission will be present. For the staff who work in ICU, death is a relatively normal part of their work. For the family of the person who dies, that day will be deeply significant and vividly present in their memories for many years to come.

CHAPTER THREE

PHENOMENOLOGY: PHILOSOPHY AND METHOD

This chapter is presented in three sections which seek to discuss phenomenology as a philosophy; phenomenology as a method; and the philosophical and methodological influences of phenomenology on this study.

Phenomenology as philosophy outlines the history of the phenomenological movement, and prominent scholars of the Preparatory, German and French phases are presented. Heideggerian phenomenology and hermeneutics are introduced with reference to the underlying philosophies and beliefs that underpin this study. The relationship between nursing and phenomenology is explored.

Phenomenology as method discusses the variety of methodological approaches to the conduct of a study that can be taken. Van Manen's (1990) suggestions for approaching a phenomenological study are specifically outlined to introduce methodological features underpinning this study. The recent publication of Crotty's (1996) critique of the nursing approach to phenomenology is discussed and his use of the term 'new phenomenology' is linked to this study.

The final section of the chapter summarises the phenomenological philosophical and methodological underpinnings of this study. It is considered that this study could best be described as New Phenomenology informed by Heidegger, hermeneutics and van Manen.

PHENOMENOLOGY: THE PHILOSOPHY

HISTORY OF THE PHENOMENOLOGICAL MOVEMENT

Phenomenological research is the study of lived-experience. Its purpose is to seek a fuller understanding through description, reflection, and direct awareness of the many facets and integral meanings of a phenomenon ... Phenomenology begins with human experience (Wilkes, 1991, p.232).

The term *phenomenology* is derived from the Greek words *phainomenon* meaning 'appearance' and *logos* meaning 'enquiry' (Walters, 1995a). Phenomenology is a branch of philosophy that was first introduced in the later part of the nineteenth century by the Viennese philosopher Frank Brentano (1838-1917). Spiegelberg (1969) uses the term 'movement' to trace the development of different schools of phenomenology. There are diverse views on epistemological and ontological questions within and between these schools. Spiegelberg describes different types of phenomenology, which are not mutually exclusive but are unified in the purpose of seeking to provide a grasp of phenomenological understanding that is full and deep. Spiegelberg (1969) and Cohen (1987) outline the history of the phenomenological movement and divide it into three phases: Preparatory, German and French.

In the Preparatory Phase the most influential philosophers were Brentano and his first prominent student, Carl Stumpf (1848-1936). Brentano's contribution included acknowledgment of the value of inner perception or awareness of one's own psychic phenomena as opposed to unreliable introspection. Brentano sought to find a characteristic that would separate psychological from non-psychological, or physical, phenomena (Spiegelberg, 1969). This was developed into the concept of intentionality which became basic to all later phenomenological analysis. Van Manen (1990) interprets intentionality as implying an interconnectedness of the human being to the world. Stumpf's contribution to the phenomenological movement was his contention that knowledge could be derived from the analysis of empirical material. He is attributed by Cohen (1987) as demonstrating the scientific rigour of phenomenology. The work of both Brentano and Stumpf was linked closely to developments in the discipline of psychology.

The German phase of the phenomenological movement was dominated by Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976). Husserl was, and is, considered to be the central figure and primary philosopher of the phenomenological movement despite the differences in his philosophy at various stages of his life (Cohen, 1987). Husserl was originally a mathematician and his work over the years shifted its balance. Initially he placed an emphasis on the objectivity of mathematics but later moved to a position where subjectivity dominated his philosophy and was seen as the source of all objectivities. A student of Brentano, Husserl shared a vision of phenomenology

as a rigorous science. This idea of rigour involved making sure of basic concepts (Cohen, 1987).

Husserl aspired to a philosophy without presuppositions. His underlying philosophy was epistemology or theory of knowledge. Cohen (1987) identifies two important concepts to emerge from the work of Husserl. The first, *intersubjectivity*, declares that plurality of subjectivities makes up a community sharing a common world, that is the intersubjective world. The second concept, *lifeworld* (*lebenswelt*) refers to the everyday world we live in, or our lived experience. This is not necessarily accessible in our “natural attitude” because of the taken-for-granted attitude of what is familiar to us. Phenomenological study, through deep reflection, provides access to the nature of what really surrounds us. Husserl considers a process of phenomenological reduction facilitates the process of reflection. Phenomenological reduction has been developed and is what is now referred to as bracketing.

Heidegger, although an established scholar, became Husserl’s assistant. Where Husserl’s major concern was with epistemology, Heidegger’s primary emphases were on ontology (the nature of being) and time. Heidegger developed and refined Husserl’s work with existentialism and is credited with the development of existential phenomenology. He placed emphasis on the role of context in a situation. His ideas support the notion that the meanings that are assigned to experiences are generated from ourselves and particular situations. These ideas were influential in the development of the French Phase of the phenomenological movement. Phenomenology in Germany is considered to have ended during the Nazi years and Husserl’s papers were transferred to France.

The prominent scholars in the French Phase of the phenomenological movement were Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961). The French philosophers developed the philosophy and science of existential phenomenology. Cohen (1987) considers the French approach to phenomenology as more literary than the Germans. Sartre was a novel, playwright and critic who was more concerned with the practice of phenomenology than its theory. He, among others, views phenomenology as an alternative to established scientific research methods.

Merleau-Ponty, a personal friend of Sartre, was more scholarly and concerned with science. He sought to demonstrate that a science of human beings was possible and saw perception as a key feature. In his book *The Phenomenology of Perception*, Merleau-Ponty contrasts the results of examining perception using positivist and phenomenological approaches. He demonstrates that phenomenology provides additional knowledge (Cohen, 1987). This provides a convincing case for the importance of considering a person's subjective experience rather than focusing solely on objective facts. Merleau-Ponty's work proposes that although the actual physical body provides existence in the world, perception and awareness are expressed through consciousness. Body and mind are unified, not separate entities, and are interconnected with the world.

Cohen (1987) briefly mentions the parallels between the phenomenological movement and developments in the clinical practice and approaches used by some therapists, particularly psychologists and psychiatrists. The value of recognising and understanding the reality of an individual person rather than only knowing the 'facts' or 'theories' concerning their condition was emerging. Phenomenology was providing a means where this valuing of individual experience could be legitimised and recognised within scientific and academic frameworks.

HEIDEGGERIAN PHENOMENOLOGY

Heidegger's work on the nature of Being has influenced this study in terms of the philosophical position on what it means to be human. Heidegger (1962), in his book *Being and Time*, shifts the philosophical focus of phenomenology from epistemology to ontology. He uses the term *Dasein* or 'being there' to seek the meaning of Being, the focus of his lifetime work. Heidegger developed hermeneutic phenomenology as a philosophical approach to uncover the meaning of Being for human beings. He considered Being had been trivialised in past philosophical approaches. These were seen as essentially reductionist, objectifying and Cartesian in origin with the self being seen as subject, and the world or environment as object. Being is the most universal concept in Heidegger's phenomenology and is a fundamental term of the research process. Heidegger (1962, p.29) states "Being is always the Being of an entity." In this context, Being of something means to inquire into the nature or meaning of that phenomenon (van Manen, 1990).

The following understandings of Heideggerian phenomenology are considered relevant to this study, and have been taken from Heidegger (1962); Reeder (1988); Munhall (1989); Wilkes (1991); Walters (1994a, 1995a) and Koch (1995a, 1995b). Although Crotty (1996) considers there is scope within Heidegger's work for differing interpretations of a wide range of issues, he is critical that the understandings offered by nurse researchers do not demonstrate that they have emerged from interaction with Heidegger's thoughts and texts. Although Crotty's critique is acknowledged, the perspective taken for this study is a snapshot of my understanding at this point.

The Heideggerian view of phenomenology is based on an existential perspective that is, in terms of understanding what it is to be human, a person cannot be separated from the world and the context in which their life is lived. To be human is to be shaped by previous experiences. Language, cultural and social practices embody and shape meaning and the possible interpretations of these practices. Heidegger considers that nothing can be encountered without reference to a person's background understanding. Every encounter will be shaped and interpreted based on that person's background in its 'historicity'. What has come before in life influences interpretation and meaning of everyday experiences and events.

Being-in-the-world refers to the way people exist, act or participate in their world. The idea that it is possible to bracket, 'being-in-the-world' while also casting aside previous assumptions and beliefs, is rejected. Heidegger considers the person constitutes and is constituted by the situation. The term *Dasein* emphasises the importance of the situation in making sense of human reality. According to van Manen (1990), *Dasein* refers to that entity or aspect of humanness which has the capacity to wonder about its own existence and inquire into its own Being.

In Heidegger's emphasis on ontological-existential questions of being, the focus is on the way in which we understand. Understanding is seen to be situated within the context of daily life. Heidegger rejected some of the beliefs of his teacher Husserl. Husserl considered himself to be a positivist and his phenomenology has been viewed as part of a Cartesian view with its basis being an extraction of consciousness from existence. Heidegger's Hermeneutic Circle describes the structure of understanding and the structure of

understanding of Being. This concerns the relationship between the parts and the whole. Our language and history give us a pre-understanding of the whole through which we understand the parts of the whole. Understanding parts of the whole influences and informs the understanding of the whole. This is a circular and ongoing process.

Heidegger believes there is no such thing as an uninterpreted fact. In accordance with this, the final interpretation in research using hermeneutic phenomenology is always considered tentative. He considers that meaning cannot be neutral and inevitably the interpreter will be influenced by pre-existing personal beliefs, expectations and meanings that exist as part of living in and experiencing the world. It is not possible to completely cast aside or bracket pre-existing understanding. Interpretation of a text is to come to understand the possibilities of being that are revealed in that text. Heidegger rejects the positivist notion of an absolute truth. Van Manen (1990) considers that phenomenology describes *possible* human experience. The experience of that experience is not necessarily universal which is also congruent with the notion of no absolute truth.

HERMENEUTICS

In ancient times, hermeneutics was the term used to describe the interpretation of biblical texts, and the term has been used in a general sense to describe the science of interpretation. Modern hermeneutics as the phenomenology of existential understanding has been developed in the works of Heidegger and Gadamer. In their work, hermeneutics is described as an encounter with Being. The relationships between language and interpretation, history, existence and reality are raised in relation to Heidegger's notion of Being-in-the-world (Allen and Jensen, 1990).

The other major focus of present-day hermeneutics, is as a system of interpretation. This is where written text has been transcribed from spoken word, or actions and behaviours have been described in writing. The purpose is to make clear or make sense of the particular object of study from those transcriptions. Modern hermeneutics is therefore concerned with describing and explaining human phenomena such as health and illness, as described in text, to

achieve understanding through interpretation of that phenomena (Allen and Jenson, 1990).

Koch (1996) explains that Heideggerian phenomenology is sometimes described as existential phenomenology and, following Gadamer's work in the 1970s, as philosophical hermeneutics. Gadamer, who was a student of Heidegger, is regarded as the central figure in philosophical hermeneutics. His work extends Heidegger's existential ontological exploration by placing an emphasis on language.

Hermeneutics is a method for studying human beings that flows out of the Heideggerian view of person. The primary source of knowledge is practical, everyday activity. Human behaviour, in text format, is studied and interpreted so that the hidden or obscured meaning is uncovered. The meaning is often obscured because it is so pervasive and taken-for-granted that it goes unnoticed (Leonard, 1994).

Hermeneutics is the method of analysis that human beings use in an everyday way to make sense of their world. This is extended to the research process and impacts on the role of the researcher. Emden (1991) describes hermeneutics as an extension of the phenomenological method that provides one way of finding multiple expressions of meaning or interpretation. There is a presupposition that understanding will be shaped by previous knowledge and experiences. Understanding will influence future understanding. Analysis of Being is achieved through the study of the ordinary, everyday existence of people in the world in which they live.

The Hermeneutic Circle is central to the research process and is a significant feature of the hermeneutic phenomenological approach. This describes a process ongoing movement back and forth between examination and interpretation of the parts and the whole of the phenomenon being studied. As new understandings and insights are developed concerning aspects, or parts, of the phenomenon being studied, the researcher's impression of the 'whole' changes. This impression of the whole then sheds new ideas and interpretations so that details about the parts are refined, which impacts on the view of the parts and so on. Koch (1995a) suggests that rather than this being truly 'new' information, a modification of understanding occurs.

One of Heidegger's main contributions to views of philosophy and science is to show that there is circularity of understanding. The Hermeneutic Circle is ontological as well as being epistemological and methodological. Packer and Addison (1989) describe how when a new phenomenon is studied, we are 'thrown' forward into it. We will inevitably have some preconceptions and understanding of that phenomenon made possible by our personal and cultural history. Future possibilities are both created and limited by the present and the past. Packer and Addison state:

If we are persevering and open, our attention will be drawn to the projective character of our understanding and – in the backward arc, the movement of return – we gain an increased appreciation of what the fore-structure involves, and where it might best be changed (p.34).

Circularity of understanding is about that we understand in terms of what we already know. In hermeneutic inquiry, projection is an inevitable and essential part of understanding in both everyday and scientific terms. Packer and Addison consider that the perspective taken often becomes careful and deliberate as opposed to being detached and neutral. The researcher's relationship with the participants needs to be engaged and concerned. They warn in science and in everyday life we should not try to throw away or disregard our culture or our past. It is suggested that knowledge cannot be built, or rebuilt, from scratch, nor can it be generated in such a way that makes it suitable for all people and all times.

Koch (1996) describes Gadamerian hermeneutics including key philosophical constructs of the hermeneutic circle, dialogue and fusion of horizons. Gadamer places a greater emphasis on language within the hermeneutic circle than Heidegger. The aim is not to understand better, but differently. Dialogue is concerned with the processes of questioning and answering. Understanding emerges through open dialogue where there is a movement between question and answer. Interviews and conversations are non-directive so that participants tell their stories. The metaphor of fusion of horizons is used to describe the emerging and coming together of different views. In practical terms for a researcher, this equates to listening to others' views, and letting it influence your own view.

Van Manen (1990) states that, in a pure sense, phenomenology describes how a person orientates to lived experiences while hermeneutics describes how a person interprets the 'texts' of life. He uses the term 'hermeneutic phenomenology', a process he considers attempts to be attentive to both aspects of its methodology. This occurs because hermeneutic phenomenology is descriptive in that it attempts to let things appear or speak for themselves whilst it is interpretive in that it claims there are no such things as uninterpreted phenomena. Van Manen acknowledges the implied contradiction of these terms, stating:

The implied contradiction may be resolved if one acknowledges that the (phenomenological) "facts" of lived experience are always already meaningfully (hermeneutically) experienced. Moreover, even the "facts" of lived experience need to be captured in language (the human science text) and this is inevitably an interpretive process (p.180-181).

NURSING AND PHENOMENOLOGY

Phenomenological research has become increasingly important in nursing. Although it has some similarities with other qualitative approaches, one of the major differences is the importance of the philosophical basis of a study (Cohen, 1987). Phenomenology was formally introduced as a potential method for nursing research in 1976 by Paterson and Zderad in their book *Humanistic Nursing* (Oiler, 1986). This coincided with increasing critique of the biomedical model as a foundation for nursing due to its positivist, empiricist and mechanistic assumptions. The reductionist features of the empirical-analytic paradigm were not seen to be congruent with the holistic approach favoured in nursing. Munhall (1989) describes how nurse researchers initiating this "interpretive turn" began to think of nursing as a humanistic science with different philosophies and understandings from the natural sciences such as chemistry and biology. This led to an increasing interest in qualitative research methodologies such as phenomenology, grounded theory, ethnography, history and case study.

There are definite similarities between phenomenology and clinical nursing practice. Rose, Beeby and Parker (1995) emphasise the shared skills of

observing and interviewing along with the significance placed on interaction and interpersonal relationships that value an individual's perception of an experience. Beck (1994) expands this, seeing that observing, interviewing and interacting with clients in phenomenology and nursing enable a deeper understanding of the client's experience to be grasped. She considers the use of the self as a research tool in phenomenology equates with the therapeutic use of self in the nurse-client relationship. Taking the view of the subject as an object is not considered meaningful in phenomenology in the same way that to view the client as an object is not meaningful in nursing. Phenomenological research and nursing are both seen as social acts. In addition, the fundamental purpose of phenomenology is to describe particular phenomena within human experience which is of significant importance and value to nurses who seek to understand the human experience of health and illness.

A review of the CINAHL database 1982 - June 1996 shows 535 studies that claim to use a phenomenology as a research method or discuss issues related to phenomenology. A phenomenological approach has been used to conduct studies in a wide range of nursing practice settings, for example, nursing homes (Nay, 1995); mental health (Walsh, 1994); and oncology (Cohen, Haberman and Steeves, 1994). Phenomena of interest to nursing such as death (Johnson, 1994); comfort (Morse, Bottorff and Hutchinson, 1994); laughter (Parse, 1994) and pain (Bowman, 1994) have been explored. Some of these studies specify a particular phenomenological approach such as using the methods developed by Colaizzi (1978), Van Kaam (1966) or Giorgi (1985). Van Manen's (1990) approach is acknowledged in 78 studies. Some studies do not acknowledge any particular approach but use more generalised guidelines for data collection and analysis including bracketing, intuiting, analysing and describing as outlined by Oiler (1982).

Nursing literature in the 1980s tended to describe 'phenomenology'. Koch (1995b) comments that it is only recently that nurses have begun debating issues related to philosophical underpinnings of phenomenologies and acknowledging differences.

The terms 'phenomenology' and 'hermeneutics' tend to have been used interchangeably in the nursing literature rather than acknowledging that they contain some different philosophical ideas. Walters (1994a) states that in nursing, phenomenological inquiry focuses on the intersubjective, or universal,

experiences of individuals. The failure to distinguish between different phenomenological philosophies has led to methodological inconsistencies in some nursing studies, which claim to be phenomenological research. Crotty (1996), Walters (1994a) and Koch (1995a) emphasise the increasing importance that nurse researchers using a phenomenological approach must be explicit about the philosophy underlying their studies as differences in philosophy will have significant implications for the methodology employed. Koch (1995a) suggests that phenomenological nursing research has been identified by its techniques and procedures alone. She considers this partly due to nursing being an emerging discipline which has focused on methods rather than exploring philosophical or theoretical underpinnings.

Phenomenology continues to be a popular approach to nursing research. The similarities between clinical nursing practice and phenomenology must contribute to this popularity. Acknowledgment also needs to be made of the contribution to practice and education made by studies claiming to use a phenomenological approach. The most notable of these is probably Benner's (1984) work, *From Novice to Expert* which identified different levels of nursing practice. This work has been applied and used to inform nursing practice and education in a huge range of settings in many countries.

The situation emerging in current literature is that philosophies, approaches and methods that claim to have a phenomenological basis have much to offer nursing as a discipline. However, it is no longer adequate to merely claim that a study is phenomenological because it seeks to explain an aspect of lived experience. The underlying philosophy needs to be consistent with the methodology employed which, in turn, needs to be congruent with the researcher's own views, beliefs and the conduct of the study. If current trends continue to develop, it is likely that future phenomenological studies in nursing will pay greater attention to the underlying philosophies of the methodologies chosen by the researcher.

PHENOMENOLOGY: THE METHOD

Phenomenology attempts to serve humanity as a rigorous science. This means going to the foundations to be more clear about what basic concepts are and what they mean (Cohen, 1987).

Oiler (1982, p.178) states, "Phenomenology is a philosophy, an approach and a method." The article from which this quote is taken was one of the earlier published nursing research articles about phenomenology. Oiler goes on to describe the essential operations in a phenomenological study as bracketing, intuiting, analysing and describing. These clearly fit most appropriately within the Husserlian approach to phenomenology. What is not apparent from Oiler's discussion is that there is diversity of schools and beliefs within the phenomenological movement and the methodology employed must be consistent with the philosophical underpinnings of the study.

A number of methodological approaches to phenomenological research are acknowledged in the nursing literature and have been used to guide research studies. Amongst the most common are those of van Kaam (1966), Colaizzi (1978), Giorgi (1985) and van Manen (1990). Omery (1983) suggests the phenomenological method is the approach itself for many researchers. Rather than using identified steps, the method is data driven and emerges as the research progresses. She considers phenomenology is approaching the phenomena without preconceived expectations or categories, using a form of bracketing to define the limits of the experience, and exploring the meaning of the experience as it unfolds for the participants.

The suggestion that the methodology can emerge as the research progresses appears quite reasonable in the context that Omery describes. In reality however, nursing research using phenomenology is conducted on human beings, usually subject to the approval of ethics committees that require some form of assurance that a recognised method for data collection and analysis will be used. That method does not necessarily need to be a rigid, step-by-step guide but general principles to ensure truthfulness and protection of the rights of participants must be followed. A research proposal that fails to adequately explain methodological procedures may well be rejected outright.

For the purpose of this study van Manen's (1990) work has been used to focus the study as phenomenological in nature. Unlike Giorgi, van Kaam and Colaizzi whose methods reflect a Husserlian approach to phenomenology, van Manen's suggestions are more eclectic in origin so fit within the Heideggerian and hermeneutic philosophies that inform this study.

VAN MANEN'S APPROACH TO PHENOMENOLOGY

Max Van Manen (1990) in his book *Researching Lived Experience* proposes a set of methodological suggestions for human science research and writing. He draws on knowledge of the work of phenomenologists such as Merleau-Ponty, Gadamer, Husserl, Heidegger and others to paint a philosophical idea of the nature of phenomenological research. Van Manen's work has been used to shape this study. He believes phenomenological research is:

- the study of lived experience
- the explication of phenomena as they present themselves to consciousness
- the study of essences
- the description of the experiential meanings as we live them
- the human scientific study of phenomena
- the attentive practice of thoughtfulness
- the search for what it means to be human
- a poetising activity

Van Manen sees the research process, researching and writing as closely related and virtually inseparable. Hermeneutic phenomenological research is therefore fundamentally a writing activity. He believes that phenomenology always begins in the lifeworld and is a search for what it means to be human. Van Manen states:

From a phenomenological point of view, to do research is always to question the way we experience the world, to want to *know* the world is profoundly to *be* in the world in a certain way, the act of researching --- questioning --- theorising is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to *become* the world (p.5).

Van Manen considers that understanding of phenomenology can only be gained by actively 'doing it'. He comments that having an understanding of the intellectual topic of phenomenology is quite different from knowing it 'from the inside'. For the novice researcher, the lack of a clear series of steps in the phenomenological research process is somewhat daunting. In order to assist the researcher develop a deeper understanding of the phenomena of interest, Van Manen (1990) describes the research process as the interplay of six procedural activities. Although these are presented in a sequential order, in practice they are seen as occurring simultaneously and continuously.

1. Turning to the Nature of Lived Experience

Turning to the nature of the lived experience requires a deep thoughtfulness and questioning of the phenomena being studied. Van Manen sees the aim of phenomenology as the transformation of a lived experience into a textual expression that captures the essence of that experience. The textual expression is then a possible interpretation of the nature of that particular human experience. He suggests that the researcher should choose a topic of deep personal interest and identify this interest as a true phenomenon or something that human beings live through.

In this study, the topic holds a deep personal and professional interest for me and evolves from many years of nursing practice experience in a variety of intensive care settings in New Zealand and Great Britain. The study offered the opportunity to explore to a deeper level the meaning of what it is *really* like for nurses to live with the experience of nursing the families of people who die in Intensive Care.

As part of turning to the nature of the lived experience Van Manen describes the processes of orientating to the phenomenon, formulating the phenomenological question and explicating assumptions and pre-understandings. This is part of the personal preparedness for the researcher undertaking a phenomenological study. For this study, my pre-understandings and assumptions have been explicated in Chapter Four. Throughout the study, orientation and re-orientation to the phenomenon, and questioning and re-questioning 'what is it *really* like to nurse these people?' have been ongoing throughout the research process.

2. Investigating the Experience as We Live It

The process of existential investigation describes the methods used to generate, collect and gather data and material relevant to the investigation of the particular lived experience. Van Manen (1990) reminds us that:

All recollections of experiences, reflections on experiences, descriptions of experiences, taped interviews about experiences, or transcribed conversations about experiences are already *transformations* of those experiences (p.54).

In recognising that this interpretation of the experience has already occurred, it is the interpreted meaning that is consciously carried forward and blended with other experiences in making an overall meaning of being and life for each person. For nurses involved with the families of people who die, meanings and memories, both positive and negative, can impact on their personal lives and future professional relationships with other families.

Van Manen outlines a variety of processes and techniques that can be used to generate understanding of the phenomena being studied. It is intended that a range of sources of information be used to provide a broad range of possible insights to the phenomena exploring all modalities and aspects of the lived experience.

Van Manen suggests using personal experience as a starting point for the gathering of information. He concedes it is quite possible for the researcher to have had similar experiences to the participants in the study, and that the structure of one's own experience may provide useful clues in becoming orientated to the phenomena. Words should be traced to their etymological sources as this may sometimes provide insight to their original meaning. Biographies, journals, diaries, art, literature and poetry may also provide valuable information about the nature of the human experience. My own experience of nearly a decade of nursing in ICU settings must also be acknowledged as a significant influencing factor.

In this study the major source of information is non-structured interviews with nurses who were working in Intensive Care at the time. Van Manen (1990) calls

this 'obtaining experiential descriptions from others' and considers gathering other people's experiences enable us to become more experienced ourselves. He states:

The point of phenomenological research is to "borrow" other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience (p.62).

3. Hermeneutic Phenomenological Reflection

In conducting hermeneutic phenomenological reflection the researcher seeks to understand the meaning of the lived experience as a whole. This involves undertaking thematic analysis and determining essential themes. As part of the process of analysis, incidental and essential themes must be distinguished. Essential themes are qualities that must be present in order for a phenomenon to be what it is, if they are not present the phenomena would not be what it is. Van Manen (1990) describes the uncovering of themes through reflection to reveal meaning. He draws the analogy that:

...themes are like the stars that make up the universe of meaning we live through. By the light of these themes we can navigate and explore such universes (p.90).

Seeking the structure of meaning through thematic analysis involves a variety of activities such as uncovering thematic aspects, isolating thematic statements, creatively composing linguistic transformations, conversing and drawing on artistic sources.

In this study, the process of isolating thematic statements and uncovering thematic structures in the transcribed interviews is approached in the three ways described by Van Manen. The wholistic or sententious approach requires construction of phrases to capture the fundamental meaning of the text as a whole. The selective or highlighting approach involves reading and re-reading of the text to identify phrases and sentences that particularly stand out. The detailed or line-by-line approach involves examining each line for its significance to the structure as a whole. Using the three approaches helps

develop the movement between the parts and the whole as described in the hermeneutic circle.

4. Hermeneutic Phenomenological Writing

Van Manen (1990) describes phenomenological writing as the art of writing and re-writing. A powerful phenomenological description is one where the experience of the phenomenon is reawakened in those who have lived through that phenomenon as they read the text.

Unlike other research methods, writing is not the final stage of the research process. It is more than merely a means of communication to disseminate research findings. In phenomenology, writing is used as a tool to help develop a deep, meaningful description of the phenomena.

Van Manen considers the content of the text is integrally related to the textual quality and form of writing. He describes a variety of techniques that can be integrated in the text in order to deepen and enrich the description including using silence, anecdotes, narratives and examples. The art of writing and re-writing mediates reflection and action, provides a measure of thoughtfulness, and exercises the ability to see and makes visible the invisible. Van Manen (1990) states:

Phenomenology is like poetry, in that it speaks partly through silence: it means more than it explicitly says. Phenomenology, like poetry, intends to be silent as it speaks. It wants to be implicit as it explicates (p.131).

5. Maintaining a Strong and Orientated Relation

In maintaining a strong and orientated relation to the phenomena, Van Manen sees the need for the researcher to be involved and focused on the experience in a full and human sense. This needs to occur throughout the research process. He considers that a phenomenological text needs to be powerful thereby having convincing validity. This can be demonstrated by the text being orientated, strong, rich and deep.

6. Balancing the Research Context

Van Manen (1990) advises that the research context must be balanced by considering the parts and the whole. In an everyday sense this can be explained by the phrase a view of the total wood must be maintained rather than just focusing on the individual trees. He recommends that throughout the study the researcher remember to step back and consider the total picture and the significance of each part to that picture. This is part of the hermeneutic circle. Van Manen suggests that the researcher regularly ask:

Is the study properly grounded in a laying open of the question?
Are the current forms of knowledge examined for what they
may contribute to the question? Has it been shown how some of
these knowledge forms (theories, concepts) are glosses that
overlay our understanding of the phenomenon? (p.34)

A number of approaches are suggested for structuring a phenomenological study including thematically, analytically, exemplificatively, exegetically, existentially or the researcher can invent an approach. However, Van Manen does suggest that it may be useful to structure the report in a way that is related to the fundamental structure of the phenomenon.

As already stated these six activities occur simultaneously throughout the research process and continued to be developed as the chapters of this study were written.

THE NEW PHENOMENOLOGY

Crotty (1996) uses the term “New Phenomenology” to describe the approach to phenomenology he considers has been taken in the nursing literature. He reviews thirty nursing research journal articles and questions whether they are in fact phenomenological research true to philosophical phenomenology. New phenomenology refers to the mode of understanding and method of inquiry that has developed in North America in the last three decades.

Crotty speaks of two phenomenologies: the traditional phenomenology of the pre-dominantly European phenomenological movement and the ‘new’

phenomenology with its North American foundations which he states claims to “..establish the subjective experience of the people it studies” (p.3). He considers that new phenomenology is actually compatible with the epistemological stance that traditional phenomenology seeks to refute. Although Crotty appears to recognise that new phenomenology has contributed to and informed nursing research, he is critical of its claims to be phenomenology. The two major failures of those using this new approach to phenomenology he states are new phenomenologists’ failure to recognise the newness of what they are doing, and the failure to recognise the value of what they are not doing.

The focus of new phenomenology is to gather the subjective meanings of people or the way that people make sense of things. Traditional, or mainstream, phenomenology explicates and describes the phenomena to which people are attaching meaning. The focus of mainstream phenomenology is on what people are making sense of and what they are striving for (what might be). New phenomenology focuses on the sense that people make of things (what is). Crotty believes there is a need to distinguish between ‘phenomenon’ and ‘experience’ rather than the terms being used interchangeably. In the nursing studies he reviews, he considers the term ‘phenomenon’ is used to describe the essence or central meaning of the experience demonstrating failure to distinguish between the phenomenon and the experience. One of the consequences of this is that phenomena tend to be viewed at the level of subjective experience. According to Crotty, this is not the case in mainstream phenomenology where objectivity is seen as the source of all subjectivities. The aim of nursing phenomenology can be viewed as a quest for people’s subjective perceptions, thoughts and feelings rather than for what is objective. Mainstream phenomenology is objective in that the focus is on the phenomena themselves rather than the person’s experience of those phenomena.

Crotty comments that the worlds of applied phenomenology and nursing phenomenology are quite different and that researchers are engaged in different tasks. He states:

...nursing phenomenologists are clearly researching human subjects, not just human ‘topics’ or ‘issues’. Their interest lies first and foremost with a particular group of people and those counterparts for whom the findings will have relevance. It is in

terms of these specific persons that the research is being carried out.

Mainstream phenomenologists, to the contrary, are engaged with a phenomenon rather than with a particular group of people...any involvement with a particular group of people is for the sake of illuminating the phenomenon, not the other way round (Crotty, 1996, p.107).

Crotty considers the overall approach of nurse researchers claiming to use phenomenology focuses strongly on experience rather than phenomena. Everyday understandings of everyday experiences have been investigated. Nursing research has tended to report and emphasise addressing, describing, identifying, describing, understanding and interpreting the experiences of people in their ordinary, everyday lives in the context of exactly how the people who are having those experiences understand them.

Crotty's work will no doubt raise debate amongst nurse academics and researchers who have an interest in phenomenology as a philosophy and as an approach to research. It appears that much of his critique is well-grounded. His challenges to the interpretation of phenomenology used in nursing research and critique of the work of widely published scholars, such as Benner, should provoke response from those who have been central in the emergence of this new phenomenology. Crotty's critique specifically addresses thirty specified research studies published from 1990 – 1992. Koch (1995b) comments, there were few signposts regarding the different phenomenologies for nurse researchers in 1989. This supports Crotty's observations of studies conducted around that time. Crotty's critique is timely, and complements the views emerging, particularly by Koch (1995a, 1995b, 1996) and Walters (1994a, 1995a), that nurse researchers need to be specific about the philosophical underpinnings of a phenomenological study and ensure that there is consistency between the philosophy and methodology used.

PHENOMENOLOGY: THIS STUDY (PHILOSOPHY AND METHOD)

There is now an established body of nursing research using phenomenology although the approaches and methodologies have been questioned by some critics. In addition, in high technology, acute care settings such as ICU where this study is based, there are still those who consider qualitative methods inferior to the rigid, controlled quantitative and experimental studies. Walters (1994a) and Koch (1995a) see value in the application of phenomenology to nursing research. However, they emphasise the importance for nurse researchers to evaluate the philosophical underpinnings of the phenomenological approach chosen due to the impact that philosophy will have on the research technique used. A phenomenological approach to this particular study is seen as the most appropriate way to provide an indepth description of an aspect of nursing practice that to date appears to have been somewhat omitted in wider nursing literature.

Crotty's (1996) critique of nursing research using phenomenology raises important issues that, as already discussed, will no doubt be developed and debated further by nurse phenomenologists and philosophers. One of the major thrusts of his criticism is towards nursing's use of 'new phenomenology' and its variation from true philosophical phenomenology.

This has raised some major issues for me as a novice researcher nearing completion of a study where my understanding of phenomenology has been gained significantly through the work of nurse phenomenologists and phenomenological studies in nursing. I see the value and contribution that these nurse researchers have made to nursing knowledge despite, as Crotty criticises, the focus of their studies being the subjects and their experience, rather than the phenomenon. Although this 'new phenomenology' is being questioned as phenomenology, it has certainly impacted significantly on nursing practice, research and education through the work of scholars such as Benner and Diekelmann. From a personal perspective, I value the descriptive accounts of nursing practice generated through nursing phenomenology and believe they contribute to the wider body of nursing knowledge that informs nursing practice.

This study does fit most comfortably within what Crotty describes as new phenomenology, that is, it seeks to describe the experiences of the participants involved. The use of the term 'phenomenon' has been used to describe what is seen as the essence or central meaning of the experience as verified by the participants. This interpretation of phenomenon and the focus on experience is consistent with Crotty's description of new phenomenology. Crotty identifies understandings and interpretations of the word 'experience' in the articles he critiques. These include feelings, emotional states, perceptions, meanings, attitudes, events, personal reactions to events and descriptions of function or role. The themes that emerged in this study are consistent with those descriptions of 'experience'.

The philosophical underpinnings of this study are influenced and informed by the work of Heidegger and hermeneutics. Van Manen's (1990) description of phenomenology and suggestions for conducting a phenomenological study have been followed. With respect to Crotty's critique, I feel uneasy about claiming this study to be a Heideggerian hermeneutic study. My understanding and interaction with Heidegger's own words is somewhat limited so my interpretation of the nature of Heideggerian hermeneutic phenomenology is significantly influenced by the work of others of whom Crotty is critical. Within the limits of my understanding to date, Crotty's concerns appear well-grounded. However, my knowledge of the traditional phenomenology of the European movement is not at a level where I feel I can provide anything more than a superficial critique of Crotty's work. For these reasons, I would prefer to now describe this study as new phenomenology, informed by Heidegger, hermeneutics and van Manen.

In the previous sections of this chapter, an overview of the phenomenological movement has been provided. Specific sections dealing with Heideggerian phenomenology, hermeneutics, Van Manen's views on phenomenology and suggestions for approaching a phenomenological study, and new phenomenology follow this. These sections provide an interpretation of phenomenology that forms the philosophical basis to this study.

The significance of Heidegger's work to this study is his view of Being-in-the-world. This refers to the way people exist, act and participate in their world. Heidegger believes that a person cannot be separated from the world and the context in which their life is lived. Previous experience shapes interpretation

which is further influenced by language, and social and cultural practices. Heidegger considers a person constitutes and is constituted by the situation and that it is impossible to completely reject or cast aside previous beliefs and assumptions. In this study, the nurses describe the context of their lifeworld of work in a broad way that encompasses the meaning and impact that nursing the families of people who die has for them as professionals in a work-setting but also as human beings in the context of living their lives. In this way their descriptions are accounts of their true experience as they interpret them and as they see them in a meaningful way.

Hermeneutics has been influenced by Heidegger's work. It is a system of interpretation. In this study, written text has been transcribed from the words of the participants. For the purposes of analysis and interpretation, the hermeneutic circle has been applied in the sense of the relationships between parts of each interview and its whole. This interpretation has then been incorporated and developed in the understanding and analysis of other interviews. There is a moving between the parts and whole of each interview but also between the interviews of different participants. Themes identified have emerged, been refined and developed in the context of the words of the individual participant but then merged and presented as a possible common thread or understanding. This seeks to achieve a possible understanding of the experience. Fusion of horizons is achieved through an open approach to the emerging and coming together of different views.

Van Manen's work has informed this study in both a philosophical and practical sense. Philosophically, van Manen is somewhat eclectic, drawing on the work of a number of phenomenologists including Heidegger and Gadamer. He uses descriptions such as phenomenology being the study of lived experience, the study of essences, the description of experiential meanings as we live them and the search for what it means to be human in his attempt to capture the nature of phenomenological research. Van Manen considers that phenomenology can only be understood by actively 'doing it'. He offers a description of six procedural steps which have been used in this study to focus the study as phenomenological in nature. As these steps have been taken, my understanding of the nature of phenomenology has been refined, developed and changed through the process of 'doing it'. That understanding never seems complete, new work and ideas emerge in much the same way as application of the hermeneutic circle to research data provides continuous and ongoing

refinement of understanding. A different, but not necessarily better or more accurate, view of the true nature of phenomenology then emerges.

In summary, the philosophical underpinnings of this study are influenced by Heidegger's view of Being-in-the-world, hermeneutics and Van Manen's approach to phenomenological research. The study seeks to provide an indepth description of the experiences of the participants with the phenomenon, or essence, of the experience seen as the central experience or common focus of the participants, in this case, Optimising the Human Experience.

SUMMARY

The purpose of this chapter has been to provide a brief overview of the phenomenological movement and acknowledge the philosophical and methodological underpinnings of this study that focus it as phenomenological in nature.

The overview of the phenomenological movement traces the origins of the phenomenological movement through the Preparatory, German and French phases and prominent scholars are identified. Philosophical influences on this study, linked to the works of Heidegger and the Hermeneutic movement, have been discussed. The relationship between nursing and phenomenology has been explored to demonstrate that similarities exist between phenomenology and clinical nursing practice.

Van Manen's suggestions for conduct of phenomenological research are outlined to illustrate the approach taken for developing the report of this study. Recent critiques of the use of phenomenology in nursing are discussed and it is acknowledged that there is evidence that phenomenological research in nursing may have deviated from the traditional philosophies and beliefs of the European phenomenological movement. Use of the term New Phenomenology is discussed and related to this study.

The final section of this chapter has drawn on the earlier sections to emphasise the phenomenological underpinnings of this study, in particular the work of Heidegger and van Manen, and hermeneutics. It is acknowledged that the relationship between nursing and phenomenology, and the use of

phenomenology as a philosophy, method and approach to nursing research continues to be debated. It is considered that the philosophical underpinnings and conduct of this study are a snapshot of my present understanding and are influenced by the interpretation of phenomenology that has been applied in nursing literature to date.

CHAPTER FOUR

DESIGN AND FEATURES OF THIS STUDY

The purpose of this chapter is to outline the design, methodology and procedures used in planning and undertaking this study. The process of developing the research question and undertaking the research is described using Van Manen's (1990) suggestions for conducting phenomenological research. The Intensive Care Units and participants will be introduced and ethical issues concerning the study identified and discussed.

AIM OF THE STUDY

The overall aim of this study is, *"to provide an indepth description of the experience of nursing the families of people who die in Intensive Care"*.

It has been estimated that death will be the outcome for 15 - 25% of admissions to ICU (McKerron, 1991). Caring for the dying and their families is therefore a significant part of ICU nursing. This study aims to look at the nature of the experience of nursing the families of the patients who are dying.

THE FAMILY IN ICU - A REVIEW OF THE LITERATURE

In determining the aim and purpose of this study, a review of the literature relating to issues concerning the family and matters surrounding access to the patient including visiting policies and procedures was undertaken. This helped to situate the study within the context of the wider literature and aided in planning and defining the topic area.

In adult, acute care settings health care professionals have predominantly focused on the individual within the family (McShane, 1991). Traditionally, little attention has been paid to the psychosocial needs of the ICU patient and even less attention to the needs of their family members (Norris and Grove, 1986). Intensive Care units were developed in the 1950s - 60s in response to

advances in medical treatment and technology. The need for ventilatory assistance for victims of the poliomyelitis epidemics and the development of practices such as cardiopulmonary resuscitation resulted in the requirement for effective respiratory management and constant monitoring of cardiovascular status (Stanton, 1991; Tucker 1992).

Walters (1995c) observes that the critical care nursing research literature has predominantly used a positivist approach. There have been numerous attempts to objectify and measure people's experiences. Although these studies inform intensive care nursing practice, they do not adequately describe the everyday nature of the experience of the lifeworld of ICU from the perspective of the patient, families nor health professionals. In an everyday sense, the social, experiential, practical and taken-for-granted lifeworld of the nurses who work in ICU appears somewhat forgotten.

Perhaps the most significant theme in the nursing literature concerning the family in ICU is a focus on the nature of family needs. Identifying and acknowledging family needs has been an important step in improving the experience of families of patients in ICU. The idea of meeting family needs, or even the fact that the family do have needs, has emerged over about the last 20 years. Meeting needs is an important aspect of optimising the human experience of the family. However, when asked to describe the experience of nursing the family of people who die in ICU, the nurses in this study clearly identified that a much broader context must be explored if the experience of the family is to be optimised rather than just improved.

The first major study of family member needs was conducted by Moulter (1979). In this study Moulter identified 45 family needs, ranked the importance of different needs and assessed whether or not various needs were being met. From this work, Moulter and others formulated the Critical Care Family Needs Inventory (CCFNI). The CCFNI, with or without modification, has been the primary psychosocial measurement tool for ICU family needs assessment in subsequent research.

Moulter's findings have been replicated in a variety of ICU settings including general ICUs (Daley, 1984), and cardiac surgery units (C. Rodgers, 1983). Studies such as Norris and Grove (1986), Leske (1986) and Lynn-McHale and Ballinger (1988) utilised the CCFNI to explore possible discrepancies between

family members and staff perceptions of family needs. More recently Daly, Kleinpell, Lawinger and Casey (1994) and Lopez-Fagin (1995) have looked specifically at changes in nursing practices as a result of information gained from the CCFNI. These studies predominantly used a survey approach and consistently identified the need for hope, the need for information and the need to feel that hospital personnel really cared about the patient as the most important family needs. Information needs specifically relate to areas such as the need to have questions answered honestly, the need to have explanations given in understandable terms and the need to know the prognosis.

Identifying and acknowledging family needs has been an important step in improving the experience of families of patients in ICU. The past fifteen years has seen quite dramatic shifts in attitudes with regard to the whole issue of family presence in ICU. In 1983 Dunkel and Eisendrath remarked that the role of the family in ICU had received little attention mainly due to the fact that families had minimal access to patients and staff in ICU. They commented:

Awareness of a family's need for emotional support can be a distraction. Staff frequently voices concern that patients do not get the care they require when families are present (Dunkel and Eisendrath, 1983, p.258).

Contemporary nursing practice as described by the nurses in this study places an emphasis on the family. An essential part of nursing is ensuring that family members are valued as an integral part of the wider context, unlike the view expressed by Dunkel and Eisendrath. Changing attitudes to family presence and visiting can be exemplified by reviewing discussion of visiting policies and practices described in the literature acknowledging however that Halm and Titler (1990) report only a small percentage of nurses actually adhere to formal visiting policies. In addition, when a patient is dying, there is acknowledgment of the need to make visiting policies unrestricted and flexible (Furukawa, 1996).

Kirchhoff (1982) showed that visiting policies in the United States related more significantly to unit or institutional variables rather than the needs of patients or their relatives. She found that restrictions on the frequency of visits, length of time per visit, number of visitors and minimum age requirements for visiting were common. Hopping, Sickbert and Ruth (1992) confirm that visiting

policies remain related to traditional beliefs. Rationales for visiting policies include increasing rest or sleep for patients, more control for nurses, ensuring an undisturbed change of shift report and decreasing crowding in the unit.

Krapohl (1995) suggests that restrictive visiting policies have often been justified by nurses who believe that the patient may have negative physiological responses as a result of visiting. No recent research supports this view. Giuliano and Giuliano (1992) compare changes in heart rate, blood pressure and cardiac rhythm in response to family visits and nurse-physician rounds. No significant differences are found suggesting that family visits are no more stressful than nurse-physician rounds for 50 patients with a wide range of acuity levels. Prins (1989) examines the effect of visits by family on patients' intracranial pressure (ICP) and found no significant differences in ICP before, during and after family visits.

Tee and Struthers (1995) state that restriction of visiting remains a common practice in most critical care units even though there is a growing body of evidence suggesting this is not in the best interests of the patient and family. They remark that visiting policies are usually within the realm of nursing's authority to change and propose an individualised, liberalised approach to visiting that acknowledges needs and preferences of patients, families and nurses. The need for change is endorsed by Krapohl (1995) who comments that often visiting policies have traditionally been based on institutional need or traditional beliefs rather than the findings of scientific research. She argues strongly for a flexible approach to visiting and suggests that visiting policies be introduced to meet patient and family needs as the human element of a patient's (family's) experience becomes lost within the routine of the regimented hospital environment. Krapohl suggests that flexible, patient-centred visiting policies are a way to ensure humanistic care. Families identify the need to visit the patient as a high priority for them. Flexible visiting meets more of the family's needs, reduces anxiety and increases satisfaction.

Increasing awareness of the importance of involving and including the family throughout the time a person is hospitalised in ICU is evident. Trends in the family-orientated nursing literature suggest that family presence is important for the patient and the family members themselves. Increasingly awareness of family needs and a more flexible, person-centred approach to visiting suggest that nurses are attempting to incorporate the family in their practice.

PURPOSE OF THE STUDY

The purpose of this study is to speak with nurses about their experiences, thoughts and feelings when nursing the families of people who die in ICU. Patients in ICU are often unconscious or sedated and unaware of their surroundings. They are usually nursed on a one-to-one basis. The nurse must remain in close proximity to the patient therefore spending many hours with family members who frequently maintain a constant vigil at the bedside of their relative.

Despite the growing body of literature investigating issues concerning families in ICU, a significant proportion of the literature tends to have a focus on the 'needs' perspective (for example: Moulter, 1979; Rodgers, 1983; Leske, 1986; Coulter, 1989; Davis-Martin, 1994; Furukawa, 1996). Published work concerning nurses and nursing often reviews a particular aspect of ICU nursing such as dealing with stress or grief (for example: Slater, 1988; Beaton and Degner, 1990; Cooper and Mitchell, 1990; McKerron, 1991).

This study takes a broader perspective and explores the experience of nursing the families of people who die. It is hoped that this study will provide support to expand the perception of the role of the nurse. Nursing work with the patient, or the technology supporting the patient, is viewed as necessary and legitimate. Work with the family is not necessarily viewed in the same way – it can be seen as something that is an added bonus when it occurs. In my experience, nursing staffing levels and unit workload tend to be determined by hospital managers who rely to a significant extent on patient numbers and the physical dependency levels of the patients. This is often not a true indication of nursing workload. Treatment and interventions on a patient who requires a large amount of technological support are seen as legitimate extra factors to be considered when determining staffing numbers. The fact that a nurse may need to spend time with the family to provide assistance and to help them through an extremely difficult time is not regarded in the same way. This is an extremely important aspect of ICU work. The result can be that staffing numbers do not allow for sufficient time for in-depth interaction with the family to occur. In this study a phenomenological approach is used in order to develop an in-depth description of the experience of nursing the families. Hopefully this will provide support to legitimise and place value on the work that nurses do with families.

TURNING TO THE NATURE OF LIVED EXPERIENCE

The idea of researching ‘something’ to do with the families of ICU patients has been an ongoing thread for me over the past seven to eight years as a staff nurse in ICU and subsequently while working in nursing education. I have explored different aspects of the ‘ICU family’ throughout my undergraduate degree and masters papers. While undertaking a post-registration Intensive Care Nursing course I conducted a small research project using the CCFNI (Critical Care Family Needs Inventory) to look at nurses’ and families’ perceptions of family needs.

Over this time I have observed nursing practice with families in the units in which I worked; I have listened to how nurses describe and discuss different families and families’ reactions and behaviours while a relative is in ICU; I have talked to and worked with families as a nurse in a professional capacity and reflected on my own practice. Some experiences have been extremely challenging yet rewarding; some have been good; others not so good; some have been distressing. As a member of the wider community, I have listened to people talk about their experiences while a friend or family member has been in ICU. This has been a topic of ongoing interest for me. I feel a strong commitment to increase my understanding of this experience which appears to impact deeply on people’s lives.

Orientating to the Experience and Formulating the Research Topic

As part of a fieldwork project for a masters paper I interviewed a woman whose husband had died eight months earlier in an ICU. Despite my knowledge and interest in the family’s perception and experience during ICU admission, I was shocked and dismayed at her story.

Nurses did not feature significantly in the story but she was aware of their constant presence. What surprised me was the extent of the impact that the time in ICU had had on this woman. She was definite that she had found the time in ICU “the worst experience of my life”. She recounted the difficulty she had visiting the unit stating that “it was not my husband but a hunk of meat lying there”. Eight months after his death she still awoke with the picture in her mind of this “hunk of meat”. She freely admitted that although she considered she was coping extremely well at the time her husband was in the unit, on reflection

she realised how totally incapable she had been in attending to all aspects of living her life. She emphasised that it was the time in ICU that distressed her more than the actual death. Her unanswered questions remain and she feels she has nowhere to turn for answers despite a good relationship with nursing and medical staff at the time.

I had always suspected that ICU admission would have a significant impact but was amazed at the deep impression this experience had left for this woman who on a superficial level appeared to be going through a relatively normal grief process. How many others have been left with a similar emotional and psychosocial legacy? The depth of her anguish was only evident when conducting the interview. She was grateful for the opportunity to be able to discuss how it “really” was with someone and thanked me for the opportunity.

This stimulated a desire to look at the experience of families of people who die in ICU some time after the event. My own belief is that, during the time the patient is in ICU, people are often unable to articulate the experience, let alone understand the impact that the experience will have for them long-term or the memories that they will retain. The perception of the experience as recalled and reshaped afterwards is what is remembered for the rest of their lives. This factor appears to have received little attention in the nursing literature with most studies of ICU families occurring while the patient is still in the unit or soon after discharge.

In relation to this study, specific planning was commenced at the beginning of 1995. The initial starting point of this study was a desire to look at the family's experience. After discussion and consultation with my thesis supervisor, the need to contextualise the study in nursing and gain the nurses' perspectives was identified and became the focus for this research. The nursing perspective as described by ICU nurses seemed an appropriate starting point for a novice researcher but experienced ICU practitioner.

I was also aware of the potentially distressing nature of the topic to family members, and my own inexperience with research interviews and the phenomenological approach. Interviewing nurses about an aspect of their work seemed a less dramatic initial step than, relatively naively, approaching families to discuss a traumatic and sensitive time in their lives.

Orientating to the phenomena therefore required me to reflect on my own practice and speak informally with nurses currently working in ICU. This helped me focus on what it is like to nurse the families of people who die in Intensive Care. Nurses have not been good record keepers of the nature of their practice with patients (Benner, 1984). If the family is viewed as a vital part of the patient, and the patient a vital part of the family, then nurses need to articulate the nature of their work with families. This important aspect of nursing practice deserves to be described and recorded. The family should be acknowledged as an essential component of nursing practice, particularly if that is how it is actually viewed by nurses in practice. The nature of nursing the family should be explored and explicated so that it becomes a recognised aspect of nursing work. For this study, a focus on the nature of nursing families needed to be developed. Throughout the research process, the need to maintain this focus has been a priority, and has been regularly revisited.

Explication of Assumptions and Pre-Understandings

Early in the planning stages of the study, my assumptions and pre-understandings about the topic were journalled. At that point, the specific phenomenological approach that would be taken had not been decided. In fact I was virtually unaware of the emerging debate concerning different phenomenologies and the need to specifically articulate the philosophical basis of a study. The possibility of the need to bracket led to these pre-understandings being declared at an early stage before final planning and data collection were commenced.

Rather than using the term 'bracketing', Van Manen (1990) speaks of explicating our understandings, beliefs, biases, assumptions, presuppositions and theories. His rationale is that it is better to make these explicit, not so that they are forgotten but so that they are held deliberately at bay. He believes clearly stating our pre-understandings should help avoid these beliefs persistently impacting upon our reflections.

In this study my own experience as an ICU nurse has significantly shaped my pre-understandings and beliefs. I strongly believe the family should be valued and seen as an integral part of the care and management of the patient. My experiences working in a variety of ICUs (and CCUs) have exposed me to a range of visiting policies and attitudes to family presence and involvement

when patients are critically ill. I have had no personal experience of someone close to me dying in ICU.

The following assumptions about nursing the families of people who die in ICU are acknowledged in this study:

1. The experience of having a family member die in ICU will remain with people for the rest of their lives. Many people will make that a pivotal point of reference to remember other events in their lives. For example, 1973 is the year my father died. Christmas 1972 becomes the year before Dad died, the Commonwealth games in 1974 becomes the year after Dad died.
2. Nurses can make a significant contribution to the way family members perceive the experience of having a family member die in ICU.
3. Some nurses seem to be excellent in their ability to relate to families and place a priority on the family; others seem more focused on technology or the patient as an individual, with the family viewed as part of the wider environment.
4. From the nursing perspective, there are times when the nurse inevitably becomes involved on both a professional and personal level with the situations encountered. This can impact on life away from the workplace.
5. Families share very personal and intimate 'secrets' with the nurse.
6. 'Nursing' the family can be impaired by treatment. The need to perform and assist with life-maintaining interventions takes priority and means the nurse may not always be able to be with the family at their time of need.
7. Individual members of the nursing and medical teams can view quality of life and death differently. For example, some individuals may consistently continue to support life beyond the time that others feel appropriate. Terms such as "flogging a dead horse" are used by some staff to describe the approach of other nurses or medical staff who seem reluctant to withdraw treatment even when it becomes apparent that the outcome of treatment will be death or very poor quality of life. These different perspectives can cause frustration and lead to conflict in the work environment.

8. Nurses need the support of colleagues so that they can nurse the family. Time spent with the family needs to be respected as legitimate work so that the nurse is not constantly interrupted while with family members.
9. Families respond in different ways. Some require a constant nursing presence and rely on the nurses for a significant amount of support. Others seem more self-supporting and rely predominantly on their wider circle of family and friends for support.
10. Nurses can need breaks or time out from the intensity of working closely with a family or families. Nurses need to be able to have some input into who they will work with, for example they may request to or not to work with a particular family or may request a 'light' day after a particularly traumatic or stressful duty.
11. Nurses who are interviewed may not share my beliefs and assumptions about the importance of the family.

The hermeneutic interpretation of data is mine, and this is influenced by my own lifeworld and experiences. From a phenomenological perspective it is important to acknowledge that the findings will be based on the participants' perspectives and not my own however it is my interpretation of their perspectives. Declaration of these assumptions and pre-understandings clarifies my own position prior to commencing the study.

INVESTIGATING EXPERIENCE AS WE LIVE IT

Van Manen (1990) says phenomenological research involves establishing renewed contact with the experience. The researcher must stand among the world of living relations and shared situations while also exploring all modalities and aspects of that lived experience. In this study this was achieved through interviews with nurses who were working in ICU at the time of the meeting with the researcher.

The Setting

Nursing staff at two Intensive Care Units were approached to be involved in the study.

The first unit is located in a provincial city. The unit is a combined ICU / CCU. For the purpose of this study the nurses were asked to focus on their experiences with ICU patients and their families. The unit admits people to ICU with a range of diagnoses, with the general criteria for admission being that the patient requires respiratory support, monitoring and/or intensive one-to-one nursing care. Not all patients require ventilation. Generally the unit is able to meet the Intensive Care requirements of the hospital and community although patients are sometimes transferred to a larger unit when specialist support services are required. Patients are normally residents of the local community.

The second unit is situated in a large city. It admits only ICU patients - a separate CCU is located elsewhere in the hospital. The unit accepts patients from within the hospital as well as transfers from provincial centres. Patients can be transferred to this unit because of the range of medical specialties available in the city. Criteria for admission are generally based on medical assessment of the person's respiratory status and the need for ventilation or close respiratory monitoring. Patients in this unit often are residents of the local area but a proportion are from out-of-town and are accompanied by relatives who are not necessarily familiar with the locality, and who lack their normal support networks of extended family and friends.

Both units have a policy of allowing only immediate family to visit although a broad view of family is taken. The visiting policies of both units allow no more than two visitors at a time. This is viewed with flexibility but is dependent to some degree on the actual staff on duty. The larger unit recommends that relatives do not visit for two specified hours in the morning while medical rounds are taking place. Once again, this is flexible depending on the staff involved, particularly if someone is dying.

Two sites were chosen to help maintain anonymity of the participants. It was also hoped that this would enable a broader range of nursing perspectives to be considered. I have worked in one of the units and know a number of the staff so

the use of two sites also increased the likelihood that some participants would not have been previously known to me.

The Participants

In the early stages of planning the study, informal contact was made with past colleagues working in the ICU area to discuss the best way to approach the recruitment of participants. Formal letters were written to the senior nurse in each institution to seek support for the study prior to making formal application to the University and Regional Health Authority Ethics Committees.

The method for participant recruitment was determined by the requirements of the University Human Ethics Committee. A letter outlining the study was sent to nursing staff at each of the units. It was requested that the letter be placed in the most appropriate place for nursing staff to view.

Nurses who were interested in participating in the study were asked to contact the researcher for further information. The procedure required by the Ethics Committee was that once contact was made, the Information Sheet (Appendix One) and Consent Form (Appendix Two) were posted to them. It was explained to the nurses that, after receiving the Information Sheet and Consent Form, if they wished to participate in the study they should re-contact the researcher to arrange a time for the interview.

Most of the participants expressed that this recruitment procedure was more complicated than they would have preferred. At the time the initial letter was hand delivered to one unit, three nurses requested that the researcher make a time to meet them. The ethical requirements concerning recruitment were explained and they were asked to contact the researcher at home or work. Only one of the three became a participant and requested information about the study when meeting the researcher in a hospital corridor by chance some weeks later. The others made no further contact.

A witness was required to sign the consent form – only one nurse had this done. Reasons for not having a witness included it was a hassle, that people at home would not understand about the research so there was no point, and that if they asked a colleague their participation in the study would then be known.

Seven participants have been included in the study. There was no particular rationale for choosing this number other than that was the number from the two agencies who initially volunteered to be involved in the study. In consultation with my thesis supervisor, I decided that an adequate amount of data had been collected. Subsequent approaches have been made by other nurses expressing interest in being involved in the study but no further data has been collected.

The Data

Data was collected in a tape-recorded interview at a venue and time chosen by the participant. Participants were asked "*would you tell me about your experiences nursing the families of people who die in Intensive Care*". Interviews lasted one to two hours. Interviewing techniques such as open questioning, silence and reflection were used to encourage the participants to talk about their experiences. Most interviews developed as a focused conversation and participants used stories from their own practice to discuss their experiences. Interviews were terminated when the participant felt that had raised all the issues they considered were relevant to the research topic for them.

The researcher transcribed the interviews and transcripts were returned to the participants to change, alter or verify as they wished. The researcher contacted each participant one to two weeks after the return of the transcript to ask how they felt about it and if they wished to record any more material. Depending on the participant's wishes, a subsequent interview was held or the transcript was returned to the researcher with alterations made. Only one of the seven participants requested a second interview.

The Analysis

On completion of each interview, tapes were coded and stored securely until they could be transcribed. Journal entries were made concerning my initial impressions of the interview. Any matters concerning the conduct and flow of the interview or issues raised that may emerge in subsequent interviews with other participants were noted.

Transcription was performed as soon as possible after the interview. The time taken varied but took from two to six weeks. The decision to personally

transcribe the participant interviews by the researcher was made to increase familiarity with the content of the interviews. Transcripts were returned to participants for verification. Any alterations they wished to make were made and the altered or verified transcripts were used for data analysis.

Once all the altered transcripts had been returned by participants and the second interview conducted, data review was commenced with a concentrated review of all the transcripts and tapes undertaken to gain an overall impression. A process of reading and re-reading the transcripts and listening and re-listening to tapes to hear each participant's emphasis was carried out and repeated over several months. The sententious, highlighting and line-by-line approaches described by Van Manen (1990) to isolate themes were carried out as part of the process of hermeneutic phenomenological reflection. This process was not conducted in a step-by-step fashion but was blended with the viewing and reviewing of transcripts and listening and re-listening to taped interviews. These processes were conducted in a simultaneous way. Returning to the original transcripts and the tapes continued throughout the process of writing the study.

The process of listening and re-listening was particularly useful in that it enabled the participant's style of conversation to be heard. A sense of familiarity with the tapes was established so that when reading the transcripts, the participant's voice and emphasis could be heard. This gave a sense of being absorbed in the lifeworld of the participant as it was being described.

TRUSTWORTHINESS OF THE PROCESS AND OUTCOME

Lincoln and Guba (1985) discuss the issue of trustworthiness in qualitative studies. Quantitative studies have used measures of reliability and validity as measures of trustworthiness to establish truth value, applicability, consistency and neutrality. Qualitative research has been criticised as failing to meet these criteria and being 'too subjective'. Lincoln and Guba criticise the quantitative criteria as inappropriate for qualitative studies and propose an alternative framework for examining studies in the naturalistic paradigm. The terms credibility, transferability, dependability and confirmability are used as alternative trustworthiness criteria for qualitative studies.

Sandelowski (1986) states:

A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognise it from those descriptions or interpretations as their own. A study is also credible when other people (other researchers or readers) can recognise the experience when confronted with it after having only read about it in a study (p.30).

Sandelowski (1986) and Koch (1994) both state that credibility is enhanced when researchers describe and interpret their experiences as researchers. Methods suggested to enhance credibility include keeping a journal and consultation with participants by asking them to read and discuss the construction derived from analysis.

Transferability relates to the ability of the description generated in the study to be recognised outside the context in which it is generated and developed. Sandelowski (1986) uses the term 'fittingness' and considers this criterion is met when the study fits into contexts outside the study setting and when the audience sees its findings as meaningful and applicable in terms of their own experiences.

Dependability relates to the auditability of the study. Another researcher should be able to follow the "decision trail" that has been used by the researcher. This can be seen throughout the written research report. The same or comparable decisions and conclusions should be able to be reached given the data, perspectives and situation (Sandelowski, 1986).

Lincoln and Guba (1985) consider confirmability of a qualitative study is reached when credibility, transferability and dependability have been established. Confirmability relates to the issue of neutrality that is valued in quantitative studies. Sandelowski states that qualitative studies place a value on subjective involvement of the researcher with the participants. The life experiences, realities and meanings of the participants are emphasised. There is an emphasis on engagement rather than detachment between researcher and participants. Confirmability therefore relates to the finding of the study rather than the stance that has been taken by the researcher.

The study describes the experiences of the particular group of participants at a point in their nursing careers. The description aims to reflect their experience at that particular time. It is acknowledged that both the meaning of particular experiences and their interpretation and place within the broader lifeworlds of the participants is an evolving, changing and dynamic process. Measures of trustworthiness have been built into the data collection and analysis process. Throughout the research process, a journal and field notes have been maintained to trace the development of data analysis. As already acknowledged, assumptions about nursing the family in ICU were identified in the early planning stages of the study.

During the final stages of data analysis and writing up participants were recontacted and seen individually by the researcher. Feedback was sought on the fittingness of the domains and the central phenomenon of Optimising the Human Experience. This had been proposed in the study for the purpose of helping establishing trustworthiness. Van Manen (1990) does not consider seeking validation from participants is an essential component of phenomenological research however I felt a personal commitment to include this and it had been submitted in the research proposal that was approved by the Ethics Committees.

Each participant specifically looked at examples taken from their own interview as well as other excerpts used to illustrate themes within each domain. Six of the original seven participants were able to be contacted, the seventh has gone overseas and no forwarding address was able to be accessed. The participants contacted were in agreement with the process of Optimising the Human Experience and the idea that nursing the family could only occur and be explored within the context of the wider nursing role in ICU. Participants identified and provided valuable insights and advice to help refine and more clearly define each theme.

As a further measure of trustworthiness, an experienced ICU nurse, who had worked in one of the units in the study, was contacted and asked to read the data chapters. She affirmed that the themes were supported by the descriptions from the transcripts. In some places she suggested further elaboration to clarify the relationship between the themes and the quoted component of the participant's interview. This was valuable feedback and in several incidences

additional material from the original transcript was added to clarify analysis. She felt she could identify with the descriptions particularly within the context of the unit in which she worked. Van Manen (1990, p10) states:

The essence or nature of an experience has been adequately described in language if the description reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner.

This nurse volunteered that she could identify with what was being said and the interpretation and meaning ascribed to the nurses' words.

ETHICAL ISSUES AND PROCEDURES

Formal approval for the study was gained from the Massey University Human Ethics Committee and the appropriate Regional Health Authority Ethics Committee. As a staff member of Christchurch Polytechnic conducting research, approval from the Christchurch Polytechnic Academic Board Research Committee was also required prior to commencement of the study.

In addition to receiving the Information Sheet participants were given a verbal explanation of the study prior to the first interview. This explanation and the Information Sheet outlined the purpose of the study and what would be required of the participants, including an estimate of the time involved in being part of the study. Participants were asked to sign the Consent Form and were advised of their rights with regard to withdrawing from the study, being given access to the findings of the study and seeking further information. Issues concerning tape recording, disposal of tapes and access to copies of transcripts were discussed along with matters relating to protection of identity of participants. The Information Sheet gave the name and contact phone numbers of the researcher so that any further issues could be raised or questions answered. The address and contact numbers of the thesis supervisor and the Patient Advocacy Service were also provided should the participant have any issues regarding the conduct of the researcher or research. A copy of the Information Sheet (Appendix One) and Consent Form (Appendix Two) have been included.

Measures taken to ensure anonymity of the participants include the use of pseudonyms throughout this report and coding of tapes and transcripts. The Intensive Care Units and cities involved in this study are not identified.

Ethics Committees required that, due to what they considered to be the sensitive nature of the research topic, a process be available for participants to work through any unresolved issues that may arise as a result of the research. Although the participants did acknowledge that the interview did remind them of some unhappy events, there was no evidence of distress during the interviews. I am unaware of unresolved issues for the participants being raised as a result of the interviews or research process or if any participants sought advice from the Patient Advocacy Service. When returning their transcripts, several nurses commented that the process of talking about their experiences then reading and reflecting on what they had said was useful to them. They considered it helped them recognise and value the importance of their work.

SUMMARY

This chapter has looked specifically at the design, methodology and procedures used in the planning and conduct of this study. The aim and purpose of the study are stated. It is hoped that this project will help to describe a part of the role of the ICU nurse that can easily be overlooked but yet can impact hugely on the lives of fellow human beings. Van Manen's (1990) suggestions for conducting a phenomenological study have been explained in the context of the rationale and procedures followed specifically in this study to work with the participants and the data to develop the description. Measures undertaken to ensure the trustworthiness of the process and outcome have been discussed with reference to Lincoln and Guba's (1985) framework for qualitative studies. The process for obtaining ethical approval for the study has been explained.

CHAPTER FIVE

THE RESEARCH OUTCOME:

OPTIMISING THE HUMAN EXPERIENCE

This is the first of five chapters that present the findings of this study. The phenomenon of Optimising the Human Experience is outlined and explained. The nature of the experience is introduced and existing use of the term 'optimise' in nursing literature explored. A schematic representation of Optimising the Human Experience is included to show the organising structure that has been used for the study. The process of optimising the human experience is explained with reference to the underlying rationale of being human, in-betweeness in nursing and skilled companionship linked to the phenomenon.

OPTIMISING THE HUMAN EXPERIENCE: AN OVERVIEW

Nurses are in unique positions, as people who have special knowledge and skills about other people and their responses to illness, and because they have front row seats to watch the dance of humanity; and, as such, they have the potential to make sense of the human existence through close interactions with humans in need of care (Taylor, 1994, p.3).

Nurses not only watch the 'dance of humanity' but are active participants in that dance when interacting with patients and their families. ICU nurses recognise the difficulty and loss that family members face while a patient is dying in the unit. Nurses as both practitioners and human beings can have a huge impact on how those last few hours or days are perceived and remembered by family members. Despite the tragic nature and inevitable outcome of this time, nurses seek to make the experience as positive and memorable as possible for the family. The essence or central meaning of nursing the families of people who die in Intensive Care for the nurses involved in this study can be described as **Optimising the Human Experience**.

What I try and make for the family, their experience, is just I know that's what they're going to remember, they're going to remember a lot about it for the rest of their lives and it's going to be really important (Gay: 1 / 1).

I don't think enough people put enough emphasis on looking ten years down the track. That those relatives have to live with this whole scenario for the rest of their life and I think if you can make it so that there are some positive things come out of it then they will go away and deal with it a lot better (Caz: 1 / 7).

Nurses seek to facilitate and establish a nurturing environment that is conducive to optimising the human experience for families. Direct interactions with the family members as individuals and a collective unit are a very important part of this process. They cannot however, be viewed in isolation. In describing their experiences of nursing the families of people who die in Intensive Care, the nurses in this study revealed a much broader context for their work than merely direct interactions with the family that is necessary if the family experience is to be optimised.

The notion of optimising the human experience has not been found in the ICU or wider nursing literature. Nursing, by its very nature, is usually associated with interactions between nurse and client or clients. In reviewing the wider literature for this study, it has been found that the descriptions of the nature of the interaction or relationship between nurse and patient can be applied to the descriptions that nurses in this study use to describe their interactions with the families. This supports the idea that these families are actually 'nursed' and that professional nursing knowledge and expertise are required to optimise the human experience in an holistic way.

OPTIMISING THE HUMAN EXPERIENCE: THE PHENOMENON

The Phenomenon

In this study the term 'phenomenon' has been interpreted as the essence or central meaning of the experience as verified by the participants. Through the processes of hermeneutic phenomenological reflection and writing, **optimising**

the human experience emerges as the essence or central meaning of the experience of nursing the families of people who die in ICU. The nurses themselves do not use the term 'optimising' in the interviews but emphasise the importance of making the time that a person is dying in ICU as 'good', 'best' or 'positive' as possible. This is both implicit and explicit in the nurses' accounts of their experiences. Optimising the human experience can be viewed as the underlying purpose and goal of nursing interactions with the family. Nurses strive to make the tragic time as positive as possible and express the desire that families may be able to look back on aspects of the time as memorable and special. This wish and desire to optimise the human experience is expressed in the interviews.

I think you try and make that situation as memorable ... less traumatic as possible and you sort of take things so that at least they can go away with some sort of positive thoughts about the whole scenario so that it is not all bad really and I think the way that you deal with it is important because it either gives people something else to go away with rather than just the tragedy of the death of their loved one. Do you know what I'm saying, I've had a lot of families that I've dealt with who have been so grateful for my input because they have gone away with something positive out of the situation (Caz: 1 / 2).

... we're with people in the most traumatic, beautiful, horrendous experiences in their lives but you can actually make a difference to ... we're specifically talking about dying patients here, you can make a difference in someone's death. That's pretty amazing that you can ease someone's burden if it's only for a day. They're going to grieve this person if they really, really love them, they're going to grieve this person for the rest of their lives (Al: 1 / 16).

... the family were so appreciative of everything that went on and they could see the dips and dives that she took ... and they were just so able to work together with the unit and paediatric staff (Eve: 1 / 8).

Optimising the human experience is intended to improve the memories of the family and make the time in ICU more bearable. In turn, nurses themselves can feel an immense sense of satisfaction at a personal level when they know they have actually improved the situation in some way. Although the fact that the outcome is that someone has died, it is believed that the experience of a family member dying was able to be improved by the involvement and actions of the nurse at the bedside. This seems to contribute to the nurse knowing that this is the best possible outcome in the circumstances.

... you just feel good that you have done the best that you can for their situation (Fay: 1 / 6).

It was a special experience for me, I was so involved intimately with the woman because she didn't have any other family here (Al: 1 / 2).

The sense of knowing that a job has been well done is felt by the nurse at a personal level in the above examples. This affirms that the nurses try to make the experience as positive as possible during the dying process and immediately following death. Optimising the human experience also appears to encompass the genuine desire of the nurses to create memorable moments or episodes within that dying process for the family. These are more specifically addressed in later discussion of the themes that emerge in the interviews. Nurses describe meeting families in the community some time after the death where family members acknowledge the kindness or contribution of the nurse to their dead relative and themselves.

Being aware how much we do sticks in families' minds, you know you can meet them two years down the track in the shop and ... "Hello, you looked after my father three years ago" ... you know, that you've had a very important part to play in their loved one's death because we are faced with that every day where we work ... for a lot of people this is their first experience of death and I think that is quite difficult (Eve: 2 / 9).

A few months later I was going to the supermarket and this couple rushed up to me and they said ... Oh, we're so glad that we've seen you, you were so wonderful with our mother and you

did exactly what she would have wanted to do and she was just so comfortable at the end (Deb: 1 / 4).

Within the context of this study, the process of optimising the human experience for the family members of people who die in ICU emerges as the central essence from the participants' descriptions of their experiences. Optimising the human experience is chosen as the term to describe this phenomenon to express the way in which nurses genuinely seek to make the time the best possible in the circumstances. Although continuing to care for the patient is of vital importance, once it is acknowledged that it is unlikely that they will survive, this group of ICU nurses see that the family must be included and supported so that their memories of the situation in the last few hours or days are optimised. There is no evidence to suggest that the actual focus of nursing actions shifts from the patient to the family, but there is a change in the overall focus and nature of nursing actions once it is accepted that death will be the outcome.

Optimising the Human Experience: Definitions and Use

During hermeneutic phenomenological reflection and writing, the phenomenon of optimising the human experience emerged and evolved as the central focus of nursing and essence of the experience for the nurses. As reading and re-reading the transcripts, and listening and re-listening to the tapes was repeated, a sense that the nurses endeavoured to assist and support the family, and create an environment where the family would retain some positive memories emerged. Nurses utilised professional and personal knowledge and skills to ensure that everything possible that may improve the family's experience occurred. The term 'Optimising' was chosen to express this central essence.

In order to ensure that 'optimising' is the central essence, use of this term has been checked with the participants. Each expressed and affirmed that they felt that "Optimising the Human Experience" captured the essence of what they felt nursing the family was about despite the fact that none of the interviews actually contained the word optimising. Subsequently a short review of the use of the term optimising in the nursing literature was undertaken.

The Concise Oxford Dictionary (1990) defines *optimise* as “make the best or most effective use of (a situation, an opportunity etc.)”. This definition effectively supports the nature of the phenomenon “optimising” as has been described in this study.

In the nursing literature *optimise* / *optimising* are often used in a physiological context. Henneman, Bellamy and Togashi (1995) describe how a peripheral nerve stimulator can *optimise* neuromuscular blockade while Cooper (1990) discusses strategies to *optimise* wound healing. These uses fit within the context of *optimising* meaning making the most effective use of. In other situations *optimise* / *optimising* is used in more general context in relationship to knowledge and skills (Redekopp, 1997) and optimising patients’ well-being (Pattison and Robertson, 1996). In the coronary care setting, Nyamathi (1990) looks at coping responses of spouses and considers formulation of nursing diagnoses to develop effective interventions enables nurses to *optimise* the health and well-being of patients and their families. In this context it appears *optimise* has also used to indicate ‘making the best of’.

In the above studies it appears the term *optimise* has been used in general discussion in the context of its dictionary definition. It is not a central feature of the study or research process. *Optimising* has been used more specifically by Irurita (1992) who conducted a grounded theory study looking at nurse leadership. She identified *optimising* as the core process used by nurse leaders to deal with the core problem and achieve influence and advancement. She used *optimising* in the context of making the best of a situation and making the most effective use of all available and potential resources.

Other than using the term *optimising*, there are few commonalities between Irurita’s leadership study and this study about nursing the family. However, use of the term *optimising* seeks to capture and convey a similar meaning in both contexts. When *optimising* the human experience nurses in this study seek to make the best of a tragic situation. In order to achieve this, they endeavour to make the most effective use of all available and potential resources within the family, themselves, other health care professionals and the wider environment.

Optimising the Human Experience: A Schematic Representation

Figure One (see page 66) presents a schematic representation of nursing the family of the dying person in ICU. The phenomenon of optimising the human experience is situated at the top of the diagram to create a sense of continuous flow towards the overall essence of nursing as making a difficult and stressful experience for the family as positive as possible. The family is placed at the centre of the upper part of the diagram to emphasise their central place in this study.

Six key strategies, or themes, that concern the direct interactions between nurse and family are acknowledged. These are Being There; Supporting; Sharing; Involving; Interpreting and Advocating. These strategies are by no means an exhaustive description of the strategies used by the nurses to optimise the human experience. In the interviews with this particular group of participants, these themes emerged as common means through which these nurses sought to optimise the human experience. The extent to which any one theme takes on a greater or lesser significance appears to be context-specific. They are called key strategies because they involve direct interaction between nurse and family. Depending on the situation, they may not be any more significant or important than other strategies that are acknowledged within the domains.

Direct interactions with the family, represented by the key strategies are enabled by three domains placed at the base of the diagram. Without the use of all three domains, it is unlikely that the human experience will be optimised to its true potential. These domains represent the context within which nursing the family occurs. The domains feed in to the process of nursing the family and subsequently optimising the human experience. Each domain and its themes will be discussed in the chapters that follow. Based on the interviews, each of the domains should be acknowledged to some extent within the wider nursing team / family relationship during the dying process if the family experience is to be optimised. This section of the diagram has been left open to acknowledge there may be other aspects or domains that form the base, and support, the process of optimising the human experience that were not identified by this group of participants or were not recognised in their interviews.

Figure One shows the organising structure for the data chapters that follow. This chapter explores the phenomenon of optimising the human experience.

The next chapter deals specifically with the key strategies or themes that describe the direct interaction between nurse and family. The remaining three data chapters discuss each of the domains individually and describe the themes relevant to that domain.

OPTIMISING THE HUMAN EXPERIENCE: SITUATING THE PHENOMENON

Van Manen (1990) considers hermeneutic phenomenological research is fundamentally a writing activity. He believes phenomenology begins in the lifeworld and is a search for what it means to be human. Through the process of conducting a phenomenological study such as this, the research trail uncovers a vast volume of existing knowledge that informs the data collected and assists develop the meaning of the nature of the experience.

In this study, the work of Taylor (1994), Bishop and Scudder (1990) and Campbell (1984) supports the phenomenon of optimising the human experience. Although each of these authors view nursing and the nurse-patient relationship in their own particular way, the common link is the acknowledgment of the professional-personal blend that contributes to the nature and depth of the bond that emerges between the nurse and the family of a dying person. The professional knowledge of the nature of the patient's illness and management of the disease process, the ability to access and draw upon the wider health care system combined with working at an intimate level with fellow human beings who are confronting a major life event sets the scene for optimising the human experience. Taylor (1994), Bishop and Scudder, and Campbell each describe aspects of this process that help to explain the unique position that the nurse can fill in assisting the family while their relative is dying. The work of these authors is acknowledged in the data chapters with reference to specific strategies or themes. Their work is discussed in this section to add to the explication of optimising the human experience and contextualise the phenomenon within existing knowledge.

OPTIMISING THE HUMAN EXPERIENCE *of the* **FAMILY**

Being There
Sharing
Interpreting

Supporting
Involving
Advocating

enabled by

**NURSE
AS
PERSON**

Giving
Grieving
Balancing

**NURSE
AS
PRACTITIONER**

Attending
Preparing
Co-ordinating

**NURSE
AS
COLLEAGUE**

Affirming
Supporting
Reflecting

Figure One – A Schematic Representation of Nursing the Family of a Dying Person in ICU

Being Human

The term *human* has also been included in the descriptor for the phenomenon of this study quite purposefully. It is an attempt to capture the uniqueness and specialness of the relationship between the nurse and the family. In the interviews, nurses describe situations where they formed deep and meaningful relationships with the families of dying people. Although professional responsibilities and job descriptions acknowledge that the family should be included or updated in terms of changes in condition or the nature of procedures, it seemed that the nurses were describing something much deeper and therefore different in their relationships with the family. This will be explored in more detail in the Nurse as Person domain.

Through the processes of hermeneutic phenomenological reflection and writing while working with the data, links to the work of Taylor (1992, 1994, 1995) began to emerge with regards to the shared humanity between nurse and patient. It seems the process that Taylor describes, can be used to illustrate the nature of the relationship between the nurse and the family of a dying person in ICU.

Taylor (1994) describes the phenomenon of ordinariness in nursing. She sees this as the shared sense of affinity that people have for each other as human beings. It is a sense of human sameness that exists between nurses and patients that contributes to their connecting with each other at deeper levels. Taylor considers the nurse-patient relationship is essentially human, meaning that it embodies all the ordinary qualities of people interacting in their shared worlds.

In the context of this study, identifying the phenomenon as a *human* experience, seeks to capture that same sense of affinity in a shared world of nurse and family. The human aspect of the experience is what makes the nurse want to reach out, be there and assist the family through a particularly traumatic and difficult period in their lives. The shared sense of being human contributes to the nurse wanting to give and assist beyond what is normally asked as a job requirement. The term *human* captures the special, yet everyday, context of a shared lifeworld.

In-Betweenness to Optimise the Human Experience

In order to optimise the human experience, the nurse at the bedside is often the health professional most in touch with all aspects of the patient's ongoing condition, the treatment plans, the support plans of the wider health professional team and the family's ongoing responses and worries as the patient's condition deteriorates. It is therefore the nurse at the bedside who often takes a central role in coordinating and communicating the activities of the health team and liaising with family members in an ongoing minute-by-minute, hour-by-hour sense. This is an important role in the process of optimising the human experience.

Bishop and Scudder (1990) emphasise the "in-between" element in nursing practice. They contend that this "in-betweenness" places the nurse in an unique position with regard to making moral decisions in health care. The position is a privileged one.

The term "in-between" was previously used by Engelhardt (1985) to describe how nurses are caught between the interests of physicians, the authorities in scientific and technical knowledge, and the patient who gives the authority for health care endeavours. This situation places nurses in an ambiguous situation with regard to exactly who is authorising them to do what. Aroskar (1985) suggests that the hospital bureaucracy and the costs of nursing services as a significant proportion of healthcare expense is a third factor that results in nurses and nursing being caught in-between. Hospital administrators are challenged to ensure the cost of health care delivery remains within monetary constraints.

In this context, the in-between aspect of nursing can be viewed as one where the nurse is disempowered and the nursing function somewhat indistinct and vague. It implies that the nurse strives to mediate and find compromise but is caught between conflicting interests and ideologies. Nurses can be seen as passive recipients of orders rather than having valuable contributions to make to the situation as a result of their own specialised knowledge base and expertise. However Bishop and Scudder (1990) emphasise the nature of in-between is one of privilege rather than compromise. They explain the nurse is accustomed to working from a perspective of in-between that supports the positions of the patient, the doctor and the administrator.

A significant proportion of nursing work is undertaken from an in-between perspective and nurses become very skilled working from this position. Nurses are used to implementing physician's orders and liaising closely with medical staff concerning aspects of patients' conditions. Nurses almost invariably are the health professionals who spend the most time with patients so are therefore in the privileged position of being most intimately in tune with patients' and families' needs and requests. Nurses, individually and collectively, are also closely involved in maintaining order within the unit and patient care, and ensuring that hospital policies are followed. The in-between world of nursing is an integral part of what constitutes the nurses' role within the wider health care context.

In optimising the human experience of the families of people who die in ICU, nursing fits and extends this view of the nurse as an in-between. As Bishop and Scudder (1990) postulate, this is both privileged and positive. The nurse acts as an in-between coordinating and harmonising multiple facets and dimensions in order to optimise the experience of family members. The nurse acts in a liaising role, coordinating the interests, perspectives and wishes of the family, patient, other patients and families, medical staff, other health professionals, nursing colleagues, hospital administration and wider societal bureaucracy. If this is not done effectively, the experience will not be optimised.

The term "in-between" is not a common term in nursing vocabulary. Although the term is not used, the idea of "being in the middle" and acting as an in-between features in the interviews.

You are caught in the middle and there's very little you can do about it. It is just a frustrating situation to be in and you use your discretion... (Al: 1 / 10.)

The family though, they come to you and talk to you about what they actually want. It's up to you then to negotiate I suppose. Negotiate with the doctors to... to look after the family's needs (Bev: 1 / 2).

Things don't stop at your own bedspace with that patient (Caz: 1 / 7).

I always explain to other families in the (unit) because sometimes if a patient is in the bed next door they wonder what is going on ... (Deb: 1 / 10).

Most of us tend to give each other a lot of support ... we do support each other (Eve: 1 / 21).

The nurse as an in-between is a pertinent description to capture the multiple dimensions that make up the nursing role and goals when optimising the human experience. It describes the interactions with all the “players” who are involved when a person is dying in ICU. It appears that in order to optimise the human experience, this in-between role of nursing is very important. It captures the way the nurse acts to blend the multiple components of the nursing role to optimise the human experience. Rather than actually being acknowledged as a strategy itself within the schematic representation, the in-between role will be acknowledged within a number of themes and strategies as one of the processes that nurses use to optimise the human experience.

Skilled Companionship in Optimising the Human Experience

The blending of the personal and professional aspects of nursing is fundamental in the process of optimising the human experience. Taylor’s (1994) work on the ordinary human aspect of the nurse-patient relationship and Bishop and Scudder’s (1990) description of the nurse as in-between contribute to developing an understanding of the underlying rationale of the process of optimising the human experience. The third view that supports this blending of personal – professional is that of Campbell (1984) who describes nursing as ‘skilled companionship’. He uses the analogy of a journey to describe the nature of this companionship:

Companionship arises often from a chance meeting and it is terminated when the joint purpose which keeps companions together no longer obtains. The good companion is someone who shares freely, but does not impose, allowing others to make their *own* journey (p.49).

Although Campbell is describing the nurse-patient relationship, his description seems to capture the nature of the relationship between the nurse and the family in ICU well. He identifies four characteristics of skilled companionship.

The first is bodily presence. A good companion is able to sense the needs of another person and accommodate oneself to their idiosyncrasies. The family may be witnessing the physical and mental degradation of their dying relative's body yet the good companion will give value to this by being tender and patient. Ashworth (1990) emphasises the importance of nurses being there for patients (and families). A skilled companion is more than merely physically present. It encompasses a whole caring person who is focused with their body and mind so that care can be designed and adjusted to embrace the needs and wishes of the family in the broadest context.

Secondly, nursing is a companionship that helps the person onward. A companion helps with the hardness of the journey, looking ahead and encouraging when all seems lost. Nurses have knowledge and skills that enable them to see how the journey might be accomplished. For ICU nurses, helping the family onward may incorporate raising awareness of all possible options and opportunities that may optimise their experience. In the in-between role the nurse is able to utilise and incorporate all aspects of the situation and facilitate and, if appropriate, create possibilities that may not occurred to a family experiencing extreme stress while facing a completely unknown situation.

Thirdly, Campbell identifies the closeness of contact between nurse and patient means a costly mutuality for the nurse. He considers nursing is costly in human resources because involves a constant presence which can be difficult to sustain. Nurses may seek protection away from the patient when there are no tasks to be done. This costly mutuality is acknowledged within the domain Nurse as Person. Nurses may find working with a particular family feels beyond what with which they humanly cope. They develop ways of maintaining balance and meaning in their lives both at work and in their personal lives. In turn nurses can receive a deep sense of personal satisfaction when they know their actions successfully make a positive difference in the lives of others human beings facing loss and grief.

Finally, Campbell identifies that the commitment of companionship is a limited one, parting is an essential element when the other person journeys on with life

or to death. The nurse freely shares knowledge, skills and resources with the family for the duration of the time that the family member is dying. Contact with the family on a personal level may be maintained for a time after death after the professional obligation to care ceases. Eventually this contact becomes less frequent and usually stops. As companions who have shared a special journey, the nurse and family move on in the process of living their lives.

Using this description of the skilled companion, the in-betweenness of nursing of nursing can be seen. The skilled companion blends professional knowledge and skills with an uniquely personal contribution by the nurse as a human being sharing the lifeworld of the patient-family. It is necessary that the blending of this personal-professional occurs if the human experience is to be optimised.

PRESENTATION OF STRATEGIES THAT OPTIMISE THE HUMAN EXPERIENCE

The findings of this study will be presented in reflective – interpretive mode. Strategies and themes are presented and described. Excerpts from the interviews with nurses will be used to illustrate themes. Links are made to the literature to expand and explain the nature of each theme. Throughout discussion the need to interpret the significance of each theme in the context of nursing practice has been a central focus.

The following four chapters will describe the strategies that nurses use to optimise the human experience of the families of people who die in ICU. These strategies have been identified in Figure One.

Chapter Six specifically explores nursing the family. It will describe the key strategies that nurses use when directly interacting with family members or facilitating processes for the family that enable the human experience to be optimised. Each of the next three chapters specifically addresses one of the domains that enable the work with the family to occur. ‘Nurse as Person’ describes the way nurses must balance their own lives so that they are personally able to effectively work with people who are confronted with the impending death of a family member. ‘Nurse as Practitioner’ focuses on the knowledge and skills that are necessary to demonstrate professional competence in patient care and liaison with wider health professional circles.

‘Nurse as Colleague’ emphasises the need for nurses to support and be supported by each other so that the wider environment of ICU is conducive to optimising the human experience.

It is with the successful blending of these strategies and domains that the family’s experience is optimised. It can be interpreted that the nurse combines the personal and professional to act as an in-between and skilled companion to facilitate this process. The key strategies and domains need to be acknowledged for the human experience to actually be optimised rather than just improved.

SUMMARY

This chapter has presented the phenomenon of Optimising the Human Experience. Nurses seek to make the tragic experience of having a family member die in ICU as positive as possible. The nature of Optimising the Human Experience as a phenomenon has been described. Use of the term ‘optimising’ has been discussed in the context of this study. Definitions and use of ‘optimising’ have been explored with reference to the literature. A schematic representation of Optimising the Human Experience as developed in this study has been presented and explained. Underlying rationale are discussed to link the nature of shared humanity, in-betweenness in nursing and skilled companionship to the phenomenon.

An overview of the approach taken in subsequent chapters to present strategies and domains identified in this study as part of the phenomenon of Optimising the Human Experience has been presented.

CHAPTER SIX

KEY STRATEGIES TO OPTIMISE THE HUMAN EXPERIENCE: NURSING THE FAMILY

This chapter focuses on the strategies that nurses use when seeking to optimise the human experience for families of people who die in ICU. The nurses in this study all consider the family to be an integral part of their work in caring for a person dying in ICU. The nurses emphasise that each family has different expectations with regard to the role of the nurse and the type of relationships they form with the different nurses involved with them while their relative is in ICU.

Families come from a vast range of backgrounds and have different experiences and expectations of the health care system, health and illness. The challenge for nurses is to somehow develop a relationship with the family so that the experience of having a relative die in ICU is as positive as possible despite the overall tragic nature of the event. The impact that death will have on family members as individuals and as a collective needs to be considered and addressed by nursing staff.

Six strategies are associated with the nurses' work of optimising the human experience for the family of people who die in ICU (see Table One).

- * **Being there** describes the perception of the constant presence and availability of the nurse;
- * **Supporting** is the help and assistance given to ease the burden and stress prior to and immediately following the death of a loved one;
- * **Sharing** is the joint participation and companionship along a journey of extreme emotion and significance for the family;
- * **Involving** encompasses including the family in aspects of care and decision-making throughout their relative's time in ICU;
- * **Interpreting** includes information-giving about the patient's condition, treatment and the wider ICU environment;

* **Advocating** is where nurses seek to ensure the rights of the family are upheld with regard to access and information about their relative.

Table One: Optimising the Human Experience: Key Strategies

OPTIMISING THE HUMAN EXPERIENCE: KEY STRATEGIES
Being There
Supporting
Sharing
Involving
Interpreting
Advocating

BEING THERE

When nursing the families of people who are dying in ICU, the nurse must skilfully balance the need to be present at the bedside and the need to allow the family a sense of privacy, space and time to say their goodbyes to their family member.

The nurse attempts to create an environment where the family is aware of the nursing presence and constant availability but does not feel crowded or pressured by the close proximity that is necessary at times. Campbell (1984) describes this as bodily presence. This ‘being there’, yet giving a sense of space

and time, is acknowledged as important both while the family member is dying and in the time immediately following death.

I'd pop in and ask her did she want me to sit with her or whatever and she was just talking to him and saying goodbye, she just had a quiet half hour (Al: 1 / 4).

We eventually turned him off and all she had there was just her, and I tried to see if there was anyone else, and I sat there with her and she wanted no-one else to come in (Bev: 1 / 21).

Being there can require the nurse to be actually physically present with the family. Tucker (1992) describes time as one of the nurse's most precious possessions. When sharing time, the family can express feelings of frustration and anger. Family members and the nurse may share silence or engage in some form of quiet interaction such as discussing issues relating to the actual time in ICU or illness events, the person's life or general issues such as the weather or a topic of shared interest. Sharing silence can have a calming effect for the family in ICU where overload of auditory stimulation can easily occur (Stockdale, 1989). The sharing of space and time by family and nurse helps to create a sense of unity and common bond.

I sat with her for the whole afternoon shift (Deb: 1 / 4).

The person that can actually just sit, just sit and talk to people ... They look like they are probably only talking about the weather. Other people look and wouldn't realise that, the outsider wouldn't know how important that is (Bev: 1 / 30).

I've found that over time patients and families like to hear about things that aren't related to the hospital ... you've got to find some way of putting a hand to them and then finding what makes them feel comfortable with you ... I don't believe in pushing myself on them, I let them take their time and I don't like going up and invading their space (Deb: 1 / 2).

While 'being there' the nurse may be required to act in the role of counsellor, comforter and supporter. The nurse is constantly present at the bedside and with

each family member as they live through and experience a range of emotions as different aspects of the situation unfold and the impact of the impending death becomes a reality. The nurse is there and can hear the innermost thoughts, feelings and fears of the relative as they try to understand their situation and struggle to accept the imminent loss. The nurse may have some indication of the family member's need to talk but other times there is a more spontaneous spilling of emotions and feelings which is only possible because of the nurse just 'being there'.

Just allowing yourself to be there and provide that listening ear sometimes is all they need ... whether anything good comes out of it or whether anything else comes out of it is irrelevant. I think to just allow them that space to do that and giving them the time (Caz: 1 / 16).

... a couple of times I relieved and the daughter was able to break down and I think it was because I had been in and out and in and out. I was a new person and I was there for that half an hour and she broke down and cried about how things were and how terrible she felt (Bev: 1 / 14).

Evans (1995) believes the nurse's constant bedside presence has a positive influence on a family member's ability to cope with the tragedy of the death in ICU and to begin the healing process. He specifically addresses issues relating to brain death however his discussion is relevant to other situations where a family member is dying. Evans considers that it is the constant bedside presence of the nurse that provides the opportunity for expression of feelings and concerns while also allowing for informal questioning and discussion. The physical presence of someone with whom the family can share their grief may be helpful. Hall and Hall (1994) also emphasise the importance of the close physical presence created by the one-to-one nurse-patient ratio that is usually observed in ICUs. This ratio, coupled with the fact that 24 hour nursing services are usually provided by a small team of nurses promotes closeness and trust in the relationship between nurses and patients and their families.

Nurses describe creating a sense of being there for the family members yet actually removing themselves from the bedside area in order to give the family a greater perception of private space and time. While not actually being

physically present, the sense of being there is created by the nurse communicating or demonstrating availability for family members.

Being available ... but not too remote from them, and it is necessary to pull the curtains around them and just sort of peak in now and again but not to sort of go off and leave them, regularly check in there ... (Deb: 1 / 9).

In many cases I think people like to be left alone for periods, each family varies on this though ... I perhaps find little things to do and just go off and leave them for a bit. I think it is important that you know when to go away as well, give them plenty of time if that's what they want ... you've just got to work that one out for yourself ... I might say I'll give you a bit of time by yourselves for a while and I'll pop back or sing out for someone or whatever (Gay: 1 / 17).

Benner and Wrubel (1989) state:

The ability to presence oneself, to be with a patient in a way that acknowledges your shared humanity, is the base of much of nursing as caring practice (p.13).

The above quote is made with reference to the patient, however 'being there' is a form of presencing that also has relevance to the family with regard to a perception of the nurse being present or available. Benner and Wrubel explain the phrase "to presence oneself" is taken from Heidegger's *Being and Time*. The phrase is used to translate the German words *answesenheit* and *zugegensein* which also mean "to enjoin" or "to be accessible". Benner and Wrubel use the phrase "to presence oneself" to describe being available to understand and be with someone. This is in contrast to standing aloof or to being physically present but being preoccupied with other thoughts. 'Being there', as a theme in this study, is an extension of Benner and Wrubel's use of the term presencing as actual physical presence may exist but it is not always required.

Being there is a key strategy when optimising the human experience for families of people who die in ICU. It describes the constant availability of the

nurse even though continuous, close physical proximity may not be necessary once it is recognised and acknowledged that the patient is dying. Being there can refer to actual close physical presence of the nurse but it is more a sense of availability to listen and maintaining a sense of presence with the family.

SHARING

The shared sense of being human between nurses and patients made them as one in their humanness and created a special place, in which the relative strangeness of the experience of being in a health care setting could be made familiar and manageable (Taylor, 1994, p.25).

Taylor (1994) describes ordinariness in nursing. She acknowledges that human life is full of diversity and activity but maintains that nurses and patients share the sense of what it means to be a human being. Families and nurses are aware of their separateness in terms of 'being an ICU nurse' or 'being a family member of someone in ICU' yet there are aspects of simply 'being a human being' that create a common bond of sharing human qualities regardless of race, religion, gender, background or culture.

Sharing is the term chosen to describe the joint participation of the nurse and family through the time of extreme emotion. Walters (1994b) remarks that the lifeworld of ICU nursing is about sharing experiences in a unique way. The close contact with the family and continuous presence of the nurse means that the total experience is shared, both the positive times and the difficult and sad moments. The nurse and family develop a shared sense of being in the world together which enables an acceptance and appreciation of each other's role to emerge. Nurses recognise and respect the human traits of family members even though, on the surface, it may appear that a particular nurse has little in common with a specific family group. This is the shared sense of being human.

In working with the families, nurses share the experience of the daily routines. They are with the family and live with them through the range of emotions that they experience. In the interviews, nurses describe how they involve the family, particularly close relatives, in physical and intimate cares and how they share the family's reflections on the person's life. Facilitating an environment within

the ICU setting where positive memories are being created about the time while the person is dying is another feature of sharing the experience.

Nurses share intimate aspects of the family experience. Taylor (1994) describes how nurses and patients take turns at being speaker and listener. This enables a close relationship to be developed where each is able to speak frankly and honestly. Dialogue ensues as nurses and patients get to know each other in a day-to-day human way. The same can be said for nurses and families. Walters (1995c) uses the term 'plain talk' to describe the ordinary, everyday language that is used with the family when communicating about their relative. It is a way that nurses can comfort and allay fears of the family while demonstrating genuine concern for their well-being. In sharing everyday experiences, families may be able to relieve some of their anguish and suffering, and are able to regain their strength to face their ordeal.

In the ICU setting, when a close rapport is built with the nurse, the family are able to express their hopes, fears and disappointments freely. While spending time with the family, the nurse builds a close relationship with the family who create an image of the patient as a person for the nurse while reflecting on aspects of their lives. In doing this, they are describing precious and sometimes very private aspects of their personal lives. This is identified as sharing because it is a two-way process where the family are talking and the nurse listening, valuing and accepting their words. The family reveal aspects of their humanness to the nurse while a certain amount of reciprocated self-disclosure by the nurse contributes to a sense of a shared relationship.

Although the medical staff give the options, we are the ones that deal with the patient and the relatives ... they build up a rapport with us and we see all facets of their personality. We go through that anger, that denial, that 'I'll get out of here' to that point of acceptance of death ... with them (Eve: 1 / 14).

The person isn't lying there saying, "I feel so ripped off, I'm dying, isn't it very sad. I wish I could go to my school graduation ball, but now I never will." But the family will say all that to you, and the family will express the pain of the patient and they'll ... they'll cry and they'll bring in photos and talk about memories and talk about special qualities of the patient,

so indirectly you get to know the patient and feel the pain through the family, for the patient that the patient can't express themselves. So the family, I think, is the emotional side of it, the patient is more clinical (A1: 1 / 7).

This aspect of sharing appears to be part of the family working through the dying process and anticipated loss of their family member. The nurse's interest and acceptance of their experiences and descriptions demonstrates valuing of and caring for the patient as a person, for their life and for their contribution to those around them. Through the process of sharing, many traditional interpersonal barriers are put aside. Family members may confide in the nurse, sharing deeply personal information about aspects of their lives and their relationship with the patient. Information that may never have been discussed or acknowledged with other family members may be disclosed.

...one of the personal things she said to me was, "I know he had a brilliant holiday and we had sex before he died" (A1: 1 / 3).

Evans (1995) sees the tasks that the family must work through as part of the grief process as accepting both the reality of loss and the pain of grief. By listening and demonstrating caring and concern for the family, the nurse is able to share the initial stages of grief with the family. Sharing in this context is possible when the nurse is able to develop rapport and a trusting relationship with the family.

Another aspect of sharing is encouraging some family members to participate in physical care of the patient. Within a family, some relationships involve close, intimate physical contact over many years such as parent-child or between spouses. Admission to hospital, particularly ICU, can mean that all physical contact or intimacy is suddenly stopped because of the nature of the patient's illness or injuries. The very public physical environment of a unit is designed so that bedspaces can be clearly viewed and monitored by staff resulting in minimal privacy which can also inhibit any form of intimacy. Intimate, physical contact is therefore frequently denied even though it may be a normal part of the relationship.

A lot of time people have lived with their relative for years and they come into hospital and it's almost as if that contact, that

intimate contact that they've had with that person is denied them really. Like not being allowed in when they are turned or washed, whatever. You know, I think that they have lived and shared the same person for 'x' amount of time and that is just cut off from them once they come in, it's as if they are not allowed to see their body or ... have any contact with them ... So I very much try to promote continuation of that contact really, in whatever realm it may be, for whoever it is (Caz: 1 / 4).

Nurses attempt to provide opportunities for a modified form of intimacy by inviting family members to share and participate in physical care activities. For the family member, this also provides a sense of being able to actually do something useful for the patient.

His sisters would say like "Can I come in tomorrow to do the wash?", because he was the eldest and he had three younger sisters ... and we'd kinda play act discussing it with [patient] (Al: 1 / 12).

Family members do not always feel confident or sure about sharing physical care. Relationships within a family change and evolve over the years. Parents are accustomed to seeing, touching and caring for a naked child. This changes as the child reaches adolescence with most adolescents shy about physical changes in their body. They may strongly resist any form of physical intimacy with the parent so the parent may not have seen their child's 'body' for many years. The nurse does not formally instruct the family about how to assist but they describe using gentle coaching and encouraging, presenting family involvement in physical cares as a shared activity between nurse and family member with the patient. Family members are gradually involved to a greater degree with the nurse providing support and guidance where appropriate.

You say, "Would you like to help me wash, what time is convenient for you, can we do it together?" Things like that (Fay: 1 / 25).

You just work together and sometimes you just give them a few prompts and then they'll watch you and you know most people sort of get the general idea just by watching (Gay: 1 / 10).

Lewandowski (1994) remarks that ICU nurses have the power to shape people's memories about what may become some of the most intimate and poignant moments in their lives. Sharing of the physical care of the person naturally extends into the nurse sharing and facilitating other activities which promote positive memories. Enjoyable, pleasurable or even amusing events that occur in ICU may be remembered as something special that came out of those last few days or hours of their family member's life.

They all joked about this and thought it was a hell of a joke, and it just seemed to work right in that situation for some reason. I haven't done it since, it hasn't felt right since, but I did it that time (Bev: 1 / 22).

In some situations nurses put a considerable amount of time and planning with family members so that positive memories of the last few days can be created. This is not necessary, appropriate or even possible for everyone who is dying in ICU but demonstrates the type of sharing that is possible in order to optimise the human experience. Sometimes planning a last visit home or a celebration of an event like Christmas or a birthday involves the nurse going to quite extraordinary efforts to facilitate the process. In sharing the planning and co-ordination of these celebrations, nurses are able to optimise the human experience under difficult and tragic circumstances.

... his birthday was a couple of days after he arrived in the unit ... and I said "Well, we should celebrate it." And they [family] said, "But it is ICU, how do you celebrate it." So, you just sort of facilitated them to come in with his friends, so they had two kinds of celebrations, one was friends and one was adults. And they just played guitars and had balloons and treated it as if it was just happening anyway. You know they got a lot out of it (Caz: 1 / 4).

Nurses in ICU share the time, space and physical care with the family in order to optimise the human experience while a family member is dying. Memories of happier times are shared with the nurse who listens to and encourages these reflections. Shared activities are a way that nurses promote memories of the time in ICU that will be able to be recalled as a positive aspect in the midst of a

tragic and difficult time. Sharing is a two way process where nurses and families interact and relate on a human-to-human level. The nurse brings specialised knowledge about procedures and events concerning the illness, the disease process and treatment. The family have a specialised knowledge of the patient, their life and their contribution to those around them. Through sharing both aspects of specialised knowledge the nurse and family co-create a shared reality and lifeworld so that the human experience is optimised.

SUPPORTING

Nurses in ICU provide help and assistance to family members as they live through the time that their relative is dying. Supporting is a more active process than 'being there' or 'sharing'. It requires the nurse to aid and nurture the family through this particularly difficult time. Sometimes the nurse will actively guide the family through difficult choices and decisions when their resources are depleted. The nurse supports individual family members and the family as a whole during the time the patient is dying, and immediately following their death, in order to try to optimise the human experience.

Nurses play an active role in aiding the family with decision-making. Families are confronted with events and decisions that many will have never considered could arise. Individual family members are trying to understand their own labile thoughts, feelings and emotions. They are also trying to consider what the possible wishes of their dying relative may be when that person is unable to speak or communicate. Nurses may hear different family members express strong views concerning aspects of treatment or prognosis that are in conflict with other family members. Although the process of a family member dying in ICU may unite family members in their shared grief, it may also cause huge rifts and stress when surviving relatives have differing views. Woolley (1990) warns that the distress and anguish for the relatives of critically ill patients may be responsible for causing a crisis within even the most secure and tightly interwoven family group. The challenge for the ICU nurse at this time is to try to support all family members. Nurses have the knowledge and experience to provide encouragement and information that may help a family make choices that are acceptable to everyone.

Sometimes you have to lead them into situations and make decisions for them, but you must always evaluate responses. I have directed relatives into areas they have felt very uncomfortable about, but in retrospect have thanked me immensely (Caz: 1 / 5).

Often for families it is a lack of understanding and a lack of knowledge and they need more time and they need the information to help them make or accept a decision or even their part of it (Eve: 2 / 1).

Nurses recognise that all family members need support. There are often 'key players' in a family, those relatives who are closest in a legal or personal sense, or those who are the traditional decision-makers within the family group. In turn, those 'key players' may be requiring significant personal support from others who are also connected with the patient. By supporting all family members, the nurse is able to help the family as a whole, support each other.

I spoke nearly the whole night to a boy's uncle ... we chatted away ... he [patient] did die, not that night but ... I found him really easy to talk to and I think at night too .. perhaps someone like an uncle who might get a wee bit crowded out during the day .. that was a good time for him to be there because it meant he sort of got the patient and the nurse more-or-less to himself (Gay: 1 / 18).

Individuals within a family will cope with the ICU experience in a range of ways. Different family members will be experiencing and expressing varying types of grief and emotion. The imminent death of someone they have been close to will take on different meanings for each person. Younger family members may never have had someone close to them die before. Older family members may be reminded of other difficult situations they have faced in the course of their lives when a close relative or friend has died. In supporting the family and the individuals within it, the nurse is able to support them accept and support each other which helps ease some of the overall burden of the stress.

Just trying to hold them [family] together .. it was ongoing and continual crisis all the time, and just trying .. keeping them well informed with what's going on .. just holding them all together really, and let them be apart (Bev: 1 / 6).

Hope is a theme that is recognised in the literature as an important family need while a relative is in ICU (Coulter, 1989; Patel, 1996). Johnson and Roberts (1996) state that hope provides life-sustaining energy that is important in assisting to help the family cope with crisis. In supporting families, nurses recognise that maintaining hope is an important element however nurses express concern that hope can only be supported when it is realistic. Evans (1995) cautions that it is important that a family is not given false hope. Part of supporting families therefore is recognising the importance of that hope but in some ways moderating the family's emphasis on it when it is evident that the patient is unlikely to survive. Supporting families may actually mean not saying exactly what they want to hear.

Some people there is hope and others there isn't. I think that's what relatives would really like to hear, but sometimes we know that that's not going to be the outcome so what's the point in giving them false hope if you know that it's not going to ... I think the important thing is to give all the options, all the possible outcomes (Caz: 1 / 11).

... I always say to them, "I might sound pessimistic, but if things turn around that is a bonus for you, otherwise if it doesn't happen then you're let down badly at the end." ... Just sort of make them realise there mightn't be ... the outlook might not be as good as they think it is going to be (Deb: 1 / 6 - 7).

Nurses describe supporting the family following the death while still at ICU. This may continue after discharge and formal termination of the family's relationship with the hospital.

I pop in and out to make sure the family is OK ... They might be dead but they are still a patient in the bed. It's a personal thing and we are supporting families as well as nursing patients (Eve: 2 / 2).

Nurses identify attending the funeral of a patient or sending a sympathy card as ways that they can demonstrate support of families after the death of a patient. This is seen as particularly important when a close relationship with the patient or family has been developed.

Nurses in [place] go to funerals, say sorry to the family that this has happened and they are sometimes quite pleased to see you and talk about things (Fay: 1 / 13).

On a more formal level, but as a measure of support for families, one nurse mentioned sending a card from the unit staff in general.

Our manager writes to the families, writes a little card a few weeks down the track or whatever and says, "We are ... just thinking of you, hoping you are keeping all right" (Al: 1 / 16).

Supporting or providing information for families after the death of a patient is not a formally recognised role of ICU nurses. It is inevitable that some nurses will later meet families as members of their local communities. This will be discussed further in the chapter 'Nurse as Person' however it is recognised that this informal role of the nurse is only possible because of the nurse's involvement and indepth knowledge of the ICU experience for that particular family. Sometimes family members will contact staff in ICU after the death to seek clarification of what actually happened. At the actual time of death, their own personal grief and distress may have prevented them being able to actually comprehend the events surrounding them. Providing information is part of supporting the family who are trying to understand, or maybe even just remember, their own personal experience and the sequence of events preceding their relative's death.

... I admitted a man who had collapsed in Emergency and died fairly soon after admission of unknown cause. The wife rang in a distressed state a few days later to find out exactly why he had died so ... I was able to reassure her and inform her of his heart attack, after talking for about half an hour she was much calmer and satisfied (Fay: 1 / 14).

Nurses have described the implementation of a variety of forms of bereavement follow-up with families who have had relatives die in their units. Anderson, Bateman, Ingallinera and Woolf (1991) outline a programme developed and implemented by staff in their medical respiratory ICU to maintain contact with relatives of patients who have died. They describe it as a method of support for families during the first year after the death. Bereavement follow-up includes sending a sympathy card signed by staff. Phone calls or written contact are maintained for one year until the anniversary of the death. Hall and Hall (1994) and Angelucci (1994) describe similar programmes that have been implemented by groups of nurses who wish to acknowledge and offer a form of support to families during the first year after a relative death in ICU.

Supporting the families of people who die in ICU is part of the way nurses work with families to optimise the human experience. It is an active process on the part of the nurse because professional knowledge and expertise are utilised to provide assistance at an emotional and practical level. Families are supported to make decisions that will impact on how they experience the time that their relative is dying both while visiting in ICU and in aspects of their lives away from the ICU setting. Follow-up support at a human level can occur where the nurse maintains some form of contact with the family in the time following the death as a personal expression of sympathy to the family.

INVOLVING

Nurses attempt to involve the families of people who are dying in ICU in many aspects of the care of their relative. Involving means actually including the family in aspects of decision-making. Where possible, nurses give family members choices about issues concerning the care of their relative. This is often viewed as a way the family members can feel empowered in a situation where so much of their power and normal involvement in their relative's life have been removed. In this way involving contributes to optimising the human experience.

Involvement of relatives in the physical care of the patient assists to de-mystify the technological environment of ICU and decrease the sense of powerlessness (Hammond, 1995). Nurses describe sharing physical care with family members and this has been discussed as an essential theme. Involving the families in

aspects of physical cares is a progression from sharing. Involving means the family are actually given more control than with sharing where the nurse acts as the main decision-maker and tends to direct family involvement. An important feature is the giving over of a degree of control to the family.

The idea of family involvement and participation in the care of relatives in ICU has been a recurring theme in the literature (Moulter, 1979; Norris and Grove, 1986). Coulter (1989) found that participating in physical care was useful for families to help them cope with the situation. Initially families may require support and coaching through the actions of what they can do with their relative. They become familiar with the routines of ICU and confident about their interactions with their relative. While they are present they may choose to take responsibility for aspects of their relative's care, rather than sharing these with the nurse.

Families will ask what they can do, "Is there anything we can do? Physical things we can do." Then it's the nurse being able to let them do it or find something that's nice for them to do ... things ... which they feel as though they are doing something (Fay: 1 / 24).

By involving families, nurses seek to assist them feel empowerment. This can be done by valuing their intimate knowledge of the person and asking their advice about what they think the patient would like. Family members then feel they are making a useful contribution to the care of their relative.

To actually recognise "What do you think?" we're thinking of putting on one of his old tee-shirts on him cos he's got no lines on him -what do you think, would he like that - they could come out and say, "Well, actually he's a bit hot, and he's a bit sweaty." We might have thought of that already, but it came from them (Al: 1 / 15).

Sometimes there's not a lot they can do, sometimes you're kinda racking your brains thinking what can I get them to do. Most families love doing things, a few people don't but most people really, really like to just feel that they are actually doing something for the person. Just wiping peoples' faces and hands,

that sort of thing, just about anyone can do that, that is quite easy. Even if the patient doesn't really need it ... they might wipe their eyes ... some families might even suction out their mouth or something sort of more technical like that ... (Gay: 1 / 2).

Nurses feel that it is important that families are included in decision-making. They are aware that families can feel a sense of complete loss of control over the course of events that is unfolding in their lives. Involving helps them experience a sense of empowerment.

... families come in, they've been shot off at the kneecaps in a split second and I think everything is all up in the air for them and their whole life has been thrown into turmoil and if you can bring some semblance of order in all of that ... put some power back to them (Caz: 1 / 9).

Actions that involve the physical care of the patient usually require some form of negotiation between nurse and family. Nurses are aware that creating opportunities to actually involve the family can be beneficial for everyone. Farrell (1989) states that many relatives feel a need to be helpful to the dying person. Unconscious patients may respond to a family member's voice or touch before they respond to hospital staff.

Often I'll do the neuros with the family there and get them to hold their hand and them to say "Squeeze my hand" because very occasionally they'll do it for them but not for us and you get a better response from the family and I think the family should know as much as they want to as well (Eve: 1 / 18).

Encouraging involvement of the family in this way is also useful when the patient is dying in that it allows the family members the opportunity to see that the patient is definitely not responding. Several nurses mentioned an emerging trend in ICU to have families present at the time of brain death protocols or while resuscitation procedures are in progress. The family presence enables them to feel involved and know exactly what was done and how the decision to discontinue treatment was reached.

I think one thing that has changed a lot since I started Intensive Care nursing is when there is an arrest or some sort of crisis situation and the patient could be dying or it looks like they might be, people are more likely, especially with children, to say to parents they realise this could be their last moments and then we'll get (them) back in and just ... they can watch us, they may find it too distressing but they can ... just let them in ... there's normally a space around the bed, they can probably fit in (Gay: 1 / 11).

One thing that could be done more is ... allowing families in to see how you actually come to that decision and with brain death seeing that their relative isn't going to breathe and they fail the apnoea and they don't have this reflex or that reflex, but how you do it and how you come to that conclusion (Caz: 1 / 15).

Involving the family in all aspects of care and decision-making while a relative is dying in ICU helps to optimise the human experience. It is hoped that family members will feel as though they have actively contributed to the care of their dying relative through being given the opportunity to be included in making decisions about the overall treatment and, where appropriate, involved in the hour-by-hour management of their relative. Involving helps the person experience a sense of empowerment at a time when family members may be feeling they have very little control over their own lives and destinies.

INTERPRETING

Nurses in ICU attempt to assist families develop an overall understanding of their relative's condition and the medical and nursing interventions that are being undertaken as part of treatment.

Walters (1995c) uses the term 'making sense' as a theme in a study that describes the lifeworld of the families of critically ill patients. Making sense focuses on the family member's understanding of the experience of having a family member who is critically ill. He states the sudden onset and abruptness of critical illness can result in confusion, personal agony and cause significant disruption to people's lives. The theme of interpreting in this study can be

viewed as a way that nurses seek to assist the family make sense of their experience.

Meyer (1992) states the nurse is a provider and interpreter of information that helps family members sort through different options as well as assisting the family to understand the necessity for procedures and interventions that may be painful or time-consuming. The ICU environment is quite alien to people who are not familiar with the sights, sounds and smells of a busy, acute unit. Staff are constantly changing and new faces appear. This busy, unfamiliar setting can increase the stress and anxiety of the family who are attempting to come to terms with the life-threatening nature of their family member's illness. It is within this context that the nurse takes on the role of interpreter for the family of the patient's condition and changing physiological status. The nurse explains the wider ICU environment and reinforces and reiterates the explanations given by other health professionals, such as medical staff, concerning the patient's prognosis and the interventions performed.

Family members are often present at the bedside for lengthy periods of time. As soon as appropriate following admission, nurses will explain the vast array of equipment and machines attached to the patient and in the surrounding bedspace. This is part of usual nursing practice in ICU. The continual bedside presence of the nurse means they play a central role in ensuring the family are kept up-to-date and informed about changes in the patient's condition (Evans, 1995).

I just normally explain what the endotracheal tube is because that is in their mouth and it's quite obvious and the ventilator, just sort of say, that machine is helping with the breathing ... well he's got drips going in and different wires coming off him for monitoring (Gay: 1 / 4).

Initially the names and functions of the different pieces of equipment are explained and nurses on subsequent shifts generally reinforce this explanation. Even when the patient is dying, family members will also add their own explanations demonstrating their knowledge to other relatives who arrive later. Families become familiar with the equipment and start to take greater notice of the numbers and trends that display physiological parameters. When a patient is

dying, family members are often conscious of deteriorations in physiological condition because of what is displayed on the monitors.

They really are very aware and they get to know to read the numbers of machines etc. They soon pick up that things aren't looking so good ... 'Oh that blood pressure looks a bit low' or they ask you 'What's normal?' - they know (Fay: 1 / 3).

The nurse at the bedside acts as the main interpreter of ongoing physiological changes in the patient's condition for the family. Nurses will offer explanations concerning prognosis or family members will ask the nurse for clarification when they notice a change in condition. In order to answer questions, the ICU nurse needs to have an advanced level of understanding of physiological processes but also needs to be able to interpret these complicated processes and explain them in terms that the family can understand.

The family said, "Oh yes, we're just so thankful that [the nurse] explained to us why he was the colour he was because we didn't really understand that" (Deb: 1 / 3).

Nurses express the need to be honest in their interpretations about changes in condition. They are aware that relatives will desperately look for any small glimmer of hope when making their own interpretations of physiological changes so the nurse must balance their need and right to retain hope, while being realistic about prognosis.

I know that things are grim, I don't ... be that hopeful because ... I don't want them to be gliding along there thinking things are going to be honky dory and then crash at the end (Deb: 1 / 22).

They'll say, "Oh, he squeezed my hand", that's a classic and it comes up time and time again with head injuries, and you have to say, "No, that is a basic biomedical response" (Eve: 1 / 17).

Family members are often updated by nursing staff about their relative's condition. B. Rodgers (1990) suggests this may include contacting relatives in the waiting room to provide periodic reports on the patient's condition. This

provision of information helps to decrease stress and enhances the relationship between the nurse and the family. Hall and Hall (1994) found that 88% of the relatives in their study who had suffered a bereavement in ICU, reported they had received much of their information from the nurses. In addition, a nurse is often present when explanations are given by medical staff. Nurses are aware that information may need to be repeated several times and in language that non-health professionals can understand. Many family members have little or only very basic knowledge about the structure and functions of the human body so explanations need to be made at a level that can be understood while still recognising the family as intelligent, interested people. Difficulty comprehending explanations about complicated physiological processes is further compounded by the duration, nature and intensity of the stress caused by the severity of the condition.

A lot of explanations, medical and nursing ... just so they know exactly what is going on and just trying to be really open so they feel free to ask anything (Gay: 1 / 1).

An important aspect of the nursing role of interpreting is providing reinforcement and clarification for explanations given by medical staff. Families may absorb only parts of the explanation. Although the health professional may feel they have provided an adequate explanation, the family may not have understood what was said. Frequent updates about the patient's condition by medical staff have been identified as a need of relatives of ICU patients (Moulter, 1979; Norris and Grove, 1986; Davis-Martin, 1994). Once these explanations have been given, it is the nurse at the bedside who has to translate, clarify and repeat the information given by the doctor while the family absorb and try to understand the information they have been given. Sometimes interventions and treatments will prevent medical or nursing staff being able to spend any length of time providing family updates so brief explanations and reassurance that the family will be able to visit as soon as practical may have to suffice (Farrell, 1989). Family meetings with medical staff may not be possible on a daily basis so the majority of information giving and explanation is done by nursing staff. However, most relatives will put significant emphasis on information given by the doctor.

The relatives only hear, so when the medical staff speak to them, they may only hear that we're going to give it a week, but there

is only a 2% chance that their relative will survive, they'll hear the 2%. They won't hear the 98% death rate ... so we have to try and build on what the medical staff have said (Eve: 1 / 15).

The interpreting role of the nurse involves explaining and clarifying the wider ICU environment as well as translating changes in the patient's condition. This is a continuous and ongoing process throughout the time in ICU. Information may need to be repeated several times while family members try to comprehend and understand their relative's deteriorating physiological status as death becomes imminent. Nurses are constantly monitoring changes in vital signs and communicating these to different family members. Professional knowledge is used to interpret and communicate knowledge at a level that enables deeper understanding for family members. Knowledge and understanding empower the family and through that empowerment the human experience is optimised.

ADVOCATING

Nelson (1988) describes advocacy in nursing. She explains how it has evolved from a position of interceding, supporting or pleading a case for the client to acting as a guardian of the clients' rights to freedom of choice and autonomy. Advocacy in nursing has changed from the early views of acting for or on behalf of another to acting as a mediator. In recent times the view of advocacy in nursing has shifted to the nurse as protector of self-determination placing the client's rights as the unconditional first priority.

In the situation of the family of a patient who is dying in ICU the family, as well as the patient, are seen as clients. Hammond (1995) states that the family is an extension of the patient and it is important that nurses remain aware that the patient is considered part of the larger family unit.

Nurses describe situations where they advocate for clients, sometimes this involves acting on behalf of or mediating. These actions are seen as part of protecting the family's right to self-determination. Nurses have knowledge of the vast range of possibilities that can be considered concerning the family's involvement in and access to ICU. By advocating for the family, these possibilities for the family may become eventualities which will ultimately optimise the family experience.

Nurses are particularly aware of the family's right to be with the patient. Interventions and treatments are usually essential and health professionals have different views as to whether family members should be present while these are being performed. Sometimes, for safety reasons, it is not appropriate for family to be at the bedside due to the nature of the intervention or the fact that the person performing the intervention may not be comfortable with an 'audience'. Nurses advocating for the family may speak out and request that the family be given even a brief few moments with a patient prior to an invasive or potentially time-consuming procedure. The family are not present therefore are unable to make the request themselves.

If you know that the doctors are going to be putting in a Swan Ganz catheter or other things, to say, "Look, would it be all right for the family to come in now for a few minutes?" Then usually the doctors say, "Oh yes, I hadn't thought of that." Whereas that's a good thing that a nurse can do then the family can sit there ... they don't worry as long as they have been in and seen the person, they are much more comfortable then (Fay: 1 / 16).

As the health professional at the bedside, the nurse is most acutely aware of the family's presence and desire for access. The nurse must maintain a constant awareness of the family's right to be present and involved especially when they are unable to state their preferences themselves for reasons such as they have been asked to leave the bedside while a procedure or examination is undertaken.

As he was going, I just left him at the bedside with the doctors and went and got her [wife] ... I knew it would be very important for her to be with him in the last minute, even if there were a lot of doctors around. So I left the bedside and went to the relatives' room and got her ... I felt that was appropriate, so she held his hand and she let him go (Al: 1 / 21).

Nurses describe situations when they feel it is necessary to act on behalf of the family even though the family may be actually present. The relationship that the nurse builds with the family means that the family has often expressed their

wishes to the nurse. The nurse also becomes aware of the ways the family communicates and is able to assess from their words and actions when they are uncomfortable or becoming distressed with a particular situation. However, Danis, Jarr, Southerland, Nocella and Patrick (1987) compare how nurses, patient and families evaluate the usefulness of Intensive Care. They conclude that health professionals need to be cautious and should not assume that they know a patient's or family's preferences about how aggressively the patient should be treated. This information needs to be clearly sought from the family rather than assumed. The nurse at the bedside is able to create the opportunity for the family to express their wishes.

The powerlessness of the family in ICU may be in part due to the fact that it appears that everyone such as doctors, health professionals, friends and family supporters are all doing their best to support the family and 'do the right things'. It is therefore very difficult for the family to actually express an opinion that they do not agree with what is happening without risking offending people who are trying to help. Nurses advocating for the family may intercede and, in some situations, speak on behalf of the family.

They just said they couldn't bear it any longer and ... Things were speeded up, it was going to be sort of a matter of hours ... it was a matter of half an hour or something after that ... and the doctor wouldn't have known that the family were so distressed ... wouldn't have been his fault, he didn't know ... but the nurse was the one that was told by the family so she did the right thing by informing the doctor and fortunately the doctor agreed (Gay: 1 / 25).

They had been refugees and there was quite a few friends ... sort of well meaning middle class women ... there was nothing wrong with them, but I thought they were sort of hanging around a wee bit much so I actually asked them to leave the family and just ... just let the family come in by themselves .. I said it is a real family time, I don't think they were ... they never would have said it themselves because it would have been too impolite. So you do find you have to stick up for people really sometimes ... and they were quite happy with that (Gay: 1 / 14).

Advocating for the family is a way that nurses attempt to ensure the rights of the family are protected and that the family is not forgotten amid the drama and crisis that can unfold while attempts are made to save the life of a person who is dying in ICU. Nurses may find themselves needing to speak on behalf of the family who, for a variety of reasons, may be unable to express their wishes to those who are involved in caring for the patient or the personal friends and supporters of the family. Creating opportunities for the family to express their wishes contributes to optimising the human experience.

SUMMARY

Nurses in ICU are aware that death is the outcome for a significant proportion of people who are admitted. Depending on the particular unit this has been estimated at 15 - 25% of the total number of admissions (McKerron, 1991). Once death becomes inevitable, the focus of intensive care shifts to providing psychological support and comfort for dying patients and their families. The aim is to make death as peaceful and comfortable as possible while the family is encouraged and supported to be an integral part of the process (Anderson, Bateman, Ingallinera and Woolf, 1991).

This chapter has explored six themes that emerged from the narrative accounts of nurses working in ICU who describe nursing the families of people who die. Nurses seek to optimise the human experience for the families while acknowledging that this is a difficult and devastating time for them. Key strategies for optimising the human experience include being there, sharing, supporting, involving, interpreting and advocating for the family. These themes are directly concerned with the relationship and interactions between the nurse and the family. Nursing involves using both personal and professional knowledge and skills when working with families to optimise the human experience.

CHAPTER SEVEN

NURSE AS PERSON

This chapter seeks to illustrate the human side of nursing practice with families. When working to optimise the human experience for family members, nurses describe a dimension of practice beyond that which is formally recognised as professional nursing. Taylor (1992) states that descriptions of nursing in the literature tend to focus on nursing acts and role responsibilities rather than nurses as people. Nursing theories define the metaparadigms of health, environment, nursing and person and outline the relationships between these concepts. 'Nurse' and 'Person' have been viewed and defined as quite separate entities. Taylor considers that the view 'Nurse as Person' has been neglected in many theories of nursing. She states that nurses have not been recognised or fitted into definitions of people or human beings. Likewise, descriptions of nursing have failed to recognise the 'person' aspect of the nurse in definitions of nursing. The common link of shared humanness is largely ignored.

This personal or human aspect of nursing is an integral part of this study. Each of the nurses describe deeply personal aspects to their own practice and ways of being that demonstrate their ability to reach out to families in an intense but profoundly human way that is quite separate from what is regarded as part of professional role responsibilities. This part of intensive care nursing is not captured in job descriptions and can not be formally requested by an employer as a condition of work.

The Nurse as Person exposes a human-to-human aspect of nursing. The nurse relates to the family on a human level in the context of shared existence in the world created because of the shared bonds of being human. As a human being, the nurse is capable of experiencing the pain, sadness and loss that the family are facing, both for them as people and for the life that is ending. Seeing and sharing such raw human emotion and experience touches the nurse in a deeply personal way at a human level. It is within the domain of Nurse as Person that this experience and its contribution to optimising the human experience can be recognised.

In order to optimise the human experience for the family, the nurse reaches out on a human level and in turn is reached and touched in an emotional sense by those with whom the experience is shared. The sense of shared humanity blends the lifeworlds of nurse and family.

Three themes are described within the domain Nurse as Person (see Table Two):

- * **Giving** occurs when nurses offer their time, their space and aspects of the person to attempt to humanise the experience for family members.
- * **Grieving** includes the feelings of loss and sadness that the nurse experiences and the processes that assist working through those feelings.
- * **Balancing** is a form of self-regulation that nurses use to ensure that they are able to work effectively in a personal and professional capacity so that their life remains meaningful to them.

Table Two: Domain - Nurse as Person

NURSE AS PERSON
Giving
Grieving
Balancing

GIVING

Giving is a theme that emerges and demonstrates the commitment and genuine desire of ICU nurses to ease the burden of the family experiencing the dying process and death of their relative. In a general sense the nurses give their professional expertise and skills as they work with the patient and family to

optimise the human experience. Giving as a theme is an expansion of this professional obligation beyond formal requirements of employment, job descriptions and professional standards.

Giving occurs when nurses offer their time, their space, and aspects of their person in an attempt to make the difficult and tragic times for the family more tolerable. This happens in an everyday sense within the lifeworld of ICU nursing. Personal and professional giving is an integrated part of ICU nursing work which is blended and harmonised within the broader perspective of nursing the family.

Giving does not require a formal health professional qualification or educational background. It comes from the nurse-person and who offers help, support or assistance to the family on a human-to-human level. Although the relationship between nurse and family comes about because of a professional situation, the decision to give appears to emerge as part of a human desire to reach out to other human beings facing difficult times.

In an everyday sense, nurses describe giving particularly in relation to families from out-of-town and overseas visitors. These people can be left somewhat stranded and alone by the absence of those who would normally provide their support network. In some situations a single family member is present. Nurses are acutely aware that families may be staying in hospital hostel accommodation, eating cafeteria meals and having to cope with their own reactions to their relative's condition. They have to deal with their own feelings in the absence of, not only their normal support network, but also what could be considered normal everyday home comforts. As the person most involved with that relative, the nurse is perhaps the only person who is able to hear that family member's experience and offer personal support. Several nurses describe situations where they invite family members to their own homes extending the hand of friendship on a human level beyond the expectations of the job.

I became the 'surrogate family' if you like and it was good ...//..It was pretty traumatic and was more extended than usual because I brought the woman home with me to stay in my house for the four or five days and was involved with the solicitor... and all that trauma and extra hassles she had to deal with. It wasn't just

a matter of packing him up and shipping him home or getting him buried or anything (Al: 1 / 1).

..there was a patient we had from [overseas] and we got to know his wife really well. She came over here for tea one night and met the kids and the kids did drawings for her... she was out here on holiday and her husband actually died (Eve: 2 / 11).

In both these situations the nurses give not only their own off-duty time but also share their family and their homes. The nurses are clear that this is a personal choice to offer this support and in each case they feel it is necessary. They want to give on a human person-to-person level. They recognise a need to provide some human care and interest beyond the professional setting and usual nurse - client / family boundaries. This is not seen as something particularly virtuous or noble but more as a human-to-human response to another person in a time of deep personal anguish.

..we're with people in the most traumatic, beautiful, horrendous experiences in their lives but you can actually make a difference in someone's death... that's pretty amazing that you can ease someone's burden if it's only for a day (Al: 1 / 16).

Watson (1985) sees that caring is part of the core of nursing. She identifies ten carative factors to explain the humanistic and scientific dimensions of nursing. Formation of an altruistic system of values, instillation of faith-hope and cultivation of sensitivity to self and others are seen as interacting to establish a philosophical foundation for the science of caring. Giving can be viewed as an expression of caring. Watson sees caring is grounded in universal human values such as kindness, concern, and love of self and others. Through altruistic values and behaviour, meaning is brought to one's life through relationships with others. Altruistic values are cultivated early in life. In nursing education these qualities should be nurtured and valued so that they are integrated within nursing practice and nurse-client relationships. The sense of giving conveyed by the nurses in describing their experiences nursing the families of people who die in ICU is a blending of the personal and professional within the nurse. It is a demonstration of how altruistic values are an integral aspect of the nurse as person. It is the personal sense of reaching out to another human being combined with a professional obligation to alleviate suffering and provide

support. The professional duty is to maintain standards of care. The personal sense is the dimension that makes the nurse want to give friendship and love in a human way.

Giving of the self and personal time outside the work setting features regularly in ICU nursing practice. The personal - professional boundaries become blurred as the nurses share such intensely emotional and significant experiences with the family. The professional requirement to provide support and information cannot be terminated as soon as the patient has died and left ICU. Although no longer formally the 'nurse of the patient', nurses speak of meeting families at social events or in the community sometimes even years after the death. In these situations, on a personal level, nurses feel they still should make time to talk to the family.

..you meet a family in Pak-n-Save or Big Fresh or whatever ... it might be an extra half an hour that you haven't got out of your shopping but that's just the nature of it - you're involved (Al: 1 / 17).

Contact with relatives following the death of family members appears to have a two-fold effect. On one hand it provides a form of grief resolution for the nurse but nurses are also aware of the therapeutic effects it has for the family. Nurses speak of ongoing contact where they can provide information or answer questions that occur to the family after the death. Ongoing contact can be initiated and sustained by the family or the nurse.

..they asked me to speak at his funeral so I read a Psalm at his funeral and that was good. That never happened to me before, but they came along and asked me to do that and I've had contact with them since... the sister came in and saw me at work. I rang her afterwards and then she came in and saw me (Bev: 1 / 10).

Giving can continue for many years after the death of a family member. The professional link no longer exists but the shared sense of being human or shared humanity seems to make the nurse as person want to continue to give. Long-term friendships with families can be formed with the common bond continuing to be shared humanity along the journey of the ICU experience. One situation

illustrates this particularly clearly where the nurse became the link for a family abroad whose son died in the unit in what was described as the early days of ICU. The decision to initially make contact with this family and maintain that contact for many years comes from the nurse as person who seeks to humanise and personalise that time for the family.

..we all just sat around and said "This is a terrible thing. These parents are going to get a cable from the other side of the world to say their son has been killed." ... we got the parents' address and I wrote and explained to them what had happened, how we'd done our best for him but he had died but that he was very brave right up until the end. I received a letter from his aunt and in time I did hear from his mother who was grateful that I had written to her. He had been buried in [cemetery] because they couldn't afford to take his body home to [place]. There was a plaque put on it and I was able to get a photo of that to send to her. We've corresponded ... it's 33 years I've corresponded with that family (Deb: 1 / 1).

Although giving occurs on a human level, in the ICU nursing situation, it is a unique form of giving that results from the combination of professional knowledge and personal involvement throughout a particularly significant time with a family. Giving is shaped by the blending of the formal and informal roles of the nurse. Job descriptions and professional Codes of Conduct prescribe the nursing role on a formal level and can be regarded as minimum standards for professional practice. These can differ from the informal role of the nurse which represents what actually occurs within the practice setting. When nursing the families of people who die in ICU, the personal 'giving' is an aspect of the informal role. This cannot be regulated, required or registered but calls on the human side of the nurse as person to recognise the shared aspects of humanity and common bonds that exist between people whatever their formal role and relationship to the situation. The nurse is in a unique position because of an intimate knowing of the dynamics and processes of the actual experience for a particular family combined with technical knowledge and expertise. Engagement in the lifeworld of the family and a human-to-human desire to reach out to others enable this 'special kind of giving' to occur.

GRIEVING

Nurses in ICU feel a sense of loss and sadness for the family and patient when a person is dying. As a person, the nurse can feel deep sorrow for those whose lives will dramatically change as a result of that death, but may also personally feel the sense of loss themselves. In order to continue working effectively in ICU, nurses know they must be able to recognise, feel and process their own grief so that they can maintain their integrity as a person.

Slater (1988) comments that within society in general, there appears to be an assumption that health care professionals are able to provide emotional support to bereaved relatives at no cost to their own emotions. This assumption is widely rejected in the nursing literature. Foxall, Zimmerman, Standley and Bere (1990) found that death and dying were significantly more stressful for ICU and hospice nurses as they encounter death on a more regular basis than nurses working in other areas. Benica, Longo and Barnsteiner (1992) comment that nurses working in settings where patients die frequently suffer repeated losses. The cumulative effect of these losses is increased stress which in turn can lead to less effective means of coping with that stress. Watson (1985) comments:

To be human is to feel. All too often people allow themselves to *think* their thoughts but not to *feel* their feelings. The only way to develop sensitivity to one's self and to others is to recognise and feel feelings - painful ones as well as happy ones (p.16).

ICU nurses' contact and involvement with death and the dying process has an impact on them as people in an emotional sense. The experience of grief and loss can be traumatic for the nurse as person. Nurses recall situations where they acutely feel a sense of grief and loss during and following the death of a patient. They speak of crying, or needing support and reassurance from colleagues and their own families following deaths that particularly affect or upset them. Nurses emphasise feeling the loss as a person. This loss appears to be felt when the nurse as person is engaged in the lifeworld of ICU nursing. There is an overall feeling of being unable to separate the tragedy being witnessed and experienced in their professional lives from their normal, everyday life as a person. This in some ways compounds as despite the deep anguish felt, there are no guarantees the nurse will not soon be facing a similar scenario the next duty, the next day or the next week. Reactions and ways of

copied with death in ICU differ. In some situations, nurses describe a sense of emotional withdrawal and numbness while in other situations, the actual experience is depicted as one of emotional involvement and strong feelings of grief and anguish.

... it's if you're just meant to switch off from one then on to the next (Caz: 1 / 13).

... I found it emotionally traumatic because I'd built up a relationship with that family and I can still remember standing there with the paediatric paddles and cutting up little strips for her and I had tears going down my face ... I don't know how capable I was at that precise moment because I felt quite emotional ... I found it extremely draining mentally and emotionally (Eve: 1 / 5).

The concept of nurses' grief has been investigated and discussed. Spencer (1994) conducted a study to specifically explore how nurses deal with their own grief when patients die in ICU. Nurses were asked how they felt when a patient died - 100% reported sadness; 98% relief; and 80% shock. One of the factors that determined the nurses' feelings was how well the individual nurse knew the family. Nurses described dealing with their grief by talking to other staff members, friends and their own relatives. Other ways of dealing with grief were to 'bottle it up', 'dismiss it', 'life goes on', 'goes with the job', and crying.

In this study, the situations where nurses speak of being most profoundly affected by the death of a patient, they also describe a close relationship with the family. The nurses' grief is only partly attributable to the actual patient death as often they do not know the patient other than through the stories and memories that they hear from the family. Much more vivid for the nurses are the pain and suffering that the family is experiencing. Their grief is therefore for the whole family in terms of the impact of the loss of the person who is an integral part of the family unit.

... It was quite sad when he died but I was more sad for the family because their pain was real, their pain was vivid in their eyes and their crying and everything else, the sense of loss that they were feeling (Al: 1 / 1).

There does not appear to be any form of predicability in terms of which situations will result in the most grief for the nurses. Although most mention situations where children or young patients die, equally, there are situations where the nurse's involvement with the family of an older person can cause considerable distress. Nurses also find that sometimes they can be seemingly disproportionately upset by a particular situation but can not understand why. In some situations they may even feel a sense of grief and sadness for family members who they do not know.

... every situation is tragic, I find. I actually find, I mean children are sad and I find that hard but sometimes I find it hard when it is the poor old chap lying there and the wee wife (Bev: 1 / 27).

I feel it sometimes even when I'm not looking after the patient I can feel the tears welling up in my eyes sometimes especially when it's young people with children or something like that especially when they [visitors] first come in ... I think Oh goodness that could be me but I can just feel ... (shook head and placed hand over heart) (Deb: 1 / 23).

Beaton and Degner (1990) raise the issue that ICU nurses are unable to 'escape' from their working environment. The one-to-one nature of ICU nursing means that it is very difficult for a nurse to actually take any time-out from the intensity of the situation except for official breaks which may be several hours apart. This is different from other health professionals who are able to 'come and go' to a much greater extent. Nurses express the need to continue functioning in a professional capacity to meet the requirements of their job despite strong personal feelings of grief and sadness. They attempt to maintain an image with other patients and families that demonstrates competence. They cannot be seen to be 'unable to cope' by openly expressing their sadness or grief in the public areas of the unit where their presence is constantly expected when they are on duty. Nurses are sometimes reassured that other families understand and are sensitive to the situation and the effect that involvement with a family and death has on them.

... we were speaking about people dying in the unit and she [wife of a patient] said she knew how things were going just by the way we were and here we are thinking that we kind of flit into one room and we feel a bit upset and then kind of breeze into the next bedspace and we're our usual selves but obviously we're not. There had been quite a tragic situation in the room next to where she was and she could just tell things weren't going well just by the looks on our faces and she actually said she could tell just by "how we were" as to what was going on (Gay: 1 / 16).

Nurses describe how they process and deal with their grief on a personal level. Several participants who have been ICU nurses for over ten years feel quite strongly that at both a personal and unit level, nurses' grief is now acknowledged and staff members are supported and encouraged to process that grief to a much greater degree.

I definitely would never have written a letter to a family whereas now I quite often have done so and that's part of finishing off your own ... the caring side of it (Fay: 1 / 13).

Attendance at patients' funerals and making contact with the family are both ways nurses believe enables them to deal with their grief as well as providing the opportunity to terminate their relationship with the family. Relationships with some families may develop over many months with a long admission. Other times, relationships develop over repeated admissions and readmissions. Families or patients may be personally known by unit staff away from the ICU setting. Following a death in ICU, the formal nursing role ceases once the patient is escorted to the mortuary but for the nurse, the feelings remain. It is on a personal level that nurses choose to attend funerals. This appears to be accepted now as a normal extension of the nursing role by staff in ICU.

... a lot of us go to funerals and that to me is one way of dealing with it, going to the funeral and saying goodbye (Al: 1 / 16).

... sometimes you don't actually look after your own needs in all that and it is not until it is all over and the family are gone that you have ... that you are left sort of hanging in there and you

don't have ... you actually feel a little unbalanced yourself ... you deal with it by going to funerals or writing cards to the relative after it or perhaps ... having limited involvement with the family after that but I think it certainly does take its toll on professionals (Caz: 1 / 13).

We often go to patient's funerals which families appreciate and we support each other doing that (Eve: 2 / 19).

Overall, ICU nurses witness and share the grief associated with the death of a family member. As a result nurses have the experience of grieving themselves. Supporting the family fits within the professional requirements of the job. However, it is on a personal level that the nurses experience feelings of grief associated with the death of a person and the implications of that death for the family for whom the nurse feels a deep empathy. In order to maximise their ability to continue functioning at an optimal personal and professional level, each nurse develops strategies for dealing with grief. When grief and loss are effectively managed, nurses can continue to work effectively with families to optimise the human experience. Grief and loss are part of the lifeworld of ICU nursing but nurses learn to live and work within this reality.

BALANCING

Balancing is a process nurses employ to provide a form of self-regulation in terms of the nature of the workloads they carry and their involvement with families. Cooper and Mitchell (1990) consider the relationship the nurse has with the patient and family can be a source of stress or satisfaction. Nurses recognise the stressful nature of the interactions and the cumulative affect that repeated exposure to death and dying can have on them personally.

Taylor (1994) states:

Some nurses hide behind their professional masks in order to protect themselves from emotional knocks and bruises that result from clinical work, thus their professional facade acts as armour to protect them from the hurts of dealing with daily drama of human anguish (p.234).

As human beings, with responsibilities and lives away from the work setting, the nurses acknowledge their limited resources in terms of a human capacity to give. Professional life must remain in balance so that they can fulfil their own personal obligations and responsibilities outside the work setting. These obligations must be met in a way that satisfies their own expectations if they are to remain working effectively in ICU for long periods of time.

It's hard, you'd just burn out if you jumped from one situation to the next all the time ... but you have to be aware of that and I don't know whether everyone is aware of that ... and you're able to have other things in my life, work is not the end, the be all and end all (Bev: 1 / 29).

Although the nurses themselves do not use the term 'balancing' in this context, it is evident in the interview texts that each has strategies which recognise their own capacities and limitations. They monitor themselves in terms of the amount of personal self that they can give in a situation but also in terms of the type of people and family situations with which they become involved. One way of maintaining this balance is when nurses feel they are able to state that they do not wish to take a particular patient or family.

I said that I didn't want to look after her again because I just couldn't really get on with her ... I didn't get on with the patient at all because I think it was a big personality clash ... I didn't want anything more to do with her basically ... I felt especially since she was dying, I thought she's not going to want to see me either ... and I just thought it wouldn't be fair on her or me (Gay: 1 / 22).

Other times nurses feel although they would very much like to be involved and continue with the care of a dying patient and family, on a human level, their personal resources will not stretch to cope with the emotional demands. The nurse may acknowledge this to the family.

I couldn't actually look after him. I went to the bedside next to his. I did say to the woman [wife] ... I just can't, I feel so upset about it that I don't feel that I can give him the quality of care

that I would normally because I'm feeling really upset about it and she really understood that (Eve: 2 / 12).

Nurses find that the trauma of working closely with a particular family can influence their ability to be involved with subsequent families. It is as though repeated exposure to grief becomes cumulative. This is sometimes directly acknowledged but other times nurses are aware that they are avoiding placing themselves in situations where a high level of emotional input is required or potentially required.

I didn't want to get that involved with another family again and directly or indirectly saw to it that I didn't. I'd still give good care and still cared about what families went through but since then I've always seemed to have the family with the two to three day stay on the unit. The family ... or I looked after the patient who didn't have family at all, so did I engineer that? I don't know (Al: 1 / 17).

There are risks for the nurse associated with repeated exposure to deep personal tragedy and grief. Rushton (1992) uses words such as suffering, sharing and compassion to describe the links between personal and professional roles with regard to what she calls care-giver suffering. She asserts that compassion exists within both personal and professional boundaries. It is inherent in nursing and caring for others at such traumatic times that some degree of personal suffering will occur. Rushton considers this may even be desirable in some situations where personal and professional growth can occur leading to more compassionate caring. Tucker (1992) expresses the opinion that nurses caring for dying patients in ICU may experience frustration, stress and ideological conflict. Giving nursing care to dying patients and being present at their death can be a source of stress on both a personal and professional level. Balancing their work appears to be a mechanism that nurses use to monitor and manage actual and potential stress.

Beaton and Degner (1990) use the term 'emotional bankruptcy' to describe physical and emotional withdrawal of the nurse from the patient. This can occur when a patient to whom a nurse has had a particularly strong attachment dies. The nurse then temporarily detaches from further involvement with dying patients. Although the family is not mentioned as part of this detachment

process, it is evident in the interviews that a similar process occurs with regard to the family. As part of monitoring the self as a person, nurses may choose to avoid working with families where the likelihood of a stressful dying process exists.

I know myself, sometimes I haven't got it to give and I don't want to get that involved (Al: 1 / 6).

The importance of being supportive and respectful of colleagues is acknowledged but generally nurses accept that balancing their personal capacity for working with emotionally demanding situations is an individual responsibility. Beaton and Degner (1990) state that head nurses recognise the effect of caring continuously for seriously ill patients and rotate responsibility among the nurses but the nurses in this study see monitoring of workload to be primarily an individual responsibility. Although factors such as the overall workload of the unit are acknowledged, it still rests with the individual nurse to decide how they feel equipped to deal with potentially demanding and stressful situations.

I guess we all take responsibility for ourselves in amongst all of this as well. You have the choice to say "No, I can't deal with that today" or whatever because ... I think generally that is well received (Caz: 1 / 14).

... you realise that you can't do everything, you don't have all the reserves in the world to call on and that in actual fact it can be healthy to say "Well look, I can't be myself under any more of this, I can't look after this patient" (Eve: 2 / 12).

Balancing is a self-regulatory process that ICU nurses individually maintain to ensure their practice and interactions with family members remain at the best possible level. An overall balance must be maintained in nurses are repeatedly working with families to optimise the human experience. From a human perspective nurses find that at times they are deeply involved with the families of dying patients. Although this challenges the nurse in terms of professional performance, the human connection can be extremely demanding for the nurse as a person. The level of involvement that will develop cannot always be predicted or planned, it is something that just happens and evolves. At a

personal level nurses recognise that they are unable to sustain intensive giving of themselves duty after duty, week after week, month after month. The personal toll is too great.

In balancing their lifeworld, nurses take into account not only what is happening in their working world but also their own personal circumstances which are always changing. Although there will always be a certain degree of unpredictability about ICU nursing practice, nurses attempt to balance and monitor their involvement and workloads so that they function effectively in all aspects of their lives.

SUMMARY

Beaton and Degner (1990) summarise the human aspect of ICU nursing:

Nurses are not hardened or emotionally numbed by daily exposure to death and dying; rather they are sensitive human beings, deeply moved by the situations in which they find themselves (p.18).

Taylor (1992) sees that patients attune themselves with nurses because of a sense of affinity with nurses as human beings. When a patient is dying in ICU nurses use professional nursing expertise to ensure that the best possible standards of patient and family care are maintained. The Nurse as Person domain recognises that there is an important aspect to this time that touches the nurse as a human being and impacts on the experience for all those involved. The shared humanity and lifeworlds of nurse, patient and family mean that there is a mutual sharing of human existence and in this situation, suffering and loss.

The nature of the ICU lifeworld is that patients and families require and desire different types of relationships with nursing staff. In turn, nurses find their own capacity to work on a deep, intense level fluctuates between duties or days. Some nurses will form close relationships with some families and it is unlikely that every nurse involved with a particular situation will develop a relationship on a intense, personal level.

In order to optimise the human experience for as many families as possible, nurses recognise that they need to balance themselves including their capacity to give and coping effectively with their grief. This can involve a form of time-out from profound, demanding situations. The nature of caring for the family of a person dying in ICU is extremely demanding at both a personal and professional level. Nurses develop and use strategies that on a personal level, enable them to cope with the ongoing demands of their work situation. The informal role of the nurse incorporates what actually happens when nursing the family of people who die in ICU. The ‘Nurse as Person’ domain acknowledges the essential personal dimension of that role.

CHAPTER EIGHT

NURSE AS PRACTITIONER

The nurse as practitioner describes how the nurse, as a professional with specialised knowledge and skills, contributes to optimising the human experience for families who have a relative dying in ICU. The nurse as practitioner bases professional practice on knowledge derived from experience and research. Professional knowledge enables a sound rationale to be applied so that specific situations are responded to in the most appropriate way (Leddy and Pepper, 1993).

Benner (1984) comments that nurses in her study provided many examples of considering the patient's family as clients. Although her remarks are directed at the family promoting a positive role for the patient's recovery, the experience of the family members themselves is a legitimate concern for the nurse. The nurse requires professional competency in interactions with the patient, family, other health professionals and the bureaucratic system when a person is dying in ICU.

The nurse as practitioner functions as an essential part of facilitating an environment where the human experience of having a family member die in ICU is optimised. In this chapter, three themes will be described to demonstrate how the nurse as practitioner contributes to optimising the human experience for the family (see Table Three):

- * **Attending** emphasises the professional nursing actions and competencies that are required to care for the dying patient;
- * **Preparing** describes how the family is assisted and supported throughout the dying process and the time immediately following death particularly in terms of decision-making;
- * **Coordinating** involves establishing effective channels of communication and sharing information between health professionals and outside agencies.

Table Three: Domain - Nurse as Practitioner

NURSE AS PRACTITIONER
Attending
Preparing
Coordinating

ATTENDING

Attending describes the professional nursing actions that are undertaken in caring for the dying ICU patient and their family. Throughout the time a person is dying, basic physical and psychological needs must be addressed and met by nursing actions which demonstrate professional competence. The nurse has to be aware of the responsibility to deliver safe care, and be sure that adequate monitoring of physiological status continues. Professional standards of care must be maintained.

I didn't go out (with the consultant to talk to family) ...you've still got to remember your legal responsibilities, writing down a few numbers (Gay: 1 / 5).

Christensen (1990) uses the term attending to describe the nursing work that takes place during the moments of contact between a nurse and a patient. A component of attending is ministering which involves the application of selected nursing knowledge and skills to meet the patient's needs. Performance of skills can be planned and part of routine care but it also includes incidental activities that are performed in response to changes in the patient's condition. Attending and ministering are aspects of the partnership between nurse and patient. In order for the nurse to optimise the human experience of the family of

a patient who is dying in ICU, the family need to be certain that the nurse has the knowledge and skills to competently care for their family member.

I think the big thing as far as being professional goes is making sure the patient is still number one in your mind when you are working. That's probably the thing that cinches it for them [family] (Gay: 1 / 27).

Benner (1984) speaks of providing comfort measures and preserving personhood in the face of pain and extreme breakdown. She considers the nurse must move on from the usual mind-set of “doing-for” and “curing” the patient once it is recognised that a person is dying. This contributes to and acknowledges the sense of personhood, meaning and dignity. Benner (1984) states:

Many nurses must face the fact that there is little they or others can do to prolong the life of a patient. On the other hand, there is often some room to enhance the quality of life, short though it may be, of the patient's last days in the hospital. While the nurse must be able to give up on trying to save the patient's life, she or he must not avoid the patient and must still find ways of providing comfort for him and his family (p.55).

Professional attending and ensuring the patient receives the best standard of care even though they are dying is a way nurses demonstrate caring for both the patient and the family. Aside from institutional policies and professional responsibilities, nurses talk about ensuring the patient is as comfortable and as pain-free as possible. Nursing actions, such as ensuring mouth and eye care are regularly performed, and that the patient is well-groomed, are part of caring and maintaining a professional standard. These are also overt ways the nurses can demonstrate to the families that they do care about their dying relative. It is necessary to convey to the family that the nurse is concerned about the welfare and dignity of their family member even though they are dying. Their status as a person and as a valued and vital member of their family group is able to be recognised and communicated to the family through the physical acts associated with providing a high standard of care. The family and patient are entitled to respect as people, even though death is imminent.

I think as long as they know that their relative isn't suffering that's the big thing with me, to know that we've given them pain relief ... we've cleaned their mouth out or any kind of comfort we give to the patient (Gay: 1 / 1).

Walters (1994b) comments that comforting the patient and providing pain relief are fundamental priorities for critical care nurses. He considers this provides recognition of both the subjective and objective qualities of the body. Although the subjective qualities are appreciated and valued, the actual physical or material needs of the body must be recognised and adequately attended. In an everyday sense, people attach a priority to meeting the physical needs of their bodies. In recognising that these needs are important, the nurse demonstrates respect for the personhood of the patient in the eyes of the family.

Although physical attending is seen as vitally important, it is not an issue that the nurses chose to explore or describe in significant detail when asked to describe their experience. Attending requires application of professional knowledge to meet the physical needs of the patient's body. ICU protocols and routines concerning regular comfort care are followed.

The physical condition you can deal with because you are clinically equipped for it. You've got your monitors, you've got your drugs, you draw them up, you fill your burettes, you talk to the patient, you change their position, you physiologically look after them (Al: 1 / 5).

Nurses see the action of providing physical care to the patient as an essential part of their role. However, they chose to emphasise the less visible aspects of nursing throughout the interviews perhaps because it is so much part of the taken-for-granted aspect of their nursing role. Demonstrating the ability to care competently for the patient is seen as a way of reassuring the family that everything that could possibly be done is actually being done. On a superficial level, attending to and meeting the physiological needs of the patient is not directly part of the nursing role with the family. However, if this is not accomplished, the nurse's competence and credibility will be doubted and the human experience of the family cannot be optimised. Nurses feel subsequent interactions with family members can be jeopardised if the family are not

convinced that the nurse has the necessary knowledge and skills to care for their dying relative.

I don't think it would matter how well you got on with them [family] .. if they thought you just didn't do things enough or whatever ... you didn't give the right care, I think they ... they wouldn't like it ... you definitely have to be doing the right thing (Gay: 1 / 28).

Attending involves undertaking the professional responsibilities associated with maintaining and monitoring the physiological status of the patient. Frontline assessment by the nurse is demonstrated to be central for optimal patient care (Benner, 1984). In order to optimise the human experience for the family members of the dying patient the nurse must demonstrate professional competence in the area of direct patient care. Although attending does not involve a direct link between the family and the nurse, it is an essential link if a positive relationship is to be established and maintained.

PREPARING

Nurses use a variety of techniques to help prepare the family for the impending death of the patient. Preparing is the term chosen to describe how the nurses support the family through the dying process and help them get ready for the time immediately following death. Families may not have had any experience of death and may be totally unaware of the bureaucratic requirements of choosing a funeral director or formally identifying the person. The shock of the admission to ICU may have thrown their lives into a state of chaos where they are unable to think about who they should notify or where to turn for help and advice. Nurses blend involving the family in decision-making with professional knowledge of a vast range of possible options so that the human experience is optimised.

Preparing is similar to the theme of Involving described in the key strategies in Chapter Six. While involving implies a sense of giving over some control and choice to the family, the focus of preparing is more directly concerned with practically getting them ready for the impending death of their relative in terms of the types of bureaucratic requirements and formal procedures they will face.

Possible options can be presented so that the family is forewarned of likely scenarios and avenues of support. This may need to be repeated and discussed with different members of the family. It is recognised that in order to smooth this stressful time, ideally the nurse needs time to establish rapport with the family and spend time developing a trusting relationship. The type of information the nurse needs for preparing the family for this time often emerges through ongoing presence, support and dialogue.

It made it all seem as if it was just a progression really ... assessing what there needs are, do they need to see someone about their financial situation, do they need some counselling options made available to them, they need to know who is going to feed the cat, but that is only stuff that you do find out if you spend time with them and talk to them about what it is that they ... where their scenarios are at and what's happening (Caz: 1 / 9).

During the time that it is certain that the patient is dying, nurses often make environmental changes so that the family are able to given space and time to be together. This can mean moving the patient to a more private area of the unit or a side room. In recognition of the fact that the family may have only a few hours left with their dying relative, visiting policies are usually relaxed. Family members are supported and encouraged to come and go as they please. In a sense the nurse's priority shifts from trying to save the life of the patient to enabling the family to spend time with their relative.

If there are a lot of people and the person is dying, we often will nurse them in the side room so then it really doesn't matter how many people come and go, so it doesn't interfere with anyone else in the unit ... You're probably just in and out and just keep your distance and give them ... the family ... time (Fay: 1 / 19).

In some situations the nurses describe a 'hands-off' approach, supporting the family in whatever decisions they make. Families may make requests so that their beliefs, customs or rituals can be appropriately observed. In other situations the family actually seem to need some form of guidance from the nurse as to what they can do or what options they can consider. Nurses are also

aware that some decisions are extremely difficult for the family to make, and that once a decision is made it may not be reversible. Without wanting to pass their own personal opinions and feelings onto a family, nurses recognise that in some situations their professional and personal experiences give them insights into options and eventualities that may not occur to the family. Other members of the family who have been unable to visit because of factors such as age, disability or injury may be able to visit at the family's request. The nurse may suggest various options and liaise with other hospital departments or outside agencies so that visits can be arranged.

I just said to them, like these are your options ... and they didn't really know. I said my feeling was that they should bring him back here initially. I said if it doesn't work out and you don't feel comfortable with it then we can look at just taking him to the funeral directors or putting him in the mortuary. I think it was really positive for them because it didn't separate the family (Caz: 1 / 8).

I rang and said "He is not well, I think you had better come". But she said "But I've got my tea on now, and so-and-so is not home". And it was, well you've got to make the decision, I can't make it for you but I said "I'm just letting you know" and at least she came in later on, but I thought .. well what could I do, I couldn't do any more (Deb: 1 / 14).

Preparing is a process that nurses facilitate to help ease the burden of sudden, irreversible decisions that confront a family when a relative is dying in ICU. It involves creating space and time so that the family can consider a variety of possible scenarios before making decisions or before being forced to make a decision that they have had insufficient time to discuss amongst themselves. The process of preparing extends to the wider ICU surroundings where the nurse facilitates an environment that is conducive to the family retaining privacy and control in their decision-making with the nurse acting as a resource in terms of options and possibilities.

COORDINATING

A large number of health professionals may be involved with different aspects of management of an ICU patient, but it is only the nurses who are constantly present 24 hours a day. Coordinating involves the nurse facilitating processes so that connections are maintained between all the people involved in the situation. This includes health workers and the family. Coordinating is closely linked to Bishop and Scudder's (1990) view of the nurse as an in-between, a term which helps to describe the position from which the nurse works to optimise the human experience for the families of people who die in ICU.

Jacques (1993), observing the work of nurses, notes that nurses are often responsible for conveying information that is relevant to the care of the patient, from one party to another. Sometimes this passing of information is not necessary for the job at hand but does ensure the effective, overall running of an area and smoothes the experience for the patient and family. Jacques found that other health professionals are routinely aided in the performance of their work by the network of nursing communication which scans the environment, selects the relevant information appropriate for various team members and then delivers the information to the appropriate person so that they can concentrate on their own specialised work. This aspect of nursing work is not clearly articulated by the nurses in Jacques' study even though such activities occur frequently. The role appeared taken for granted by both the nurses who perform it and others who benefit from it. He comments that for much of this 'invisible' nursing work, the visible outcome belongs to another party. Coordinating may be facilitated by nurses and contributes significantly to optimising the human experience, however the nursing contribution may be invisible.

The nature of ICU nursing means that nurses are usually responsible for only one patient per shift with whom they are in close proximity at all times. Responsibility for only one patient inevitably means that the nurse at the bedside is often the health professional most aware of all the aspects of the situation. The ICU nurse is the health professional most referred to as the person responsible for meeting the needs of the family of the critically ill person and determining the extent of family involvement in the ICU setting (Hickey and Lewandowski, 1988).

The nurse shares time with the patient and family so knows the unique blend of factors that impact on their particular circumstances. Other health professionals such as medical staff, physiotherapists and social workers may be involved but, due to commitments to other patients, do not have the time to access the depth and breadth of information that is disclosed to and shared with the nurse. The need for referral to another member of the team or the lack of resolution of an issue involving another health professional may be signalled to the nurse by the family. Staff from other disciplines may need to be contacted by the nurse at any time including outside normal working hours. The nurse is therefore placed in a position where acting as in-between, and coordination and sharing of relevant information with all the health care team is an important and vital professional role.

... The family though they come to you and talk to you about what they actually want. It's up to you then to negotiate I suppose ... negotiate with the doctors to look after the family's needs (Bev: 1 / 2).

In terms of the coordinating role of the nurse, the most frequently cited examples are situations where the nurse acts to communicate the family's wishes to medical staff. The nurses see it as part of their job to facilitate communication with medical staff and act in a family advocacy role. Unlike the nurses, ICU medical staff have responsibility for a number of patients in the unit and, depending on the institution, a range of responsibilities outside the ICU area. Doctors make decisions concerning the medical treatment of patients and therefore, to some degree, have the power to prolong life through continuation of medical treatment and instigation of new therapies and treatment regimens. Medical staff may keep the family informed about treatment but are not able to share space and time with the family like the nurse who is at the bedside. By sharing space and time with the family, the nurse becomes aware of their realities and, when appropriate, seeks to ensure they are communicated to medical staff.

... the doctor wouldn't have known that the family were so distressed ... it wouldn't have been his fault, he didn't know ... but the nurse was the one that was told that by the family so she did the right thing by informing the doctor and fortunately the doctor agreed (Gay: 1 / 26).

If you make commitments to people that you stick to them, like if you say you are going to switch that person off the ventilator at such and such a time, that you do because relatives often place a lot of emphasis on issues like that (Caz: 1 / 11).

In order to optimise the human experience while a family member is dying in ICU, the nurse attempts to coordinate and facilitate meeting bureaucratic and institutional requirements. For example, a significant proportion of deaths in ICU become coroner's inquests and formal identification of the deceased by a relative in the presence of a police officer must occur prior to the body being released from the hospital. Obviously, deaths occur at any hour of the day or night but the legal formalities must still be completed. The nurses attempt to coordinate this process so that the least possible disruption and distress is caused to the family. This is another example of the invisibility of much nursing work. The family are probably unaware that coordination is occurring away from the bedside because this formal requirement is met in a way that causes the least possible distress and disruption for them. They have to accept the requirement to identify the body whether it occurs in the unit before they leave the hospital or whether they are required to return to the hospital mortuary at a later time. In situations where the family does face the additional distress caused by returning to the mortuary, they will usually be unaware that it could have been any different.

As long as they appreciate that the death certificate has to be done, the coroner has to say it is OK ... that is something that nurses need to do I think ... is make sure things do move along quite quickly (Bev: 1 / 24).

If it is going to be an inquest, a coroner's inquest, I make sure they ... I get the policeman there before they go because I think it is very important they don't have to come back ... I always try to get that sorted out before they go because there's nothing worse than having to come back (Deb: 1 / 14).

Farrell (1989) describes how meeting the statutory requirements for registering a death and disposing of the body can be a distressing experience for relatives. Practical information concerning the death and funeral for a family member

would also be useful (Hall and Hall, 1994). Nursing actions such as careful explanation regarding the need for post-mortem examination and providing written information regarding legal requirements and funeral arrangements can help to alleviate some stress. As a caring gesture, Farrell suggests the nurse should ensure relatives have some support from friends or other family members when they leave the hospital.

The nurse is in a position where facilitation and coordination of communication between health professionals and related disciplines is required to ensure that all legal and professional responsibilities are met. When a patient dies, certain procedures must be followed such as the formal identification of the deceased. If the nurse fails to coordinate or facilitate bureaucratic procedures, the family will be subjected to delays and unnecessary additional stress. By acting as coordinator the nurse is able to minimise disruption and optimise the human experience within the context of meeting legislative and institutional requirements.

SUMMARY

The nurse as practitioner acts as a health professional ensuring that professional standards are maintained and that the legal and bureaucratic requirements are met following death in ICU.

An essential part of optimising the human experience when a relative is dying in ICU is demonstrating professional competence and care in interactions with the patient. Family members must be assured that the nurse has the knowledge and skills to deal with all aspects of patient management. The nurse as practitioner coordinates communication between health professionals and appropriate outside agencies. The role of various health professionals often needs to be explained and clarified with the family. Aspects of death in ICU that are particularly unpleasant for the family such as formal identification of the body are coordinated by the nurse in order to optimise the human experience and to avoid the added burden of returning to the hospital mortuary at a later time.

Nurses use professional experience and knowledge to prepare and assist the family with difficult decisions that may have to be made concerning impending

death and the issues and arrangements immediately following death. They are aware of a vast range of options that may be explored and are able to smooth the process of decision-making for families by presenting a range of possibilities when matters concerning death arise.

The nurse as practitioner uses professional skills, knowledge and judgement to ensure that the family experience is optimised when a person is dying in ICU.

CHAPTER NINE

NURSE AS COLLEAGUE

The domain Nurse as Colleague is concerned with the relationships among nurses and between nurses and other health professional groups. The themes that emerge are concerned with the broader context of facilitating an environment where the human experience can be optimised rather than directly describing the relationship between the nurse and the family. The Nurse as Colleague domain is not as extensive as other domains that have been discussed. However, the lifeworld of ICU is such that collegial relationships and working effectively as a team are essential if the human experience of the families is to be optimised.

It has already been acknowledged that nurses use different approaches and place different emphases on working with the families of patients who are dying. Throughout the interviews there is a persistent theme that as a group, the nurses try to be as consistent as possible in their team approaches to families. There is also frequent reference to the need to be supportive of colleagues and their practice. This is a reciprocal type of relationship where nurses acknowledge that they, in turn, need to feel their own decisions and actions will be supported by colleagues. In creating an environment where the human experience of a family member dying in ICU can be optimised, nurses give examples of both supporting and being supported by colleagues.

Three themes will be explored to illustrate the domain nurse as colleague (see Table Four):

- * **Affirming** describes the way nurses maintain consistency of the overall philosophy and nursing approach with the family;
- * **Supporting** is the personal and professional assistance given to colleagues to ensure they are placed in the best possible situation to work effectively with the family;
- * **Reflecting** is the process that nurses use to evaluate and share the effectiveness of their own and their colleagues interactions with families.

Table Four: Domain - Nurse as Colleague

NURSE AS COLLEAGUE
Affirming
Supporting
Reflecting

AFFIRMING

Affirming refers to the fact that individual nurses practise as members of the wider ICU nursing team who seek to maintain a consistent approach in all aspects of patient and family care. Nurses seek to uphold and confirm the team approach and ratify decisions and practices of each other. The requirement to provide 24 hour a day, seven day a week nursing care means that a number of nursing staff will work closely with a particular patient and their family. The nurses recognise that as individuals there will be minor variations in their approaches and interactions with the family and in their patient care. There needs to be consistency in the overall philosophy and nursing approach so that individual practice is congruent with the approach of the nursing team as a whole. Nurses clearly articulate the need to affirm and endorse the actions and practice of colleagues. A consistent, team approach with the family can be maintained while still tolerating, or even encouraging, some individual diversity.

...it's important among those three nurses, the day, the evening and the night to be aware of what the other has said and to not give conflicting information. Consistent information from the three shifts is important and you are piggy in the middle. In my experience, they [family] do ask nurses because the nurse is the

one who is at the bed for 24 hours, there's always the white uniform there (Al: 1 / 10.)

Benner (1984) recognises the importance of working effectively as a team. Under the domain of organisational and work-role competencies, she considers building and maintaining a therapeutic team is necessary to provide optimum therapy. In the ICU setting, patient therapy is extended to include the family. Working as a team certainly helps to optimise the human experience for families and also to maintain staff morale.

Nurses are aware that families notice and, in some situations, comment on differences between nursing staff. These comments can relate to information that has been given or the way patient care is performed. In these situations there is the potential for conflict between nursing staff unless clear channels of communication are maintained. Benner (1984) believes that differences of opinion amongst health team members are inevitable and necessary. She states that different relationships will elicit different responses and that this can be positive. Nurses need to be aware and accepting of differences between themselves and colleagues and reassure families that the goals are the same.

They [families] subtly do it saying "Oh well, so-and-so said that ... " and sometimes they play us off against each other (Eve: 2 / 6).

They'll say, one nurse does it this way and I say well there's lots of different ways of peeling a potato but the potato is peeled just the same ... I think it is just we all do things differently (Eve: 1 / 18).

Nurses recognise that family members often need to ask the same questions many times. The stress of the situation, lack of sleep, uncertainty about the future and a multitude of other factors interfere with the ability to hear and understand explanations. Differences in practice or techniques, that from a professional point of view are quite minor, need to be explained to the family to reassure them that a consistent approach is being taken by different nurses even though it may not have appeared that way to them. In providing this reassurance, affirmation of the practice of colleagues is given. In turn, a

consistent message is given to the family by all members of the nursing team by both words and actions.

Perhaps we do talk slightly differently, every staff member, but they get given the same answer probably in the long run (Fay: 1 / 3).

They are watching you do things, and then somebody else comes along and does it differently, they'll say, "That's not the way that she does it, you're supposed to take the tape off before you do that". That can get very frustrating because it can build up animosity among nursing staff if it is not spoken about (Al: 1 / 11).

In some situations there may be significant differences of opinion between nursing staff about management of the case, particularly the decision whether or not to continue treatment. Complex ethical issues such as longevity versus quality of life or futility of treatment may arise and cause friction amongst staff. Some members of the nursing team may feel that treatment should be discontinued or that the efforts to prolong life have become unreasonable. In a particular situation, a nurse may become too uncomfortable to continue to be personally involved in a particular case because of the treatment (or non-treatment) approach. A practical way this can be resolved is by those who are in agreement with the medical decision choosing to continue involvement with the patient and family. However, in some situations a nurse believes they are the most appropriate person to work with a particular patient and family even though they do not personally agree with the decision to continue or discontinue treatment. Maintaining consistency in the team approach is still seen as a priority in this situation.

It's not really fair on them [family] to know there's a big division ... there's a big fight going on ... I think you've got to show a united sort of front, even if you don't agree (Gay: 1 / 25).

In general, the nurse as colleague affirms the actions and approaches of other nursing staff as part of providing a consistent, team approach to working with the patient and family. This is extended to the overall health care team where

effective communication ensures that consistency in information is maintained. Daly (1982) comments that consistency of information by all health professionals helps prevent disorganisation of the family unit. Nurses need to be aware of the nature of explanations given by colleagues so that they can affirm and support those explanations. In order to optimise the human experience for the family while a relative is dying in ICU, wherever possible nurses affirm and endorse the practice and decisions of their colleagues in order to demonstrate consistency in the overall nursing and team approach.

SUPPORTING

The nurse as colleague has a role in providing support and assistance on personal and professional levels to others who are involved with caring for the families of people who die. Nurses support other nurses but the coordinating role of the Nurse as Practitioner means that it is often the nursing staff, acting as colleagues, who provide support to other health care professionals who may have personal knowledge and involvement with a particular family.

The personal toll of working with people through this immensely emotive and often tragic time has been acknowledged. Walters (1994b) describes comforting other staff as part of the role of the critical care nurse. Experiences are shared in a unique way and the sense of being in the world together enables colleagues to develop an appreciation of shared feelings. In times of distress, it is often other ICU nursing colleagues who are the first line of support on a personal level when a nurse has been working with a particularly challenging or demanding situation. Fenton (1985) examined the role of clinical nurse specialists and finds that a significant proportion of their time is spent providing emotional support to other staff. Nurses in the present study do not distinguish between 'levels' of nursing staff. Supporting other staff and in turn being supported by others is acknowledged as part of everyday ICU nursing practice for all staff.

Farrell (1989) sees impending death in ICU as affecting the patient, the family and the ICU staff both individually and collectively. The morale of the whole team can be affected by a patient death. Staff may feel that they have failed to meet their responsibilities to the patient and relatives; they may feel personal sadness at the death of the patient and what that loss will mean to the family. Farrell recognises that staff themselves may need support and comfort at this

time. He suggests regular informal meetings for staff of all disciplines so that staff are supported and encouraged to express their feelings and experiences. It seems the people most appropriate to provide that support are professional colleagues who work in or understand the particular area.

It's difficult for you, I think sometimes to get support from anyone else from out of the unit, because no-one else actually acknowledges the scenario, sometimes you've got to be 'in-house' to get the dynamics of the whole thing ... That's where supportive colleagues is, I think, very important (Caz: 1 / 13).

As part of the supporting process, nurses maintain an awareness of the workloads their colleagues are carrying and acknowledge the unique dynamics of each situation. Sometimes a particular staff member may have had an especially difficult time due to the actual mix of duties they have worked or the type of patients and families with whom they have been involved. As colleagues, nurses are aware of events in their each others' lives such as family crises, bereavement or pregnancy which may make working with highly emotive situations more difficult. Balancing has been addressed in the Nurse as Person domain and has been discussed as a personal responsibility. The Nurse as Colleague recognises that individual nurses are best to determine the nature of the workload they can manage, however, as a colleague the nurse does maintain an awareness of others. It may be necessary for a colleague to gently offer a lighter day in terms of workload. A nurse who has faced a traumatic situation in their work or personal life may be feeling vulnerable and unable to speak out stating their preference for a lighter workload. The Nurse as Colleague supports someone in this situation by recognising that a particular scenario may be difficult for them and offers an alternative.

I've had so many cards from the unit, so many phone calls and even people phoning up a month down the track ... I said I'll sit in through report and see how we get on and I just went up the other end ... the support is there and the option to say "No" without being thought less of as a nurse (Eve: 2 / 18.)

As colleagues, nurses are aware of relationships and bonds that develop between individual nurses and particular families. Nurses are aware there are some families with whom they seem to develop a particularly close rapport.

Several nurses described finishing a duty with a patient but then were distressed when they found the patient had suddenly deteriorated and died before their next duty. This is particularly distressing in situations where there actually seemed to be some improvement in the patient's condition. As part of being supportive colleagues, on occasions nurses would contact a primary nurse, or someone closely involved, and inform them of the death even on their days off.

It has happened to me that someone has rung and said that so-and-so has died which is actually really nice, rather than reading it in the paper. Although you know it is going to happen, it's just nice ... so that is consideration from other staff members to you (Fay: 1 / 10).

The nurse as colleague maintains an awareness of the overall workload of the unit and is supportive to other nurses whose workload is particularly challenging. This support may be in practical terms such as making sure someone receives assistance with patient care when required or is relieved for regular breaks when working alone in situations, such as with patients in side rooms or isolation. Support may be more in terms of emotional support. Farrell (1989) specifically mentions that nurses need to offer staff who have been caring for a dying patient on a long-term basis the opportunity to care for other patients as a respite from the stress of the situation. Some situations are personally and professionally more difficult to deal with than others and, as colleagues, nurses feel the need to maintain an awareness of the situations in which their colleagues are placed.

I know it made it easier for the nurses in there [patient in isolation] if different people came in, and I think others did ... so the nurse didn't feel isolated (Bev: 1 / 14).

Offering personal and professional support to colleagues is seen as critical to maintaining an environment where nurses are able to work effectively with families. Supporting each other is part of the team approach to ICU nursing where no one nurse can be solely responsible for the outcome of a situation or experience of a particular family.

Most of us tend to give each other a lot of support, I think that is one thing where the unit is very good, we do support each other

... I think if you support a nurse and it helps the nurse and the family (Eve: 1 / 21).

Optimising the family experience requires nurses to support each other in terms of actual nursing actions. This is a form of professional support. The nurse caring for the patient may need to be with the family away from the patient. In this situation colleagues will take over some of the patient care tasks that require general registered nurse skills rather than specific interpersonal skills and an intimate knowledge of the particular family situation.

I did that with her [wife] while somebody else took the tubes out and all the lines and that. That's another thing that was a wee bit different, normally we see to the patient but in this instance I went with her and left another colleague to take him into a private room (Al: 1 / 3.)

The family experience while a relative is dying in ICU is able to be optimised when a positive working environment exists for the nursing staff. The nurse as a colleague supports others on both professional and personal levels so that as a team the nurses are able to work effectively with all families.

REFLECTING

The nurse as colleague works with others to review the effectiveness of personal and team nursing practice. Part of reflecting involves discussing what has happened and how the situation may have been managed differently from a range of perspectives. This is directly related to how nurses learn in the practice setting. Palmer, Burns and Bulman (1994) comment that reflection is an idea that is used in ordinary, everyday life whereas, within educational circles, it has become a complex, difficult to explain and perplexing phenomenon. Reflecting as a theme in this study is used in the more everyday sense. Reflecting is used to describe the process nurses use to think back on, meditate on and evaluate a situation that has arisen within their practice.

Schon (1987) speaks of reflection in action and reflection on action. Nurses appear to use a form of reflection on action frequently on an informal level. In a formal sense reflection on action is the retrospective contemplation of practice

that is undertaken to uncover the actual knowledge used in a particular situation by analysing and interpreting the information as recalled (Palmer, Burns and Bulman, 1994). In the nursing setting, this type of reflection can be useful because it encourages speculation about how the situation could have been handled differently and what other information may have been useful.

Rather than use the noun 'reflection' which implies the more formal, educationally derived concept, the term 'reflecting' is used in this study. This illustrates the processes that nurses working with the families of people who die in ICU describe as the way they evaluate, review and discuss the effectiveness of their practice with colleagues. Nurses 'chat' with others at tea breaks, on night duty or during periods of lighter workload. Although superficially this may appear to be just nurses 'chatting', it is an important component of maintaining consistently high standards of care. It usually occurs spontaneously and could be viewed as an informal form of peer review. They are able to be honest about their thoughts, feelings and reactions and may find that theirs are the same as others. Nurses share experiences and learn from the experiences of others. Nursing actions and interactions with families are discussed, analysed and evaluated on an informal basis.

Reflecting by talking things through may be deliberately initiated by a nurse who seeks out a colleague whom they believe is supportive and able to listen. It is evident in the interviews that this occurs both at work and outside work hours. The idea of reflecting occurring spontaneously, and between or amongst colleagues, is consistent with the oral tradition of nursing where information and knowledge is often passed by word of mouth rather than in written form.

I think it is really good if you've got people at work to talk to ... people at work, like [name], I could talk to about anything ... (they're) always a good listener and handles ... gets so involved in these situations anyhow but ... I'm just able to talk to people about it I think. We just get it off our chest (Bev: 1 / 27).

Nurses find that when they are involved in a situation where perhaps they felt they have not been able to function at the level they expect of themselves, it is useful to reflect on their own practice with colleagues. Colleagues who are aware of the broader context of the situation and the people involved, such as

the family and other health professionals, can offer valuable insights. Sometimes nurses need reassurance that their practice and decisions were appropriate in the circumstances.

I did speak about that, I normally do ... I felt I hadn't worked as well as I could have. I normally do try and speak to a few colleagues about it and that what they said, I'd probably helped her realise just how hard it was going to be (Gay: 1 / 23).

Reflecting seems to be an important part of the balancing and debriefing process. Debriefing tends to be used when a more formal review of the situation occurs and usually involves all health team members involved in the scenario. A person with group facilitation skills may be involved. Although the term debriefing was mentioned by several nurses, it was acknowledged that it has not been part of normal procedures in that particular ICU. Debriefing had only occurred some time after a particularly tragic scenario, although some nurses questioned its effectiveness, others were more positive that it had been of use.

We had a debriefing with the medical staff about why things were done ... just little things like that ... why was this done and what could have been improved or not improved so that's pretty helpful for everyone concerned (Fay: 1 / 11).

Reflecting with colleagues occurs as part everyday ICU nursing practice. By sharing experiences, nurses are able to learn from each other and evaluate the effectiveness of a range of nursing actions. Discussing and reviewing the approaches taken means that nurses are able to then use that experience to optimise the situation for families that they work with in the future. This is a healthy dialogue about nursing. It enables nurses to share their philosophies and beliefs about nursing in ways that promote the likelihood of maintaining consistency and support for each other professionally and personally in future situations which involve similar circumstances.

SUMMARY

The nurse as colleague is a vital aspect of optimising the experience of people who have a family member die in ICU. The nurse as colleague involves both

giving and receiving support and advice as part of a larger nursing team who are committed to maintaining a consistent approach with the family to optimise their experience. It is difficult for a nurse to give personalised, supportive care if this is not the norm and the usual standard of practice or expectation of colleagues and leaders in the particular practice area (Peterson, 1988). The nurse as colleague enables optimisation of the human experience by emphasising the necessity to affirm the practice of other nurses, and provide personal and professional support for colleagues. Nurses reflect on experiences to process the overall effectiveness of specific nursing interactions with a family so that individual and team nursing practice can be informally evaluated.

The human experience of the family members can only be optimised when nurses work effectively as a team which involves both supporting and being supported by each other.

CHAPTER TEN

DISCUSSION AND CONCLUSION

Discussion concerning the findings and the key strategies associated with optimising the family experience has been blended throughout the data chapters. The purpose of this final chapter is to reflect on the findings in the context of its broader contributions.

A summary of the findings of the study is provided and its contribution to nursing knowledge discussed. The implications of the study from the perspectives of nursing practice, education and research are examined. Limitations of the study are acknowledged, recommendations for practice outlined and suggestions for further research are made. My own personal learning that has resulted from doing this study is discussed with reference to the topic and to undertaking research using a phenomenological approach.

FINDINGS OF THE STUDY

This study has explored the lifeworld of ICU nursing with particular emphasis on nursing the families of people who die. Interviews with seven nurse participants revealed the nature of their work with families within which the phenomenon of optimising the human experience could be identified.

The theme **optimising the human experience** proposes that nurses endeavour to make the time surrounding death in ICU as positive as possible, given the overall tragedy of the experience. They use strategies such as being there, supporting, sharing, involving, interpreting and advocating in their interactions with members of the family. Nurses work with the family to try to make their last hours or days with their relative a special time that they will be able to look back on with some positive feelings or memories if at all possible. The constant presence of the nurse, because of the one-to-one nurse-patient ratio that usually exists in ICU, means that the nurse is in a position to develop a close relationship with the family.

However the relationship with the family is not sufficient alone to optimise the human experience. From the interviews, three domains were identified that enable optimising of the human experience to occur. The domain **nurse as person** acknowledges the fact that the nurse, as a fellow human being, wants to personally help other human beings who are suffering. Sometimes nurses are unable to switch off from the tragedies in their working lives to normally engage in their own personal life. As a consequence, nurses develop strategies that do enable them to manage their grief and maintain balance in their own lives so that they are able to continue working effectively with families suffering tragedies. In order to continue optimising the human experiences of families in an ongoing sense, nurses must learn to manage personal issues so they can remain working with dying patients and their families over a prolonged period of time.

If the family experience is to be optimised, the family must also be certain that the nurse has the necessary knowledge and skills to competently care for their dying relative. The competent practitioner is able to access resources and present a range of options to the family so that they can make choices about matters that may enhance their overall perception of the time. Because of the time spent with the family, the nurse becomes an in-between link between the family and the health care team. Strategies are used to ensure open and effective communication is maintained between all the health professionals involved in a particular situation. This occurs within the domain **nurse as practitioner** and is a necessary component of optimising the human experience.

The last domain is **nurse as colleague**. In order to optimise the human experience of the family, there needs to a degree of continuity and consistency amongst the team of nurses who are directly working with the family and patient. Nurses need to support each other in maintaining professional standards of care and in being prepared to value time spent with a family as a legitimate and vital part of nursing work. Colleagues can be a valuable source of support in a personal and professional capacity. The support of the nursing team for each individual practitioner is necessary for the human experience to be optimised so that the family perceive a sense of continuity and predictability about their relationship with nursing staff at the bedside. In turn, a nurse who feels supported and affirmed by colleagues when working with the family will function as a more effective team member, enhancing the overall working environment of a particular unit.

One of the important features of this study is that the interviews with the nurses clearly identified that they consider the families of people who die in ICU are actually nursed. The family and patient are seen, in an inextricably blended way, as the recipients of nursing care, knowledge and actions. Work with the family to optimise the human experience can be justified from the participants' perspectives as a vital and legitimate part of nursing work.

CONTRIBUTION TO KNOWLEDGE

This study has specifically explored an aspect of nursing practice that has not been described in an in-depth way in a New Zealand context. No published research concerning nursing and families in ICU in New Zealand has been found. However, it is important to re-iterate that due to the nature of this study and the small group of participants involved, generalisations about the nature of nursing families in ICU cannot be made. The study therefore provides a sample-specific description of nursing practice. It is an participant verified interpretation of nurses' descriptions of their practice in two specific settings in the mid-1990s.

This study legitimates, from the perspectives of the participants, the importance of nursing work with families of people who are dying in ICU. Nurses work with, and interact with, a much wider group than the patients for whom they are officially mandated to care. In this situation, the nurses' descriptions reveal that the family can clearly be regarded as recipients of nursing care even though there is no official sanction for this care. Nurses believe that if a close relationship with the family is able to be developed, it is more likely that the family will have some positive memories of a particularly significant and tragic time in their lives.

Much of the published literature concerning families in ICU uses a needs-based focus (see Chapter Four). Walters (1994b, 1994c, 1995b, 1995c) has used phenomenology to develop a description of the lifeworlds of critical care nurses and nursing. This study is different in that it focuses specifically on describing nursing the families of people who are dying from the perspectives of the nurse participants. The findings add to the wider literature that provides and expands descriptions of the personal and professional roles of the nurse. What perhaps is

different in this study is that the strategies identified to optimise the human experience can be seen to be supported and enabled by the three domains of nurse as person, nurse as practitioner and nurse as colleague.

The concept of optimising a human experience may contribute to nursing knowledge because it articulates the way in which nursing work seeks to make the best of a particular situation or set of circumstances. Nurses often work with people and their families who are facing sadness, loss and grief whether that be the death of a loved one, a change in health status or an alteration in life circumstances. In many of these cases, the nurse seeks to optimise situations that may be tragic, but it is still worthwhile to help the family to make the best of what exists. The phenomenon of optimising the human experience may also capture the essence of nursing in other practice settings, or at least it may cause nurses to reflect on their work with families.

IMPLICATIONS OF THE STUDY

Nursing research becomes meaningful when it is placed within the broader context of nursing knowledge and its relationship to practice is clear.

Nursing Practice

This study supports the view that the family are an integral part of ICU nursing practice. When a patient is dying, the focus of nursing care can shift from intense technological intervention aiming to prolong or save life, to establishing and nurturing an environment where the family's experience is optimised. The nurses in this study expressed a commitment, at a personal and professional level, to seeking to optimise the human experience.

In the practice setting, optimising the human experience occurs when the nurse caring for the patient has the commitment, time and skills to work with the family. The individual nurse at the bedside must have, and demonstrate to the family, an appropriate level of professional competence. Families become very aware of patterns and routines that are obvious measures of professional competence. The implication for practice is that ICU nurses must be appropriately supported and the unit resourced adequately for staffing levels that enable experienced ICU nurses to work with patients who are dying.

The dying patient may not require nursing interventions demanding a high level of technological expertise from the nurse. New staff or pool or casual staff may be assigned the dying patient with experienced ICU nurses engaged elsewhere where their technological skills are perceived to be best utilised. However, if optimising the human experience for the families of dying patients is recognised as an important priority, there are implications for the allocation of staffing in a way that best meets the requirements of all patients and families. Less experienced staff may not be able to demonstrate the confidence or level of professional competence to which the family of a dying patient have become accustomed. The family may have developed a relationship with a staff member who it is preferable is able to continue working with them even when the demand for technological expertise is reduced. Nurses who have developed a close relationship with a family may want to continue working with them as a way of working through their own feelings of sadness.

Nurses clearly articulated the personal toll that working with tragic situations day after day can have on them as people. Support measures need to be instituted at an individual, unit and institutional level to assist them continue working effectively. This could include employer-funded individual counselling services, clinical supervision, critical incident debriefing and/or acknowledgment that in some situations attendance at a patient's funeral is actually part of nursing work.

Nurses need to be reassured about the importance in personal and outcome terms for support for colleagues, and of being supported by those colleagues. In areas where there is a high staff turnover or frequent use of pool or casual staff, it may be appropriate to organise staff meetings or debriefing sessions so that staff working different duties actually have the opportunity to meet. This would enable nurses to discuss issues or situations that have occurred and how they perceive the nursing team is operating. It would provide a forum for all staff with a range of levels of experience to be able to share ideas and collectively discuss any matters where individual staff members have ongoing concerns. Maintaining a mutual awareness of the nature of the workloads of other staff and offering assistance both individually and within the group, when appropriate, can help contribute to a healthy working environment. Some situations have been identified as particularly difficult, such as working in isolation or siderooms, where the nurse can be left alone hour after hour. The

presence and support of other staff who regularly check if anything is required supports the nurse and gives the family a chance to become familiar with a number of staff who may work with the patient on subsequent duties. Staff who have been working with a particular patient or family should, wherever possible, be given the option to continue or not continue working with that person on subsequent duties. They may want to continue with someone who they feel they work effectively with, or may choose to have a break from the particular situation. It is an important individual responsibility for each member of the nursing team to maintain an awareness of the workload and circumstances of their colleagues.

Nursing Education

ICUs are often regarded as specialty areas where pre-registration students are not usually placed for clinical experience. Many students will complete nursing degree programmes having never worked in an ICU. The impact of acute illness and hospitalisation, along with understanding death and dying for both the patient and their family, are included in comprehensive nursing programmes. Students are encouraged to develop a view of the individual as part of a wider network of people who are significant in their lives.

As students learn the role of the registered nurse in acute care settings, a focus on the achievement of tasks and skills can emerge. Technical mastery of equipment can become a priority for the student gaining experience in clinical settings. This is an important aspect of developing a safe level of practice that is supported by clinical staff and tutors. It is important that in their desire to develop clinical competence, students do not lose sight of the human face of person and their family who are confronting a major life event. The significance of illness as a family experience can be emphasised in theory but that emphasis must be followed-up and supported in the clinical setting. Students can be challenged to take a patient / family focus and place value on how that patient and family define the meaning of this experience for themselves. This encourages students to develop into practitioners who maintain an awareness of the family and place importance on their experience in every practice setting.

In ICU, formal nursing education tends to occur mainly through orientation programmes and specialist ICU courses. At present in New Zealand there is no nationally accredited ICU course. A registered nurse appointed to a position in

ICU for the first time is confronted with the need to develop technical mastery of new equipment and skills. Benner (1984) equates this to the advanced beginner level of practice. Orientation programmes support the new staff members as they adjust to this practice setting and acquire the necessary skills and expertise to practise safely. Throughout the orientation period it is vital that new staff are encouraged to view the patient and their family in an holistic way that acknowledges their importance as the central focus of nursing. Although new staff will be introduced to formal visiting protocols, they also need to understand the everyday interpretation and implementation of these protocols within the particular unit. Nursing handovers and reports that routinely acknowledge the family and any significant issues concerning them help to emphasise the important place of the family in ICU. Less experienced staff may need support and guidance from colleagues about adjusting observations and intervention, once it is recognised that someone is dying, to ensure the family are given optimal access and support.

Post-registration ICU courses should specifically acknowledge the importance of the family and the impact of the experience on the family. Depending on course design, this can be done both explicitly and implicitly to acknowledge the importance of direct interaction with the family.

This study suggests that the nurse as person and nurse as colleague domains are essential for optimising the human experience. Nurse education at both the pre and post registration levels needs to emphasise nursing work such as dealing with ongoing grief and death, stress management, communication strategies, conflict management and group process and maintenance that will help support a healthy personal and team environment.

Nursing Research

This study informs nursing research both from a methodological and content perspective.

In terms of implications for nursing research it is acknowledged that nursing research claiming to be phenomenology needs to be philosophically and methodologically congruent. There is growing awareness that the underpinnings of a particular study need to be articulated and this has been addressed in this study.

It appears that some of the ways that nurses using a phenomenological approach to research have interpreted phenomenology has been critiqued by writers such as Crotty (1996). It is acknowledged that this study fits most comfortably within Crotty's description of 'new' phenomenology because it seeks to describe the experience of a particular group of people. The phenomenon of optimising the human experience has been proposed as the central theme or essence of the study. Providing an indepth, rich description of an aspect of nursing practice has been the aim of the study. In acknowledging this study as 'new' phenomenology, informed by Heidegger and hermeneutics and following van Manen's suggestions for the research approach, it is hoped that there is consistence in the underlying philosophy and methodology, and that this provides a sound academic rationale for the conduct of the study. As the project is clinically-based, the need to develop an approach that informs nursing practice has been regarded as a priority.

The descriptive account of nursing practice developed in this study attempts to illuminate the nature of nursing. Qualitative research provides the opportunity to develop indepth, detailed descriptions of nursing that can present a sound rationale for nurse resourcing. Workloads cannot always be quantified and objective measurements of nursing do not adequately capture the qualitative value-laden components of nursing, including caring, empathy, hope and respect. Yet these dimensions of nursing are recognised as critical elements of the profession's practice (Milne and McWilliam, 1996). Ordinariness in nursing, the nurses' role as in-between and the view of the nurse as a skilled companion all offer insights as to the complex way in which nursing uniquely contributes to the experiences of the people for whom it is mandated to care. In published nursing research concerning families in ICU a significant emphasis has been placed on quantitative tools. Although these inform nursing practice, they are not designed to expose the multidimensional complexity that can be captured in a qualitative study, so their use to practice is different. Nurse researchers need to be aware of the need to continue developing descriptions of an indepth nature to justify the use of nursing resources and articulate the nature of the nursing contribution to family as well as patient well-being in both a short-term and long-term capacity.

LIMITATIONS OF THE STUDY

It is important to acknowledge the restrictions and boundaries of this study which are limitations to this research.

Phenomenological research describes human experience which may not be necessarily universal (Van Manen, 1990). This study seeks to describe the lived experience of the seven participants involved in the project. The findings are therefore specific to this particular group of nurses at the time of data collection, analysis and writing. The findings in their present form cannot be generalised to ICU nurses as a larger group. Such claims are beyond the purpose and boundaries of this study.

In Chapter Four, the approach for this particular study was explained. It is acknowledged that the need to maintain a meaningful clinical focus is a central aim of this study. Phenomenological research can draw on a wide range of data sources such as poetry, literature, drama and art. In order to ensure the strong clinical focus is maintained these wider sources of data are not accessed in this study. Although this is acknowledged as a potential methodological limitation, the need to keep a central clinical focus and ensure the secure grounding of the study in the actual lifeworld of ICU nursing as it currently exists is seen as an important priority. A conscious decision was made that it would be the interviews with the nurses that would be the source of data for this study.

The New Zealand Health Care System is currently in the process of ongoing structural and economic change. Nursing services in many institutions have undergone dramatic restructuring with traditional nursing hierarchies disbanded and replaced with a range of management systems. Both ICUs in this study are in hospitals that have restructured nursing services in the past two years. Ongoing review of nursing systems continues and occurred throughout the period of this study. It is important to reiterate that this study seeks to be an accurate and valid description of the nurses' experiences at the time of data collection and writing up. The shape and nature of nursing services of the future are unknown. Inevitably, the experience of nursing and the lifeworld in which nursing occurs will be influenced and changed by broader institutional policies and constraints.

There are methodological limitations to this study. The method of recruitment, largely determined by ethical requirements, meant that only those nurses who volunteered interest in participating in the study were able to be recruited. As notices for recruitment stated that the study was about nursing the families of people who die in ICU, it is likely that only those nurses who had a personal interest in the topic contacted the researcher. This group of volunteers were experienced ICU nurses although this level of expertise was not a stipulated requirement. Several had ten or more years experience in ICU work and the least experienced nurse had worked in the area for two years full-time. Nurse participants were recruited from two units, most did not have ICU experience outside the unit in which they were currently employed. This may have been a limiting factor on the study in that accepted norms for practice, particularly over issues such as family presence and involvement, often evolve from the group of personalities employed within a unit.

This study seeks to be a 'snapshot' of the experiences of a small group of nurses. They have described their experience of nursing the families of people who die in ICU as they have lived it in the particular units in which they work in mid-1990s New Zealand.

RECOMMENDATIONS FOR PRACTICE

The following are recommendations for practice which emerge from the study: These recommendations have been deliberately kept quite broad to emphasise that generalisations based on the findings of the study would be premature.

- Nursing the family is an important aspect of ICU nursing practice when working with dying patients. This needs to be recognised as valid work by all members of the health care team.
- Nursing and hospital management need to recognise the importance of nursing work with families. Patient condition and dependency level alone may not accurately reflect the requirement for nursing.
- Adequate resources in terms of staffing numbers should be provided so that nurses are able to attend to families who always have unique and special needs.

- Nurses need to have as much control as possible over their individual workloads in terms of the personal demands that can arise when repeatedly working with people who are facing crisis and death.
- Formal debriefing and personal support services may assist nurses to continue working at an optimal level.
- Team support and healthy relationships between colleagues are essential if a positive working environment is to be maintained amongst nursing staff.

FURTHER RESEARCH

This study was designed to expand and build on other studies that have looked at the general area of families in ICU. Further research that continues to explore and describe nursing in ICU is recommended.

The limitations of this study have been stated including the small sample size and the likelihood that participants who volunteered to be involved in the study have a strong commitment or interest in the families of patients. A replication of the study by the same or a different researcher with other participants from different ICUs would be an interesting comparison to see if the phenomenon of optimising the human experience emerges. In a replicate study, specific groups of ICU nurses could be targeted, for example those with less than one year's experience. The nurses in this study mainly had more than five years full-time ICU experience and their interviews demonstrated a high level of technical competence and confidence. Less experienced nurses who do not have this confidence may be concerned with developing technical mastery than actually working with families.

In this study the participants were asked to specifically focus on their experiences with families of people who die. A replicate study could look at nurses' work with the families of ICU patients in general (those who do and those who do not die) or other family sub-groups such as parents of young children, spouses, siblings, or children. Nurses could be asked about their experiences when caring for those whose family member dies as a result of a long-term condition as opposed to a sudden death from trauma or acute illness.

Replicate studies may support the findings of this study or may ascribe other meanings to the nurses' experiences. As the central theme of this study is *Optimising the Human Experience*, it would be useful to specifically design studies to explore and expand this phenomenon. Further qualitative studies could be conducted to develop this phenomenon by asking nurses specifically about their perceptions of the appropriateness and the place of optimising the human experience in their work. Alternatively, development of a questionnaire based on the findings of this study and surveying a larger group of ICU nurses would provide information about appropriateness of the phenomenon, strategies, themes and domains identified in this study.

Another important dimension to further research in this area would be to use a similar methodology with the relatives of people who die in ICU to explore the experience from their perspectives. Although this study indicates that nurses seek to optimise the human experience, talking to relatives may support or refute that finding in terms of how they perceive being nursed. In any research conducted with family members it would certainly be worth considering conducting interviews some months after the ICU admission as it appears that most studies with relatives have been undertaken while the patient is in ICU or fairly soon following discharge.

WHAT I HAVE LEARNED FROM THIS STUDY

My own assumptions about this study were explicated in Chapter Three. In reflecting on my personal learning for this study these have been reviewed. I have also recently been able to work some casual duties in a unit where I was previously employed. This has given a renewed, personal, at the 'coal-face' perspective on ICU nursing.

The study has affirmed my belief that ICU nurses do have a commitment to the family. When a person is dying, the nurses are aware that the time is very important to the family and acknowledge that it is a time that will be remembered by those people for the rest of their lives. The emergence of the phenomenon **Optimising the Human Experience** has been verified by the participants as capturing the essence of the time but also fits comfortably with my own perceptions and beliefs. I like the description.

The interviews with participants emphasised the importance of working effectively as a team in ICU. Individuals need to be supported in their practice and there is a complementary individual responsibility to support the practice of others. The fact that nurses need to be competent practitioners and able to sustain themselves in the challenging circumstances of ICU seem important features in the nurses' work of optimising the human experience.

Good ICU nursing is not just about saving lives, mastering technology and demonstrating a repertoire of skills. It requires a unique combination of knowledge, skills and genuine human concern coupled with a willingness to reach out to others in a time of need. Knowledge and skills can be learned but the ordinary, everyday humanness in nursing is difficult to teach. It is often the human action of reaching out to others in need by the nurse to the family that makes a traumatic and difficult time more bearable.

During the interviews, the participants shared some poignant stories of their practice. Even participants with whom I have previously worked surprised me with stories of situations that I remember, where they did something very special with a family unbeknown to many of their colleagues at the time. These stories illustrate the unacknowledged and usually unrecorded ways that nurses genuinely seek to help others. This heightened my awareness of some of those very special features of nursing practice and the personal qualities of its practitioners.

In a more academic sense, this whole experience of planning and conducting a project of this nature has been completely new to me. I doubt that I could effectively acknowledge the amount of learning that has occurred. The experience of planning a project, seeking official permission and gaining approval of ethics committees seemed all consuming at the time. The process would not be so daunting again.

The decision to use phenomenology seemed so obvious and simple at the beginning. My aim was to describe an experience so phenomenology seemed to be the best approach. Exploring and critiquing the literature concerning phenomenology in nursing was exciting and at times, frustrating. The critiques of use of phenomenology in nursing were confusing and seemed to complicate my understanding of what I thought I was doing. Just when I started to feel something was making sense, something else would emerge to return me to the

state of confusion. Even now all I can say is that this final report is a snapshot of my understanding at this point.

The writing up of the study has been interesting. Certainly the final report does not resemble anything I could have imagined would have been produced. This is not really something that I have the words to explain. From a phenomenological perspective, I think it has something to do with the relationship between the parts and the whole. As each part of the study develops it impacts on the shape of the whole. As the whole takes shape, the parts change to fit with, and further inform, the whole. At some point the cycle must be halted and a final report presented. The final report is not an absolute truth, it is one possible interpretation of data that attempts to illuminate the lifeworld of the participants from the perspectives of how they describe nursing the families of people who die in ICU.

SUMMARY

The purpose of discussion in this chapter is to round off the findings, contribution and implications of this study. The limitations of the study have been acknowledged but suggestions for further research that would extend and expand its contribution have been made. My personal learning as a result of undertaking this study has been immense both in terms of increased familiarity with the topic area and learning about the research process.

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APPENDIX ONE

MASSEY UNIVERSITY

MA Thesis

The Families of People Who Die in Intensive Care - A Nursing Perspective

INFORMATION SHEET

This is an invitation to participate in a study that explores the experiences of nurses who work with the families of people who die in ICU.

My name is **Cathy Andrew**. I am a graduate student at the Department of Nursing and Midwifery at Massey University enrolled in a Masters thesis which may be converted to a doctorate at a later date. I am a registered nurse and have been working as a Nursing Tutor at Christchurch Polytechnic for two years. Prior to that I worked as a staff nurse in Intensive Care for eight years.

This study has grown out of my interest in families and the experience they have when a relative is a patient in Intensive Care. I am particularly interested in speaking to you about your experiences as an ICU nurse working with the families of patients who die. I know that ICU nurses share some of the most deeply poignant and intimate moments with families. I believe it is important we record the nature of these experiences which show the contribution that a nursing presence can make.

As a participant you will be asked to consent to :-

1. Tell me about your experience of working with families of people who die in Intensive Care. This is a very broad area and the interview does not need to follow any particular direction. This interview will be taped and then transcribed.
2. The transcript will be returned to you to make any alterations or adjustments you would like. You will have the opportunity to discuss these further if you wish.
3. After all interviews with nurses have been completed, I will contact you to discuss the common themes that have emerged. I will seek your opinion as to whether the description captures the essence of how you see this time from a nursing perspective.
4. The initial interview will probably take up to an hour of your time. Review of the transcript can be done at your leisure and any discussion

of that should take up to 30 minutes. Discussion of the themes that have emerged from the analysis should also take about 30 minutes. These interviews will be conducted at a venue of your choice.

If you choose to participate in the study, you have the right to:-

1. Refuse to answer any question and to withdraw from the study at any time.
2. Stop the tape or request that the tape be stopped at any point during the interview.
3. Ask any further questions about the study that occur to you during your participation.
4. Provide information on the understanding that it is completely confidential to the researcher. All information is collected anonymously, and it will not be possible to identify you in any reports that are prepared for the study .
5. Be given access to a summary of the findings from the study when it is concluded.

I am aware that working with the families of dying patients can be rewarding but can also be extremely stressful. If participation in the study causes you distress or surfaces unresolved issues from your personal or professional experience I am willing to facilitate a process to assist you deal with these issues through the most appropriate channel.

I can be contacted at work: Department of Nursing, Midwifery and Health Education,

Christchurch Polytechnic
ph. (03) 364-9074 ext. 8288

My supervisor is :

Dr Judith Christensen
Department of Nursing and Midwifery
Massey University
Palmerston North
ph. (06) 350-4332

APPENDIX TWO

MASSEY UNIVERSITY

The Families of People Who Die In Intensive Care - A Nursing Perspective

CONSENT FORM

I have read the Information Sheet for this study and have had the details of the study explained to me. I am aware this study has been approved by the Massey University Human Ethics Committee and the Southern Regional Health Authority Ethics Committee (Canterbury). My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I have had enough time to consider whether I wish to participate in the study and understand my participation in the study is voluntary. I have the right to withdraw from the study at any time, and decline to answer any particular question in the study. I agree to provide information to the researcher on the understanding that it is completely confidential and that anonymity will be maintained in all reports.

I agree / do not agree to my interview being taped. I am aware that I can turn off the tape at any point or request that taping be stopped. After the final interview I will be given the option of receiving the tape or it being destroyed following examination of the thesis. I may receive a copy of the transcript. I agree that Cathy Andrew may use the transcript of my interview if the study is extended.

I consent to participate in this study under the conditions set out on the Information Sheet.

Participant Signature:

Date:

Researcher Signature:

Date:

In my opinion consent was freely given and the participant understands what is involved in this study.

Witness:

Date:

Copies to: 1. Participant
2. Researcher