

**The Lived Experience of Having a Close Relative in an
Intensive Care Unit**

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The Lived Experience of Having a Close Relative in an Intensive Care Unit

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

Signature

A handwritten signature in black ink, consisting of a large, stylized initial 'L' followed by a smaller, less legible signature.

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Abstract

The Lived Experience of Having a Close Relative in an Intensive Care Unit

This study explored the experience of family members with a close relative in an Intensive Care Unit. Using Colaizzi's method of phenomenology, interviews were conducted with two participants who had relatives in different Intensive Care Units. Current literature has focused on identifying the needs of family members' visiting a relative in ICU and their level of satisfaction with care but little attention has been paid to exploring their experience. Six themes emerged from the data: seeing and being terrified; wanting and needing to be there; lack of information gives rise to mistrust; needing support in order to cope; feeling out of control; acknowledging 'humanness'. Together the fundamental description and fundamental structure of the phenomenon provide understanding of the family members' experience of having a relative in an ICU. Recommendations for nursing practice, education and further research are made based on these findings.

Introduction

This small study explores the lived experience of having a close relative in an Intensive Care Unit. Constrained by the framework of a 40-point dissertation, I have used phenomenology to reflect on and describe the stories of two participants who had close relatives admitted to an Intensive Care Unit (ICU). For the purpose of this study, the family member is the person visiting ICU and the relative is the person admitted to ICU.

As a nurse working in an ICU, it is normal for me to deal with ‘strange looking’ machines, multiple intravenous infusions and very sick people. For family and friends who visit, the ICU environment can be quite alien, and may only have been seen on television. Family and friends are likely to have difficulty recognising the person attached to numerous pieces of equipment as their relative. The fact that their relative is seriously ill can cause both overwhelming stress and distress possibly impacting on their ability to cope (Azoulay et al., 2005; Carter & Clark, 2005; Lam & Beaulieu, 2004; Mendonca & Warren, 1998; Van Horn & Tesh, 2000).

For ICU nurses, this highly technical environment is part of everyday life. The plethora of equipment is necessary to monitor the patients’ progress and interpretation of the information guides medical treatments and nursing care (Hardicre, 2003; Walters, 1995a; Zaforteza, Gastaldo, Pedro, Sanchez-Cuenca & Lastra, 2005). More often than not, this equipment is essential to survival. This is normal within an ICU. However, for family and friends it is anything but normal (Cooper, 1993).

It has long been recognised in the nursing literature (Benner, 1984; Hudak & Gallo, 1990; Oh, 1990; Walters, 1994; Walters, 1995b), that care for the patient in ICU includes care for the family. This extended caring requires astute clinical judgements, wisdom, skill and coming to terms with the human significance of critical illness as well as the acknowledgement of the patient and family’s plight (Benner, Hooper-Kyriakidis & Stannard, 1999). Factors, which can influence the care given to families by nurses, include the nurses’ practices, concerns and skills as well as the unit’s culture and

the patient's length of stay (Benner, Tanner & Chesla 1996; Chesla & Stannard 1997; Darbyshire 1994). Also influential are previous life experiences, brought by family members to the situation, which may influence the way they react to having a relative admitted to ICU (Burr, 1997; Mendonca & Warren, 1998; Reeder, 1991).

The Researcher

I am a Registered Nurse who has worked in a Neurosurgical Intensive Care Unit, Neurosurgical Theatre, as well as a General Intensive Care Unit. The foundations of this small study are a result of my experiences both as a nurse and as a family member of a patient in an ICU. My experience as a family member, together with my role as a nurse, drew me to explore the phenomenon of interest in this study. I have lived the experience of having a close relative in an ICU.

My father was diagnosed and admitted for surgical removal of a brain tumour while I was working in the Neurosurgical Theatre where he was to have his operation. He was admitted post-operatively to the Neurosurgical Intensive Care Unit in which I had previously worked.

When I visited my father following his surgery I felt an overwhelming sense of relief. I saw a 'normal' post-operative patient. According to my knowledge and experience, everything was as it should have been. The environment was dark and, unlike other wards, the patients had their heads towards the centre of the room rather than against the walls. My father had a thick bandage around his head and several drips and there were drains attached to him. Despite being a daughter and relative, what I was seeing was normal for me as a nurse. My mother, on the other hand, found seeing him like this extremely difficult. When she panicked and left the room quickly, I found it hard to understand her reaction. A few days later, I realised that we had interpreted his situation in totally different ways.

Later, when working in the general ICU, I began to observe family members more closely. I found myself wondering: what is their experience of this? What are they seeing and what do they understand? Another

insight that occurred while reflecting on these questions was that negative labels are sometimes applied by staff to family members (Bogoch, Sockalingam, Bollegala, Baker & Bhalerao, 2005). These labels are often based on first impressions and, if not revised, are likely to affect the family's ongoing experience and relationship with staff. Pondering further I asked other questions: what is it like to be in a situation that does not make sense? Is the experience so overwhelming that family members (and friends) act in ways that are 'out of character' for them? It was concerns such as these that led me to study the lived experience of having a close relative in an ICU. I wanted to know more about family members' experiences. I wanted to be able to assist them more adequately. For the purpose of this study, a 'close relative' was defined as a spouse, defacto partner, sibling or child that visits a person in an ICU.

The Research Approach

A number of research studies have attempted to clarify what is important for family members and their needs, but have neglected to explore their experience (Burr, 1997; Lam & Beaulieu, 2004; Sessler, 2005; Walters, 1995b). Some studies suggest that nurses do not always perceive the needs of families accurately and that this may adversely affect the family's experience (Browning & Warren, 2006; Kosco & Warren, 2000; Leung, Chien & Mackenzie, 2000; Mendonca & Warren, 1998; O'Neill & Grove, 1996; Scott, 1998; Tin, French & Leung 1999; Titler, Cohen & Craft, 1991). Perhaps there is a need for nurses to develop a greater understanding of families' experiences in order to avoid this incongruence? It was for this reason that I chose a phenomenological approach for this study. I wanted to understand the experience as lived and told from the perspective of family members. I hoped that this would assist other nurses to expand their own understanding of the family members' experience.

Nursing in intensive care units presents a challenge with respect to balancing the technological environment (science) with the humanistic (art) aspects of care (Hawthorne, 1995; Pearson, 1993; Walters, 1994; Walters, 1995a; Zaforteza et al., 2005). Holistic care is caring for the whole person (body mind and spirit) including caring for the family, whilst

avoiding the reductionism that comes with caring for the disease or the technology (Bishop & Scudder Jr, 1997; Hawthorne & Yurkovich 1995; Medland & Estwing Ferrans, 1998; Streubert Speziale & Rinaldi Carpenter 2007; Walters, 1995b). If this reductionism occurs, it can impact negatively not only on the patient but on the family and this, in turn, can further impact on the patient in a negative way (Hawthorne & Yurkovich, 1995; Medland & Estwing Ferrans, 1998).

Phenomenology seeks to understand human experience rather than control or predict the behaviour of the population being studied. It facilitates exploration of the 'life world' of the individual as an individual in context (Bishop & Scudder Jr, 1997; Knaack, 1984; Koch, 1995; Streubert Speziale & Rinaldi Carpenter, 2007; Walters, 1995b). Since phenomenological inquiry requires that the integrated whole be explored, it is a suitable method for the exploration of phenomena important to the further development of nursing knowledge and practice (Beck, 1994; Bishop & Scudder Jr, 1997; Corben 1999; Knaack, 1984; Koch, 1995; Lawler, 1998; Streubert Speziale & Rinaldi Carpenter, 1995; Walters, 1995b).

Phenomenology

According to Streubert Speziale and Rinaldi Carpenter (1995) the phenomenological movement began around the first decade of the 20th century and consisted of three phases; the Preparatory, German and French, with the German phase being the most significant. The preparatory phase was dominated by Brentano [1838-1917] and Stumpf [1848-1936]. During this period the clarification of the concept of intentionality was the primary focus; "intentionality means that consciousness is always conscious of something" (Streubert Speziale & Rinaldi Carpenter, 1995, p. 32). In this study, the participants were always conscious of their relative being in ICU and the fear that he or she may die.

During the German or second phase, Husserl [1857-1938] and Heidegger [1889-1976] were the prominent leaders (Streubert Speziale & Rinaldi Carpenter, 1995). Husserl, a philosopher and mathematician, frequently

cited as the father of phenomenology (Byrne, 2001; Cohen, 1987; Jasper, 1994), believed that philosophy should become a rigorous science that would restore contact with deeper human concerns, and that phenomenology should become the foundation for all philosophy and science (Cohen, 1987; Streubert Speziale & Rinaldi Carpenter, 1995). The concepts that were developed during the second phase of the phenomenological movement were of 'essences', 'intuiting' and 'phenomenological reduction'.

The third, or French phase, of the phenomenological movement was influenced by Marcel (1889-1973), Sartre (1905-1980) and Merleau-Ponty (1905-1980). The primary concepts developed during this phase were 'embodiment' and 'being-in-the-world'. These concepts refer to the belief that all acts are constructed on foundations of perception, or original awareness of some phenomenon and this is what must be described (Streubert Speziale & Rinaldi Carpenter, 1995). In this study, the participants' perceptions of the situation shaped their experience.

Phenomenological research describes experience as it is lived in the everyday. Furthermore, the term 'phenomenology' has meaning as a philosophy, methodology and method (Byrne, 2001; Koch, 1995).

Phenomenologists believe that all knowledge and understanding is embedded in everyday human existence. The truths and meanings of life emerge from people's life experiences and thus cannot be quantified or reduced to numbers or statistics (Bishop & Scudder Jr 1997; Byrne 2001; Walters, 1995b).

As a methodology, phenomenology, links a particular philosophy to the appropriate research methods thus bringing philosophical notions together with practical and applicable research strategies (Byrne, 2001). The purpose of phenomenological inquiry is to reveal the structure and/or essence of the lived experience through description and/or interpretation of the experience. It is not a method that aims to explain or predict the experience (Beck 1994; Bishop & Scudder Jr, 1997; Byrne, 2001; Rose, Beeby & Parker, 1995; Streubert Speziale & Rinaldi Carpenter, 1995). As a

method, phenomenology is an organised approach to answering research questions (Byrne, 1995). As Byrne (1995) identifies, the researcher should ask, “is there a need for further clarity on the chosen phenomenon?” (p. 35). One way to conclude that further clarity is needed is that there is little if anything published on the subject, or perhaps that what is published needs to be described in more depth (Byrne, 1995). Another indication is that the issue continues to ‘gnaw’ at one’s consciousness thus signalling a need for improvements in practice. Past research has tended to investigate issues that impact upon families’ experiences rather than on their experience as it is lived. This will be discussed further in Chapter Two. Because the focus of this study is ‘the lived experience of having a close relative in an Intensive Care Unit’, I needed to hear the stories of others who had experienced this phenomenon. I sought to produce a rich description of the experience through immersing myself in the stories in order to describe their meanings in detail.

The participants and others who had similar experiences confirmed the descriptions.

Organisation of the Dissertation

Chapter Two is a review of the literature associated with this topic. Because so little has been published on the relatives’ experience a broad and inclusive approach has been taken to reviewing the factors that impact on relatives’ experience.

Further discussion of the phenomenology and articulation of the specific methods used are the focus in Chapter Three. This includes project design, ethical considerations and issues of trustworthiness.

Chapter Four presents analysis of the data, description of the participants’ experiences and identification of the main themes.

Chapter Five discusses the study findings and conclusions. It also includes recommendations for practice development and further research.

Conclusion

Having lived the experience of having a close relative in an intensive care unit with the benefit of experience and knowledge gained from working in an Intensive Care Unit, I realised that my mother's experience of the situation was quite different from mine. Observation of family visiting patients and interest in their experience led me to explore the phenomenon of 'having a close relative in an Intensive Care Unit. Phenomenology was chosen as a methodology and method for this study because of its emphasis on experience as lived. The paucity of literature about the experience of having a close relative in an ICU suggested that this phenomenon should be explored further.

Introduction

This chapter offers a review of the literature relating to having a close relative in an Intensive Care Unit. There is an abundance of literature on identified needs of relatives and the other issues that impact on their experience. However, as identified in Chapter One, there is a dearth of literature on the actual experience of these relatives. This literature review takes a thematic approach, in particular addressing the themes of stress, anxiety and coping, identifying and meeting the needs of families, and visiting. The databases used for the literature review included Proquest 5000; CINAHL and PubMed.

Stress, Anxiety and Coping

Numerous studies have stated that having a close relative admitted to an ICU causes such overwhelming stress and anxiety that it may result in poor mobilisation of coping strategies (Carter & Clark, 2005; Daley, 1984; Farrell, Joseph & Schwartz-Barcott, 2005; Halm et al., 1993; Hopkins, 1994; Kosco & Warren 2000; Leung, Chien & Mackenzie, 2000; Mendonca & Warren, 1998; Reeder, 1991; Roland, Russell, Culpepper Richards & Cox Sullivan, 2001; Rose, 1995; Rukholm, Bailey, Coutu-Wakulczk & Bailey, 1991; Scott, 1998; Samples Twibell, 1998; Stover Leske, 1998; Tin, French & Leung, 1999; Van Horn & Tesh, 2000; Walters, 1995b). It has been suggested that unless family members are recipients of care whilst their relative is in ICU, they may demonstrate stress through their negative affective and behavioural responses towards nursing and medical staff and that nursing interventions need to be developed to facilitate positive coping strategies for family members (Azoulay et al., 2005; Carter & Clark, 2005; Halm et al., 1993; Samples Twibell, 1998; Van Horn & Tesh, 2000). Changes in behaviours include alterations in eating, sleeping and activity patterns (Azoulay et al., 2005; Carter & Clark, 2005; Halm et al., 1993; Samples Twibell, 1998; Van Horn & Tesh, 2000); the most significant change being the alterations in sleep patterns. All authors noted that the majority of their participants identified a reduction in the amount and quality of sleep (Azoulay et al., 2005; Carter & Clark, 2005; Halm et al.,

1993; Samples Twibell, 1998; Van Horn & Tesh, 2000). Sleep deprivation can manifest in family members as reduced concentration, decreased ability to make decisions regarding care, increased irritability and feelings of exhaustion and lethargy (Azoulay et al., 2005; Carter & Clark, 2005; Halm et al., 1993; Samples Twibell, 1998; Van Horn & Tesh, 2000). Similar recommendations on how these behaviour changes could reduce stress levels are made. The authors consistently argued that nurses should develop strategies to aid family members to cope, advocate for open or more flexible visiting practises, suitable waiting room facilities and improved information-giving, including more time with the physicians. Interestingly, all authors identified that female participants had higher stress scores than men, therefore experienced higher stress levels (Azoulay et al., 2005; Carter & Clark, 2005; Halm et al., 1993; Samples Twibell, 1998; Van Horn & Tesh 2000).

Literature highlighting the stress, anxiety and coping experienced by visitors demonstrates the need for information and access to the patient as being fundamental for family members of patients in ICU. Further literature has concentrated on identifying the needs of the family, whether these needs are met and whether the nurses' perceptions of family needs are the same as the families' perceptions.

Identifying and Meeting the Needs of Families

Numerous studies have been carried out in order to identify the needs of families of patients in Intensive Care Units. Most have been replicated both in method and results. To expand on this information, other studies have looked at whether these needs are met from the perception of both families and the nurses.

Possibly the most influential study on the needs of family members is the work carried out by Molter (1979). This study, one of the first to explore the needs of relatives from their own perspective, became the foundation for subsequent studies carried out on the topic. From this study Molter (1979) developed a 45-item needs statement. Using descriptive statistics the top 10 needs were ranked as:

1. to feel hope
2. to feel that the hospital personnel care about the patient

3. to have the waiting room near the patient
4. to be called at home about the changes
5. to know the prognosis
6. to have questions answered honestly
7. to know specific facts concerning the patient's progress
8. to receive information about the patient once per day
9. to have explanations given in understandable terms
10. to see the patient frequently

(Mendonca & Warren, 1998, p. 60).

In 1986, Leske modified the tool, adding an open-ended component and randomly ordering the 45 needs statement. The resulting tool, named the Critical Care Family Needs Inventory (CCFNI), has become the key tool used when assessing needs of the family and identifying whether these needs have been met. It has also provided the foundation for other researchers exploring the needs of relatives (Daley, 1985; Leung, Chien & Mackenzie 2000; Kosco & Warren, 2000; Mendonca & Warren, 1998; Rukholm et al., 1991; Scott, 1998; Warren, 1993). In these studies the need for information was rated highest. The information believed to be important to families included: knowing what is wrong, having questions answered in understandable terms and being informed of any change (Daley, 1985; Leung et al., 2000; Kosco & Warren, 2000; Mendonca & Warren, 1998; Rukholm et al., 1991; Scott, 1998; Warren, 1993). Other research has explored the needs of relatives at a different number of hours post admission to ascertain if there was a change in needs and if they had been met (Browning & Warren, 2006; Mendonca & Warren, 1998; Warren, 1993). Some studies explored both the relatives' and nurses' perception of family needs. Although it was noted that there were some similarities, the authors suggested that the incongruence between the families needs and the nurses' perception of family needs was significant. It appears that the nurses do not place as much importance as the family on the receiving of information in a timely manner and in understandable terms. Being called at home if there were any changes, being able to maintain proximity to their relative or being able to visit when they wanted had more importance placed on it by family members than nurses. The

authors further noted that the families who participated in their studies did not feel that these needs had been met (Browning & Warren, 2006; Daley, 1984; Kosco & Warren, 2000; Reeder, 1991; Scott, 1998; Tin, French & Leung, 1999; Warren, 1993; Waters, 1998).

Most of the authors identified that it is important to understand family needs so that nursing staff can provide truly holistic nursing care and reduce the anxiety of family members. They have suggested that not meeting these needs causes increased anxiety, stress, eliciting feelings of anger and frustration in the family members.

Although the ability to see the patient was ranked tenth most important, it appears that this inability to be with their relative causes significant distress and stress for the family. Nevertheless, it would seem that most visiting policies have been written to suit the health professionals in ICU rather than family.

Visiting

According to Bournes and Mitchell (2002) the experience of visiting a relative in an Intensive Care Unit is one of waiting: waiting to be let in, waiting for a procedure to be completed and waiting to see if there is any improvement. The anxiety, stress and uncertainty associated with waiting (Bournes & Mitchell, 2002) can be exacerbated by unit visitation policies that are inflexible and outdated (Berwick & Kotagal, 2004; Farrell, Joseph & Schwartz-Barcott, 2005; Ramsey, Cathelyn, Gugliotta & Glenn, 2000; Roland, Russell, Culpepper Richards & Cox Sullivan 2001; Widick Giganti, 1998; Yow Daniels, 1996).

In 1995 the Department of Public Health United States of America recommended that visitation to ICU should be limited to immediate family members and only for short periods (Roland et al., 2001). Since this recommendation, changes to visiting policy have been slow despite research demonstrating that visiting has no adverse effect on the patient (Berwick & Kotagal, 2004; Farrell et al., 2005; Gonzalez, Carroll, Elliot, Fitzgerald & Vallent, 2004). Although this recommendation was directed

at ICU in the USA, it is usual for New Zealand hospitals to look to overseas trends prior to developing nursing practices and policies.

In early 2001, in order to establish the visiting 'trends' for ICU's in New Zealand, a small group of Intensive Care Units were asked to forward their visiting policies for a comparison with overseas hospitals. What was evident in these policies were restrictions such as limited hours of visiting, limited numbers of visitors, visitors limited to immediate family members only, no children (age not specified), limited time depending on the condition of the patient, (that is, the more critical the condition, the less time the family is allowed to visit) and restrictions during doctors' rounds. One organisation went as far as issuing a press release identifying that "out of hours visiting disrupts patients' treatments, therefore, potentially putting the patients' health at risk" (Waitemata District Health Board 2002). The fact that these policies are separate from the organisation's general visiting policy is also significant in that it implies that people in ICU have differing needs.

Early literature argued that visitors compromised patients' health and/or recovery by increasing blood pressure, intracranial pressure and heart rate as well as the number of ectopic beats and the amount of pain relief required. Further, it was stated that infection rates were also believed to increase with more lenient visiting policies, especially if young children were allowed to visit (Andrew, 1998; Berwick & Kotagal, 2004; Widick Giganti, 1998; Roland, Russell, Culpepper Richards & Cox Sullivan, 2001). However, more recent research has demonstrated that the physiological changes associated with relatives visiting indicate a reduction in stress for the patient, thus assisting to promote recovery (Ramsey et al., 2000; Roland et al., 2001; Yow Daniels, 1996). Investigation into the effects of children visiting has shown that patient infection rates do not increase (Widick Giganti, 1998; Roland et al., 2001) and that having children visiting ICU was beneficial for the patient. It is interesting to note however, that patients experiencing an 'open visiting' policy, thought some restriction was necessary. Moreover, this was viewed as a professional responsibility and patients expected nurses to recognise and intervene

when the needs of the patient took priority over the needs of the family (Yow Daniels, 1996).

Could it also be that visiting is not perceived to be an important enough issue to be addressed and/or revised? Among the studies that focused on the needs of the family Molter (1979) used a Likert scale to rate the needs of the family. Receiving information was prioritised over seeing the patient frequently. This finding was supported by other studies that also suggested visiting the patient was not as great a need as receiving adequate information (Daley, 1984; Halm et al., 1993; Rukholm et al., 1991).

So why does visiting have such an impact on the 'experience' if it is not an important need? It has been suggested that if families do not have access to their relative, this can increase dissatisfaction with care, increase stress and anxiety, cause conflict with nursing staff and impact on communication between the family and ICU staff (Ramsey et al., 2000; Reeder, 1991; Roland et al., 2001; Samples Twibell, 1998; Stover Leske, 1998; Van Horn & Tesh, 2000). The majority of literature discusses the role of the nurse as a gatekeeper who decides who can have access and when (Berwick & Kotagal, 2004; Farrell et al., 2005; Gonzales et al., 2004; Ramsey et al., 2000; Roland et al., 2001). Possible reasons for gate keeping included: concern for potentially adverse physiological effects on the patients, concern that patients receive adequate rest and concern about potential interference with provision of care (Berwick & Kotagal, 2004; Farrell et al., 2005; Gonzalez et al., 2004; Plowfield, 1999; Ramsey et al., 2000; Roland et al., 2001). However, organisations with open visiting policies in ICU reported a reduction in stress levels for both patients and families; greater participation in care by family members; greater satisfaction in care; a decrease in family complaints and an increase in job satisfaction for the nurses (Berwick & Kotagal, 2004; De Jong & Beatty, 2000; Dowling & Wang, 2005; Plowfield, 1999; Roland et al., 2001; Widick Giganti, 1998; Yow Daniels, 1996).

Although visiting is not ranked as the highest need, the literature suggests that restricting access to patients can increase the stress and anxiety levels

of the family, possibly leading to anger and conflict with the ICU staff. Visiting policies have been slow to change despite the literature highlighting the benefits of more flexible policies for patients and families.

Conclusion

This chapter has provided a review of some of the literature available. It is by no means an exhaustive review of what has been written about families of ICU patients. However, most of the literature that is available is based on quantitative studies, thereby reducing the human experience to numbers and statistics with very few studies exploring the experience of the families. If nurses are to meet the needs of families, I would suggest that some understanding of the experience is required.

Introduction

In this chapter I will outline the process of identifying the question and selecting an appropriate methodology. I will discuss the work of Colaizzi (1973) who developed the procedural steps that guided the collection and analysis of the data and discuss my own beliefs and presuppositions about the phenomenon. Ethical considerations pertaining to this project will be discussed and criteria for judging the rigour of the research will be outlined.

The Question

Reflecting on my own experience as a relative and observations of patients' relatives as a nurse, I have wondered: What is their perception? What are they going through? And, how can I help? I believe that experiences are primarily individual but I also believe there may be some shared experiences that could inform the nursing care of families who have relatives in ICU.

Having decided upon the question – the lived experience of having a close relative in an ICU, the next step was to determine the methodology.

Methodology

Methodology refers to the philosophy or theoretical framework that guides the selection and implementation of research methods. As a methodology, phenomenology facilitates the exploration of human experience as it is lived (Byrne, 2001; Colaizzi, 1978; Lawler, 1998; Rose, Beeby & Parker, 1995).

Phenomenology

Various research approaches are becoming more widely acceptable in nursing research (Corben, 1999; Streubert Speziale & Rinaldi Carpenter, 2007). In the past, research credibility required adherence to scientific and/or experimental processes (Lawler, 1998; Streubert Speziale & Rinaldi Carpenter, 2007) however, more recently the acceptance of qualitative approaches has grown significantly (Streubert Speziale & Rinaldi

Carpenter, 1995). One of the pitfalls of the scientific or experimental research is that it does not allow for the investigation of experiential meanings (Colaizzi, 1978; Leonard, 1989). Phenomenology however, facilitates the exploration and understanding of the 'human agency'. It recognises that intentionality in human action is constituted or shaped by concerns, purposes, goals and commitments (Colaizzi, 1978; Leonard, 1989). Phenomenology is the exploration of humans by humans in ways that acknowledge the value of the holistic and the integration of all patterns of knowing (Chinn, 1985; Streubert Speziale & Rinaldi Carpenter, 1995). Phenomenological inquiry strives to articulate the perceptions of human experience (Streubert Speziale & Rinaldi Carpenter, 1995).

According to Brentano and Stumpf (cited in Streubert Speziale & Rinaldi Carpenter, 1995) the concept of intentionality is of central importance in phenomenology. Intentionality signals that consciousness is always conscious of something, or as Merleau-Ponty explained that:

interior perception is impossible without exterior perception, that the world as the connection of phenomena is anticipated in the consciousness of my unity and is the way for me to realize myself in consciousness" (cited in Streubert Speziale & Rinaldi Carpenter, 1995, p. 67).

This highlights the fact that one does not hear without hearing something or believe without believing something (Cohen, 1987; Streubert Speziale & Rinaldi Carpenter, 1995).

Other important methodological terms are *essence*, *intuiting* and *phenomenological reduction* (Husserl, 1931; Heidegger, 1965 cited Streubert Speziale & Rinaldi Carpenter, 1995, 2007).

Essences are: "unities of meaning intended by different individuals in the same acts or by the same individuals in different acts" (Natanson, 1973 cited Streubert Speziale & Rinaldi Carpenter, 1995, p. 14).

They represent the basic units of common understanding of any phenomena (Streubert Speziale & Rinaldi Carpenter, 1995, 2007).

Intuiting is the accurate interpretation of what is meant in the description of the phenomenon under investigation. This requires that the researcher

imaginatively vary interpretation of the data until a common understanding about the phenomenon emerges.

Phenomenological reduction describes a return to original awareness regarding the phenomena under investigation, or as described by Husserl, “back to the things themselves” (cited in Streubert Speziale & Rinaldi Carpenter, 1995, p. 33). It begins with the suspension of beliefs, assumptions and bias about the phenomenon. However, complete reduction may never be possible (Streubert Speziale & Rinaldi Carpenter, 1995, 2007) and in relation to suspension of beliefs or bracketing, Colaizzi (1973) argues that experiences and knowledge cannot be set aside. They must be identified and utilised (Colaizzi 1973, 1978).

In relation to the concept of bracketing, Colaizzi (1973) defines intentionality as

the means by which man goes beyond himself in relating to all which is other than himself. It is comprehensive, pervading and revealing itself in man’s total situation, both in his external behaviour and in his experience. And because man is an incarnated subjectivity whereby his external behaviour and experience are not separate but are inextricably related to each other, then the intentionality manifested in external behaviour can never be adequately studied without also accounting for the intentionality of experience and vice versa. (p. 23).

According to Colaizzi self-interrogation of the phenomenon leads to the discovery of beliefs, hypotheses, attitudes and hunches held about a phenomenon. This provides a preliminary basis for the research question and an opportunity to compare one’s own presuppositions as a researcher with those of others (Colaizzi, 1973, 1978). Thus, rather than bracketing or setting aside personal presuppositions, it is important that these are acknowledged and utilised to surface the participants’ experiences.

As a researcher and a nurse who has experienced having a relative in ICU, I cannot expunge my own experience of the phenomenon nor can I deny that the experiences of others may differ from mine. I must recognise and

affirm both my own experience and the experience of others. These cannot be objectively eliminated.

Framework for analysis

Colaizzi (1973, 1978) provides the following framework (Table 1) to guide the data analysis.

Procedural Steps	Operations
Describe Phenomenon	Discover fundamental structure by individual phenomenological reflection
Collect Descriptions	Obtain fundamental description by method of phenomenological study
Read all descriptions Extract significant statements Spell out meaning of each significant statement Formalise meanings into clusters of themes Write exhaustive description Validation Incorporate new data	Obtain fundamental description by method of empirical phenomenological reflection
	Discover fundamental structure by method of empirical phenomenological reflection

Table 1: Colaizzi’s procedural steps and operations that guide analysis

Drawing from Colaizzi’s (1973) framework I will now describe how I implemented these steps and operations.

Individual Phenomenological Reflection

This recognises that the researcher’s previous knowledge pertaining to the phenomenon derives from already ‘understanding’ it and being able to describe the phenomenon (Colaizzi, 1973). In my case, because I had experienced having a close relative in an ICU, I could reflect, albeit to a limited extent, on this experience. I have therefore outlined the presuppositions I brought to the study on page 23.

Phenomenological Study

Phenomenological study investigates the phenomenon further by gathering descriptions from a plurality of subjects. I gathered information from two people who had experienced having a close relative in ICU. These

were taped and transcribed to ensure I did not lose anything from the original description. Field notes about body language and emotional responses were also recorded during the interviews.

Fundamental Description through Empirical Phenomenological Reflection

Colaizzi (1973) argues that there needs to be equal emphasis on empirical and reflective procedures. As the researcher I listened, read and reflected on the transcripts in an effort to fully understand the data. I tried to remain true to the participants' stories rather than imposing interpretation through using a specific theory or preferential bias. I sought, when writing, to produce a description of what was fundamental to the experience. This involved identifying and extracting significant statements from the raw data. Prior to extracting the significant statements from each story, it was necessary to 'tidy' the transcripts. The 'ums' and 'ahs' were removed and the stories were sorted into a loose chronological order. Re-crafting the stories involved organising and clustering the themes to make them visible. Although Colaizzi (1973) states that repetitive statements should be discarded, I believe that the very nature of the repetition was an important part of the participants' experience so I chose to keep them in.

The re-crafted stories were returned to the participants for validation.

It was encouraging to find that the participants' responded by saying: 'Yes this is what it was like'. Colleagues who read the stories later and had experienced similar situations themselves also responded by stating: 'I can relate to this', or 'I know what they were going through'. This was reassuring and validated the interpretations as true to the experience.

Once obtained, the fundamental description of the phenomenon (the experience) becomes the foundation for explicating the meaning of the experience, or in Colaizzi's (1973) terminology, the fundamental structure of the phenomenon.

Conscious effort was made not to impose my beliefs or presuppositions onto the interpretation as it was being rewritten. This was difficult at the

time because many of my assumptions regarding nursing care were challenged by the data as outlined on page 23.

Fundamental Structure through Empirical Phenomenological Reflection

Because of the lengthy nature of an exhaustive description, Colaizzi (1978) advocates that this should be reduced to a fundamental structure. The purpose of finding the fundamental structure is to make explicit what is implicit within the essence of the experience. To achieve this, I reflected further on the themes developed in the fundamental description, asking, ‘what does this mean? ‘What is really being said?’ And ‘what is the experience?’ The process and final description of the fundamental structure is outlined in Chapter Four.

Ethical Considerations

After gaining approval for the project from the Postgraduate School, ethical approval was granted by the Regional Ethics Committee (Appendix A & B), the University and the hospital from which I was recruiting participants. One of the concerns raised by the Regional Ethics Committee related to acquiring ‘accidental’ information that I may become privy to during the course of the interviews. For this reason information received about patients’ conditions and/or interventions was used only to help tell the story. When describing the relatives’ experience, I also took steps to ensure that my role as a researcher did not conflict with my role as a nurse. Those who agreed to participate in the study were given an information sheet by an intermediary person and were also encouraged to ask any questions relating to the study prior to agreeing to participate.

Recruiting Participants

Upon receiving ethics approval, I spoke to the nursing staff from the selected unit about the project. My purpose was two fold:

- 1 to outline the proposed research and criteria for participating.
- 2 to enlist the support of staff in identifying potential participants.

Recruitment was achieved by placing ‘Invitation to participate’ posters and information handouts (Appendix C & D) on the walls and tables in the ICU

waiting room. I made regular visits to the ICU to answer any questions the staff had and to replenish the participant information leaflets.

Participant Profile

The criteria for inclusion were:

- First time visitor to ICU
- Over the age of 18 and under 70
- Be a close relative of someone who was critically ill
- Able to understand and converse fluently in English

Due to constraints on the size of the study and the potential loss of 'essence' in translation because I speak only English, non-English speaking participants were excluded.

Participants who had visited an Intensive Care Unit previously were also excluded because I wanted to capture first and relatively 'uncontaminated' stories of experience. In order to capture experiences relating to unexpected admission rather than booked or post-operative admissions I chose relatives of patients who had been admitted to ICU for more than 24 hours. I wanted to focus on admissions that were urgent, serious and related to critical illness.

Sampling

Selection was made on a 'first come first selected' basis according to the above criteria. Once the potential participants had read the information and agreed to participate, they signed a consent form (Appendix E). Mutually convenient arrangements were then made for interviewing.

The relatives being visited were being nursed in two different ICU settings. The first participant (whom for the purpose of this study I called Mary) was visiting her husband. The event leading to his admission included initial assessment in an emergency department, transfer to a coronary care unit and emergency surgery prior to admission to a specialised Intensive Care Unit.

The second participant (whom I called Ann) accompanied her adult daughter to a general ICU following an initial assessment in the emergency

department [at the time of admission, Ann was away from home on business].

Data Collection

The interviews were carried out at a time and place of the participants' choosing. Interviews lasted between 60-90 minutes and were taped for transcription. The interviews were semi-structured with open-ended questions, for example:

“How did you feel when you first heard your relative was admitted to an Intensive Care Unit?”

“What was it like seeing him/her for the first time?”

“What else was happening at the time, and how did that make you feel?”

Other questions were used to clarify aspects of the story and redirect the participant to provide detailed information about their experience.

Achieving Rigour in Qualitative Research

I have chosen to follow the framework outlined by Guba and Lincoln (1989) and Lincoln and Guba (1985) to establish and achieve trustworthiness of this project. Closely related are the criteria of credibility, dependability, transferability and confirmability.

Credibility and Dependability

Credibility is the term used to describe confidence in the truth of the data. This means that the participants can recognise the reported findings as their own experience (Polit & Hungler, 1997; Streubert Speziale & Rinaldi Carpenter, 2007). Dependability is met through securing the credibility of the project findings (Polit & Hungler, 1997; Streubert Speziale & Rinaldi Carpenter, 2007)

Following the interviews, the tapes were transcribed verbatim and returned to the participants so that they could add, change or delete any of the information provided. The participants in this study believed that the transcripts accurately represented their experiences.

Returning the fundamental descriptions to the participants during the analysis phase provided another opportunity to ensure that nothing essential was missed. Both participants were happy with what had been described and declined to make any changes.

Transferability

Transferability refers to the extent to which research is potentially useful in other contexts. Qualitative research findings are not transferable in the sense that they do not provide for every individual response. The findings relate only to participants involved in the research. However, provision of details about the experiential context, enables readers to determine whether or not the findings may be relevant in similar, albeit slightly different circumstances.

Confirmability

Confirmability is the amalgamation of credibility, dependability and transferability. People and colleagues from other contexts, including ICU nurses and people who had similar or like experiences, were given the opportunity to read the narratives, to confirm the findings and accept their 'truth' whilst providing the 'phenomenological nod'.

The researcher also plays an essential role in maintaining trustworthiness because researcher bias influences analysis of the data. Having had both personal experience of the phenomenon and experience as an ICU nurse, it was easy for me to rationalise the actions of the staff in relation to the participants' stories. However, this was not the purpose of the research. I have had to constantly remind myself that I am focusing on the perceptions and experiences of the participants and that I am describing their experiences from a non-clinical perspective. As a result I have found myself re-evaluating my own practice and wondering how many times I have been guilty of failing to understand the relatives' perspective.

My assumptions about the phenomenon are based on what I know as a nurse and as the daughter of a man admitted to a Neurosurgical Intensive Care Unit. They include:

- Admission to an Intensive Care Unit is traumatic for both family and patients
- Patient care includes care of visiting family
- Families tend to forget their own needs because they are worried about their relative
- Families need to have a break from the ICU environment
- Families need to sleep and rest as much as the patient does
- Nurses have the best interests of family and patients at heart

Each of these assumptions has been challenged by the research findings yet, as will be seen in Chapters Four and Five, the challenges relate more to the implications for practice than that the assumptions themselves are incorrect.

Conclusion

This chapter has provided an overview of the methodology and methods used in this study. The research question was derived from personal experience and Colaizzi's (1973, 1978) framework was selected because it fitted conceptually and philosophically with my intention to explore the experience of having a close relative in an Intensive Care Unit. I have outlined the process of data analysis and discussed criteria for judging the rigour of the study.

The following chapter presents the study findings and demonstrates the process used to obtain both the fundamental description of the phenomenon and the fundamental structure of the experience.

CHAPTER 4 **Research Findings**

Introduction

Chapter Three outlined the research methods employed during the study including the method of data analysis and provided some examples. In this chapter the findings will be presented, firstly as themes that describe the experience of having a close relative in an intensive care unit. These themes resulted from formulated meanings and provide a fundamental description of the phenomenon. Following this, I will also identify the fundamental structure of the phenomenon. After transcribing and re-crafting the participants' stories significant statements were extracted, grouped and regrouped into six key themes that describe the phenomenon of having a close relative in ICU from the perspective of visiting family members.

Table 2 provides examples of significant statements and the formulated meanings derived from those statements

Significant statement	Formulated meaning
To see A for the first time was horrific. She was bloated with fluid. She was sedated. She didn't look like my daughter at all. My youngest had tried to prepare. But nothing could prepare me for this.	The illness can change the relatives' appearance so much that it is difficult to believe that the person you are seeing is truly your relative. Although some preparation was given, it was insufficient to prevent the shock of seeing the relative for the first time.
I thought if I am in there, then I will know he is okay	Whilst in ICU the relative becomes the focus of the family members' attention. There is a wanting and needing to be with the relative to the extent that little else matters. There is also a need to know the relative is okay which is established by being with the relative.

Significant statement	Formulated meaning
Why hadn't the staff phoned to tell me he had been moved [to coronary care]?	Frustration and anger from the lack of consideration of the staff not informing the family member that something is going on.
No-one else was allowed in to see him, so no one came with me. There was no one to talk to about how it felt.	Isolation from family and friends. No one to support the family member.
In ICU they kept the control. I would have been more than happy to wash him. That could have been something I could have done. I wasn't even asked if I wanted to do any of that stuff.	[In ICU] the control over the physical aspects of care were kept under the control of the staff. The family member wanted to participate in providing cares for their relative, but was not given the option.
The surgeons were very blasé. When he rang, he said that the operation went well. Considering this was the most important thing that had ever happened to us, he was very casual about it all.	For doctors this is a common every day occurrence but for the relative and the family member it is a significant life event and needs to be acknowledged as such.
No one spoke to us for the first four days. I had to identify myself every time. I had to identify myself as her MOTHER!	A lack of communication and acknowledgement of family for who they were and their role in the relatives' life by the staff.

Table 2: Examples of significant statements and formulated meanings

Theme Clusters

The following theme clusters emerged from the data:

- Seeing and being terrified
- Wanting and needing to be there
- Lack of information gives rise to mistrust
- Needing support in order to cope
- Feeling out of control
- Acknowledging 'humanness'

Seeing and Being Terrified

With the advent of technology, accessibility to medical information has become easier for the general public. Also, as a result of television and other medical dramas, public awareness of what happens behind the closed doors of an ICU is greater than it has ever been. Although this may help to prepare family members to cope with seeing a relative in ICU, the reality of seeing a relative in such a situation is something for which one can never be fully prepared.

The tubes and equipment, the unnatural body position and the physical effects of illness which impact upon his or her physical appearance all mean that the person can be difficult for family members to recognise. Thus the first look at their relative can evoke feelings of fear and horror. Mary explains:

It was terrifying. He looked so different from what I expected. Being a nurse, I have seen the machinery before, and you see it on the TV. My experience as a nurse did help. He was on a ventilator post-op. No one said that he would be on one. Maybe that is why it was frightening. Some of it had meaning for me. I knew about chest drains and what a ventilator was. I can't imagine what it would have been like if I hadn't. But NOTHING [strongly emphasised by Mary] prepares you for him. Him having all that machinery there and the sounds. He kept trying to wake up. He just did not look right. He looked terrified and that was terrifying for me.

He looked terrible, I think it was because he was unconscious, still anaesthetised. You don't see the people you care about like that.

Wanting and Needing To Be There

When someone within the family is seriously ill, the family may react by insisting that they stay with the person. Being there comforts the family in terms of knowing what is happening. They can see what is happening and can access information from the medical and nursing staff.

The need to be with their relative can be all encompassing to the exclusion of 'normal life'. Mary remembers:

When I did go home [after seeing him], I couldn't sleep. So I rang up and asked if I could come in. It was about 5 o'clock. They said I wasn't allowed. I told them I really wanted to be there. They agreed to let me come in until shift change at 7am. I got the impression I wasn't supposed to be there. I shouldn't have been there.

Mary's need to be with the relative is almost primal. It's like an instinctive need to protect a member of her family. The restrictions to visiting enforced by the staff do not relieve her anxiety and worry. Mary's belief that she should be able to visit whenever she needed to, often led to disappointment and resentment especially when she was asked to leave the bedside.

Not being with the relative can lead to feelings of guilt, especially when it impacts on family life. Ann recalls being 'pulled' in different directions:

Feeling guilty for being at home. Not being with A [the relative]. My mother is staying with us. I have to be home for my mother. So I wish my mother wasn't there. That way my time would be freed up to spend with A [the relative]. I wouldn't be as tired as hell all the time. I wouldn't have to be

a bad daughter and abandon my mother today in order to be a good mum.

But I have to abandon my mother. I have to be a good mum.

I have to be with A [the relative]. So you feel guilty.

Proximity to the relative is also important. Even if the family member is not allowed inside the intensive care unit, being close by helps significantly, especially when things are not going well.

Ann asks and then explains:

Wouldn't it be better to have someone there? When she is going bad like that, to have someone who loves her there? When they are losing her. You could be there. For that last little bit. When everything is going off the rails. All the alarms beeping and everything is going to shit. It would be better to be there. Or at the least in the waiting room. Just in case.

For both Mary and Ann, being with the relative became the main focus of their lives.

Lack of Information Gives Rise to Mistrust

When the family does not receive information, they are left wondering and worrying about what is truly happening. Receiving vital information after a critical event is unsettling at best, often leaving them to wonder about what is not being said and whether the medical and nursing staff can be trusted to give them information at all.

Critical incidents that are not relayed to the family members at the time elicit feelings of anger, frustration and mistrust with the medical and nursing staff. Ann and Mary experienced this on more than one occasion.

Mary: I was a bit pissed off really. I didn't feel like I trusted people and that went right back to when he was transferred to coronary care. I was really disappointed that the hospital

hadn't told me of his transfer. I really thought someone should have rung me.

From then on really, and when they sent me out so they could 'do things'. It was the little things in the end that made you not trust what was going on.

I didn't believe that people would ring me if anything went wrong. That was really hard. I remember when he was in coronary care and [he] had some more chest pain, I wondered if they would ring me because they didn't bother last time. Then they did it again when they sent me out.

Ann: Several incidences have occurred, where we did not get to hear about it until one or two days afterwards. That is frustrating, and it makes me angry.

The other day, I had left the hospital. I would have made it as far as the car park. Apparently she started going all to shit. I had gone home. They did a scan and all this other stuff to her. She was in a bad way. **WHY DIDN'T THEY RING US?**
[strongly emphasized by Ann]

The manner in which information is delivered impacts upon family members. For instance, if the staff relay information in a manner that does not give hope, it is difficult for the family member to maintain hope. Information delivered in a manner that allows the family member to maintain a positive outlook makes it easier to deal and cope with, regardless of the nature of the information. When the information is given in a way that engenders hope, the family member is more likely to trust the person providing the information. Knowing what is happening and what may happen is important. Ann and Mary wanted to know what was happening, when it was happening, as well as what could happen. Fundamentally, they wanted and expected honest information from the staff. They wanted to be able to trust the staff. As Ann put it:

Talking to the doctors it is hard. The male doctors, Dr Death and Dr Doom I call them. Because that is how they make you

feel. The lady doctor, I call her Dr Hope because she is always telling me that things can be real bad, but this is a long haul. That they are going to get there. They are not giving up. She gives you hope. Dr Death and Dr Doom, take your hope away... She could be Dr Death and Dr Doom rolled into one but she gives you **hope** [Ann emphasized the word hope]... Just be honest, don't sugar coat or um and ah about it. Honesty! Don't leave us feeling like mushrooms – kept in the dark all the time.

For Ann, the choice of names Dr Death and Dr Doom has negative connotations and indicates the extent of their adverse impact. Dr Hope, by comparison, appears to acknowledge and convey the information differently. She seems more open and empathic as she progressively provides information; Ann trusted the information given to her by this doctor. All of the doctors may be 'honest' with the information yet the manner in which they communicate may impact on the families' perspective of that honesty.

Needing Support in Order to Cope

Family members supporting relatives in ICU need support themselves in order to cope with what is often an overwhelming and life changing experience. There is some expectation that support will come from other family members and friends. However, the family members' perception of the illness may be of such a personal and private nature that they need to deal with it by themselves. Mary explains:

I had cut people off. It was such a private thing I didn't think I needed the rest of my family, my friends. Going to ICU to see M [the relative], needing to do it by myself. I didn't even let the children go. I didn't think they would want or should see him like that. In hindsight it was an incredibly hard thing to do. Really lonely I should have had someone to talk to. But I wanted to do it alone. Emotion takes over. You act in a bizarre way, so you aren't you.

When Mary looked to other family members for support, it was not forthcoming. This added to her anxiety about the relative as well as her anxiety over other family members, particularly if she did not think they were coping particularly well.

My 17 year old made me angry. I don't think her way of coping was healthy, so I worried about her. I needed her to be there for me, but she wasn't.

If not received from other family members or friends, the family member may look to the staff for support. When support from that staff is not forthcoming there is a sense of being let down by staff who do not seem to care for the family. This, in turn, can lead to an increase in anxiety and further worry. Mary remembers:

I cried. I cried a lot. I would cry in the car. I would cry at home. I would cry in ICU. I would cry in the ward. I cried everywhere. In ICU the staff nurse was amazing. He just put his arm around me. He explained everything that was happening and was wonderful support. It didn't seem to be a problem for him. He was very comfortable with it.

The nurse who took him down to theatre didn't know what to do when I started crying. She was no support. On the ward, they looked the other way. It made them uncomfortable.

For Mary, this led to feelings of isolation. As a result of not including her friends, or receiving the support she expected from her family and receiving only intermittent support from ICU staff, Mary was left feeling rather lonely and scared. Mary remembers:

Feeling scared and on your own. Lonely because no one is there with you. No one else was allowed in to see him, so no-one came with me. That was hard. If I had to do it all again I

would have someone there with me. There was no one to talk to about how it felt...

For Ann, it was more about having to cope with situations that arose outside of the hospital, giving rise to anger and feelings of frustration. Energy required to cope with what is happening at the hospital has to be channelled elsewhere leaving the family member tired and exhausted.

Ann states:

She [the mother-in-law] was crossing my boundaries. Invading our space. Treading on toes. When someone does that to you. When you have a member of your family dying. When you are feeling so helpless. When you need love and care. When someone invades. This negative anger starts to build and build...I was going crazy... I was so tired.

Having to deal with what is going on at home and feeling responsible to maintain a 'normal life' results in the family member being pulled in different directions, further adding to the feelings of being unsupported and frustrated.

In an attempt to deal with such an overwhelming situation, maintaining normal life is impossible despite best efforts by the family member.

Family members may try to overcompensate for loss of their usual routine as a way of minimizing the impact of the situation. As Mary states:

Their lives went on. Here I was madly racing around, going to the hospital, going home to cook, back to the hospital whilst their lives just went on. It was bizarre. I think they were a bit shocked to know what it was like for me. I made sure I was home for them when they came home from school. Silly really, I was never home in time when I was working.

The overwhelming situation becomes a matter of survival, doing what needs to be done to get through, taking one day at a time.

Mary: We got through the operation. We got through all that other stuff that happens. You never thought about it, you just did what needed to be done. I kept thinking he was going to die. I just kept thinking I am going to be a widow. But you get through it.

Ann: Living in limbo is difficult. The waiting to see what is going to happen. Being helpless. Not knowing. Living on this roller coaster of emotions. Surviving.

Surviving, waiting to see what is going to happen and being helpless all add to the anxiety of the situation. There is almost a sense of loss of control over the situation and that coping is the most that can be managed.

Feeling out of Control

No control over what happened, no control to make it better, no control to change it. This lack of control is disempowering and leaves the family member feeling helpless and insignificant as they are unable to do anything and do not have the power to help the relative. When faced with this lack of control, the family member tries to regain some control anyway they can. Ann remembers making a conscious decision to regain control by demanding answers to questions:

So to see A [the relative] there. I just felt so small and helpless. This was a thing that I had no control over. I couldn't sort it out. I couldn't control or change it. I couldn't make it better because it was out of my control. I just felt small and insignificant...Tonight, when I go up there. I am going to be a pest. I am going to ask the questions. I want the answers. No bullshit. Just the facts. What is going on. Tell me what is happening.

Another way family members may try to regain control is by 'doing things' for the relative, for example, assisting with the provision of nursing care. When nurses do not allow the family to participate in the care giving, the feelings of helplessness increase. Regaining some control over the

situation is important for the family member. When unable to participate in the care of the relative, the family member begins to challenge the nursing staff and assert themselves as a way to regain some control.

Mary senses that the nurses try to keep control by providing information in exchange for participating in the care of her relative. Mary states:

They gave me lots of information but they wouldn't let me wash him. In ICU they kept the control. I would have been more than happy to wash him. That could have been something I could have done. I wasn't even asked if I wanted to do any of that stuff. Strange really but they would send me home so they could do it... I asked to shower him, made sure he got some pain relief that sort of thing. I became, I suppose one of those people – an interfering relative.

Mary further describes this sense of control by the nursing staff when she tells of what it was like at the bedside:

I didn't know what to do with myself. I was in the way, but I wasn't. They didn't make me feel like I was in the way, but quite clearly I was. I couldn't help feeling I was in the way. They were doing all sorts of things all around you all the time...I suppose I was scared that I would get in the way. Make them angry. Annoy them. They weren't necessarily making me feel that way. It was just me. I didn't want to annoy them. I wanted to stay. They might send me out if I annoyed them.

The sense of losing control adds to the feelings of insignificance, that they, as the family members, are not important. Needing to 'be with' and 'do for' is important for the family members. Having some control over this situation by being able to participate in caring for their relative provides a sense of value and acknowledges who they are in the relatives' world.

Acknowledging 'Humanness'

Possibly the most significant theme in terms of the family member's experience was the lack of acknowledgement by the staff that they were people with lives and that the relative existed as more than an ill person.

When the family member was not acknowledged as being a part of what was happening there were intense feelings of anger and frustration. Ann recalls:

No one spoke to me for the first four days. I had to identify myself every time. I had to identify myself as her MOTHER [strong emphasis on mother]...For the first four days that I visited, I saw the same person. Everyday I spoke to the same nurse. Looked at her everyday. On the fourth day, she says, 'Who are you?'... I wanted to kick her fat arse! I wanted to yell REMEMBER ME? [Ann placed a strong emphasis on these words] Or are you just being a snarky old cow. Just because you don't like the look of me? Because I can't be bothered putting on make-up. Because I can't be bothered doing my hair! Because my DAUGHTER, my FRIEND, is dying! [strong emphasis on both daughter and friend]

The lack of acknowledgement by the staff of the family member as a person or as a part of the relatives' world added to the feelings of insignificance and helplessness as well as anger and frustration. There is the sense that the family members' right to be with the relative has been challenged. For Ann the perception was not so much 'who are you?' but more of, 'why are you here?' Mary also remembers not being acknowledged:

As a relative, I felt quite left out by the doctors. They didn't include me. It was happening to M, so he was the most important one. The staff in ICU did include me, but overall you are the person that is left out. This made me quite angry... They [the doctors] came to see M all the time. They

never tried to see me. There was never any effort to talk to me.

For the family members, acknowledgement of the relative, as a person, was possibly more important than receiving acknowledgement for themselves. The family members wanted the staff to view the relative as an individual, not as a disease or routine. When this happened, the family members experienced frustration and anger towards the staff. I believe Mary summed it up with the following statement:

When they left him in the chair, they wouldn't put him back to bed. I thought he needed to go back to bed. The nurse part of me knew what they were doing. But there was a part of me that thought they didn't look at the little person when they needed to.

The perception of the relative as a 'little person' gives a sense of the enormity of the situation, almost as if the relative is an innocent bystander in a series of catastrophic events. The 'little person' becomes lost in the flow of the routine. Mary adds:

They were so off-hand about it. I wanted someone to acknowledge how important it was. That he was looked at as a person. They were looking at him as more a routine than looking at him as a person.

Mary remembers how angry she felt when her relative was viewed as part of the routine by both nursing and medical staff. Mary describes how she felt:

Considering this was the most important thing that had ever happened to us, he [the surgeon] was very casual about it all. He was happy with everything that was happening. But it was all so understated... I wanted to yell at him! I wanted to slap him about a bit. I felt really angry. He undermined the whole

thing...It was important. I wanted him to see that it was important to me. Important to us. I felt that about everything. It was important. To the surgeon, it was a walk in the park, but not for us.

For Ann the experience was different. It was about the way in which the nurses interacted with her relative. When they spoke to the relative the same way they would if she were awake, Ann felt valued because the relative was being valued.

I feel that certain women, nurses, have gotten attached to A [the relative]. I know they aren't supposed to. I suppose they have gotten to know her, they really do. Because they listen to us...There are some really wonderful nurses that are really supportive. They talk to A and tell her things. Treat her like a person...There is this one, that will go to A and say 'its no good kicking up a fuss' when she freaks out a bit. I like that. Because that is what A is like. She can be a little cow. I think it is so cool she gets spoken to like that. It is affirmative. It is assertive.

Taking notice of the family and showing an interest in getting to know the relative as a person made it easier for the family to cope with the anxiety. For Ann, it was not a case of liking or getting on with the nursing staff, it was more about her perception of how they cared for her relative.

Ann describes one staff member:

There is one, you would swear she should be at NASA [implying she is a 'space cadet'], but I like her. She has everything ready before the beeps go. She takes her job very seriously. When she is in there with A she is very serious. You ask her **anything** [Ann emphasized the word anything] and she tells you. But she doesn't smile. She is a bit of a cold fish. But she is really really good at what she does... Others are just so indifferent with A. They are at the door chatting to

one another. When that happens I do that Marge Simpson growl. Meaning get your 'arse' back in here.

When family members received information from the nursing staff, there was a sense of empowerment and inclusion. There is an acknowledgement from the staff that the family is important. Acknowledging that the family members and the relative are individuals with needs that extend beyond the physical to include the emotional and providing care to meet these needs, helps reduce the stress, anxiety, frustrations and fear that family members experience. The perception of this acknowledgment gave the family members confidence in the staff's ability to care for the relative, regardless of whether or not they liked or disliked the individual staff members.

Fundamental Description of Phenomenon

Although the themes derived from the data have been presented separately and sequentially thus far, they are very much interlinked. Like the participants' stories they must not be viewed in isolation because doing so risks minimizing and/or losing the experience. In drawing the themes together, I will now provide a fundamental description of the phenomenon.

Admission of a close relative to an ICU causes high stress and anxiety levels amongst family members. If news of the admission comes from other family members instead of hospital staff, anxiety levels increase, as information about the relative's condition and what is happening is not available. The driving need to be with the relative to provide support becomes the main focus for the family member, almost to the exclusion of all else. For some, this can elicit feelings of guilt as they neglect family life. When the family member is unable to be with the relative, whether it is due to the visiting policy, the requirement of staff to provide cares or for the relative to undergo some procedure, the family members become anxious and frustrated.

They are frustrated in that they cannot be where they need to be with the relative and anxious because they need to be with the relative to know what is going on and to make sure everything is all right.

With the advent of television programmes and the internet, family members have some awareness of what may happen and what they are likely to see, however, the reality of the situation is often more terrifying than what they imagine. More often than not the relative is unrecognisable because of the physical changes due to the illness and the equipment that surrounds them. Whilst hoping for the best and fearing the worst, the reality of that first look at the relative brings the realization of the seriousness of the situation.

When with or away from the relative, the family member needs to know what is happening. There is an expectation that this information will come from the medical and nursing staff. More often than not, if information is not received, the family member feels left out or ignored by the staff. For the family member, this only adds to their feelings of frustration, anger and fear. If the relative's condition changes and the family member is not informed at the time, they begin to doubt the integrity of the staff and are often left wondering if they would be informed if the worst was to happen. The family member in this situation is left feeling betrayed and loses faith and trust in the staff caring for their relative. When information is received, the manner in which it is given has an impact on how the family member perceives the situation as a whole, in that it can either give or take away hope and engender trust or mistrust.

Whilst coping with the reality of their relative's admission to ICU, the family member also needs to cope with what is happening outside of the hospital. The family member often looks to other family members for support and assistance to continue the smooth running of 'normal life', leaving them free to spend time at the hospital. If the support is not received from other family, it is the staff who are looked to in order to fulfil this need for the family member. When staff are unable to provide support, the family member is left feeling isolated and alone. There is a

need for the family member to have someone available that they can talk to about the situation or to have a shoulder to cry on. If they do not receive support, their ability to cope diminishes as the situation can become too overwhelming for them. Coping then becomes a case of survival, doing what needs to be done on a daily basis to just get through.

For the family member, the enormity of the situation evokes feelings of helplessness and loss of control. They were not able to do anything to prevent the situation, nor are they able to do anything to improve the situation. The family member attempts to regain control by whatever means possible. When this fails they become angry and frustrated and communication between themselves and the staff often breaks down leading to more anger and frustration. The family member also needs acknowledgement of the enormity of the situation from the nursing and medical staff. When this is not forthcoming for the family member, it adds to their feelings of helplessness, insignificance and loss of control. The family members also look to the staff to recognize them as an important part of the relative's life as well as the relative as a person rather than as a disease or part of the routine. When the relative is not viewed as a person, the family members' perception of the staff is one of uncaring, and the family member begins to doubt the ability of the staff to care.

Fundamental Structure

The final part of Colaizzi's (1973, 1978) method is the articulation of the fundamental structure. This is a concise statement of the phenomenon, which integrates all of the identified themes.

The lived experience of having a close relative in ICU is an emotional event, which can be described as living on a roller-coaster. Feelings of fear, anxiety and frustration are exacerbated by lack of information and support.

Seeing the relative for the first time causes horror and fear. The need to be with the relative becomes the main focus and trying to maintain normal

routines causes stress and anxiety particularly if the family member feels that this detracts from being with the relative.

Family members try to regain some control over a situation where they perceive they have no control. Assisting with the care of the relative is one way that they can achieve this.

Acknowledging the enormity of the situation and treating the relative and family as people, assist family members to cope with what is happening. Lack of, or poorly delivered information engenders mistrust and causes family members to question the honesty and integrity of the ICU staff.

In a nutshell, the participants summarised the experience as follows:

It was so overwhelming. It was like being hit by a bus. Just so sudden and unexpected. So huge. So overwhelming. It was a real life altering experience. It was like: “Whoa, we turned a corner and went off in a whole different direction. But we got through it”.

(Mary)

This experience has been one of the cruellest I have ever had. You are just so helpless. It is out of your control. In the hands of the doctors and God. You just hope and pray that the right decisions are made. It is cruel and hard, because I can't help her.

(Ann)

Conclusion

In this chapter I have provided a description of the phenomenon of having a close relative in ICU, as lived by the participants. Using the method outlined by Colaizzi (1973, 1978) I extracted significant statements from the participants' stories, formulated meanings about the significant statements, clustered the themes and provided a description of the phenomenon.

In the final chapter I will discuss the findings, the implications for practice and recommend further research into this phenomenon.

Introduction

In this chapter I will discuss the findings of my study alongside existing literature relating to the topic and make recommendations for practice, education and research. Exploration of the experience of family members' visiting a close relative in ICU revealed six themes as described in the previous chapter.

Seeing and Being Terrified

Seeing a relative for the first time in ICU is a terrifying experience. For family members, prior knowledge and preparation received from other family members is often insufficient to counter the shock of that first sight which only adds to the anxiety already being experienced. The equipment and noise surrounding the relative can be bewildering further adding to the fear and anxiety. It is in these early stages that family members attempt to cope with what is likely to be an overwhelming situation. Preparation of family members prior to that first visit is essential to assist in alleviating some of the fear. Current literature provides little guidance. To date, no one appears to have explored the need for family members to be prepared by nurses for entering an Intensive Care Unit to see their relative for the first time.

Wanting and Needing to be There

Most family members feel they need to be with relatives in times of crisis. They need to be there to give support and to make sure their relative is receiving the best care. Being with the relative is often thwarted by the ICU staff and, whether intentional or not, the family members' perception is that the staff control access to their relative. For the family member, not being with the relative when they want to be often leads to feelings of distress and anxiety. Away from the relative they worry about what is going on and how their relative is fairing. This is congruent with the findings of Lam and Beaulieu (2004) and Walters (1995b). These authors identified the need for family members to 'be with' or 'be by the bedside' of their relative during this time of crisis, labelling this need as 'connectedness'. Other studies have identified that more liberal ICU

visiting policies are beneficial for ill relatives as well as their family members and that there has been an improvement in communication between family members and staff (De Jong & Beatty, 2000; Gonzalez et al., 2004; Roland et al., 2001).

Lack of Information Gives Rise to Mistrust

Family members need to receive information about their relative on a regular basis. The general expectation of family members is that information should come from the medical and nursing staff. If the family member feels that they are not being given all the relevant information in a timely manner, their ability to trust the staff diminishes.

This trust is part of the therapeutic relationship that should develop between the family member and the staff at the start of the experience. These findings are supported by Stover Leske (1998) and Auerbach, Kiesler, Wartella, Rausch, Ward and Ivatury (2005) who have also argued that early contact between family members and ICU staff is beneficial in establishing a mutually respectful and trusting relationship.

Family members also need this information to help them cope with the situation. My findings suggest that this is a way of staying in contact with what is happening to their relative. Lack of information leads to anxiety, fear and mistrust, whereas receiving information reduces anxiety levels and reassures the family member that the best care is being provided. Others have supported this need (Browning & Warren, 2006; Daley, 1984; Leske, 1989; Mendonca & Warren, 1998; Molter, 1979).

Auerbach et al., (2005), Dowling and Wang, (2005), Lederer, Goode and Dowling (2005), Medland and Estwing Ferrans, (1998), Warren, (2002), Waters (1998) have argued that when this need is not met, family members' satisfaction levels decrease. That is, they become dissatisfied with the care their relative is receiving and this is what the participants in this study experienced (Auerbach et al., 2005; Kosco & Warren, 2000; Stover Leske, 1998).

Needing Support in Order to Cope

The admission of a relative to ICU is often sudden and unexpected. For family members this often means dealing with a crisis situation for which

they were not prepared. Those providing support to the ill relative are also invariably providing support to other family members. The overwhelming situation and external responsibilities can become overwhelming. In some instances the family member may isolate themselves not wanting to burden others.

It is therefore essential that family members receive support from nursing staff. If such support is not forthcoming, the family member is less likely to be able to cope and may also perceive that staff are uncaring both of themselves and their relative, exacerbating any feelings of anger and mistrust. This finding is supported by Lederer, Goode and Dowling (2005). However, Waters (1998) suggested that there are inconsistencies within the literature about provision of support by nursing staff. This may relate to different perceptions by family members and nursing staff as to what they perceive to be appropriate support.

Feeling Out of Control

The sudden and unexpected nature of a relative being admitted to ICU brings with it a sense of feeling out of control. From the family members' perspective, they are unable to change or help improve the situation and have to rely on others to 'make it better' for their relative. For family members it appears that loss of control magnifies with each negative experience.

The findings of this study suggest that family members perceive that the nurses control accessibility to the relative, the information given and the ability of the family member to physically be with and touch their relative. This is supported by Auerbach et al., (2005), Roland et al., (2001), Gonzalez et al., (2004), and Ramsey et al., (2000) who suggested that nurses believe that they need to be 'gatekeepers'. This causes anger and frustration for family members and they try to find ways to regain control. The family members in my study changed the way they interacted with the staff, becoming more assertive in ways that have also been noted by Bogoch et al., (2005), Dowling and Lederer (2005), Plowfield (1999), and Ramsey et al., (2000). Another way that family members attempt to

regain some control was through participating in the care of their relative. This finding has also been supported by Auerbach et al., (2005), Lam and Beaulieu (2004) and Plowfield (1999).

Acknowledging 'Humanness'

The family member views the relative as someone with whom they have a connection. In this study it was mother-daughter and wife-husband. Having a connection with the relative allows the family member to share and understand one another's humanness which can give a sense of belonging to something that is important. When ICU staff do not acknowledge this humanness, resentment and anger is often felt by the family members because the lack of acknowledgement implies that they are not important. Thus, there is a need for the family members' to be acknowledged, another finding that is consistent in other studies (Andrew, 1997; Burr, 1997; Dowling & Wang, 2005; Walters, 1995b). This acknowledgment must encompass the enormity of the experience for the family members'. If they feel that the medical and nursing staff view their experience as an everyday occurrence it only adds to their anger and frustration.

Although this study explored the experience of the family member, there is some congruence with the literature in regard to family needs. The experience is greatly influenced by the meeting of these needs. That is, when the needs are met the family member has a positive experience and when not met a negative experience.

ICU staff have the power to meet the needs of the family and the power to influence the experience. The following recommendations are some suggestions on how these needs can be met.

Recommendations for Practice

Having a relative admitted to ICU is never going to be a pleasant experience however, nursing staff are in the ideal position to ease the burden and assist the family member to cope. Therefore, these

recommendations are based on what can be done to make having a relative in ICU a more positive experience.

Flexibility of Visiting

The debate about open visiting policies, the benefits and the disadvantages to patients, staff and family members has been ongoing for nearly a decade. As discussed in the literature review, infection control, rest and care provision have been cited as reasons for limiting visiting in the context of intensive care (Berwick & Kotagal, 2000; Farrell et al., 2005; Gonzalez et al, 2004; Ramsey et al., 2000; Roland et al., 2001; Yow Daniels, 1996). Although some ICUs have open visiting, there is a modicum of control as the staff restrict family access to their relative. Visiting policies that can be modified to suit the needs of the family members and relatives could be beneficial. Therefore the recommendation is:

- Implement flexible visiting policies to benefit family members and patients.

Open Communication

Effective communication is clearly a key factor in any human context. Receiving information about a relative's condition, particularly when the relative's condition changes or deteriorates and the way this information is relayed, is important. The family member needs to be informed about changes and involved in the decision making process.

Recommendations for improving communication have included; utilisation of health care workers that work in a liaison role between family members and ICU staff, use of information leaflets available to family members in the waiting room and information kiosks that enable family members to access information from the internet and intranet (Dowling & Lederer, 2005; Dowling & Wang, 2005; Lederer, Goode & Dowling, 2005).I would support these recommendations and additionally suggest acknowledging the presence of family at the bedside and talking to them about their relative. Further recommendations are:

- Learning and using the names of family members'
- Learn about the ill relative and their life

- Acknowledge the enormity of the situation for the family member and relative
- Involve the family member in discussions about the progress of their relative
- Ascertain whether the family member wishes to be contacted at home

Support for the Family

Family members require support to assist with their coping ability and nurses are in the strongest position to provide this support. Support can be provided by allowing the family access to the patient, providing information updates on the relatives' condition and allowing the family member to show their emotions.

Taking time to find out about previous experiences with serious illness, current concerns, and support networks so that the information can be incorporated into a plan of care that is communicated to other staff could also be useful. Being able to talk to other family members that have been through or are going through the experience may also be beneficial.

Therefore, recommendations to assist with the support of family members include providing support by:

- Facilitating more flexible access to the patient
- Ascertain what support the family member has available to them
- Informing family members of support services available, for example, the hospital chaplain
- Ask what they know about their relative's condition in order to provide up to date information
- Ask the family member if there is anything outside of the ICU that may cause additional stress

Include the Family in Caring for Their Relative

Allowing the family to participate in the provision of care is another way that nurses can assist the family to cope with the situation. As a result of participating in care and feeling acknowledged, the family member is less

likely to feel helpless and may gain a sense of some control over the situation (Auerbach et al., 2005; Lam & Beaulieu, 2004).

Involving the family in care may include:

- Asking the family member how and if they would like to assist with cares such as washing or feeding their relative
- Asking the family if they would like to assist with their relatives' physiotherapy treatments such as passive limb exercises

Preparing the family to see the patient

Providing some preparation for the family prior to seeing their relative for the first time may reduce some of that initial shock, although as discussed in this study the family may never be fully prepared. The use of written information and visual cues are ways that preparation can be achieved:

- Have some written information about the unit environment available for family members to read
- Have pictures showing the equipment and bed-spaces available in the waiting room for family members to view whilst waiting to visit
- Explain to the family member how their relative may look
- Give the family members time to ask questions about their relative's appearance and condition before they enter the unit

The majority of recommendations for practice are not difficult to implement. However, to avoid making assumptions about what is best for the family, it is essential for the nurse to ask the family members, "What does this experience mean to you?" "What can we [the staff] do to help you through this?" This assists in gaining a better understanding of the experience from the family member's perspective .

Recommendations for Education

Ongoing education for all registered health professionals is a legislative requirement. Whether formal or informal, education should be aimed at improving knowledge and health care practices. Ways in which this can be achieved are many and varied, such as inviting family members to talk to staff about their experiences, or inviting family members to write their own stories. Another way is to utilise the research that is available, as a

point of discussion for all the staff, not just nurses. Reviewing patient satisfaction forms, complaints and case summaries from the Health and Disability Commissioner provide valuable insights into family member's experiences and thus are good sources of learning for nursing staff.

Limitations

Although purposive sampling was chosen for this study, time limitations excluded a lengthy recruitment process therefore, there were only two participants. This limited the number of shared stories, thereby limiting the description of the experience.

The participants came from two different ICUs, one a private specialised unit, the other a general public level 2 unit. The nature of these units may have impacted on the experience of family members. The specialised private ICU is only open during the week therefore, any patients requiring extended care are transferred to another ICU, or they are transferred to a general ward. The public general ICU has limited facilities and is unable to cope with long-term ventilation requirements for seriously ill patients and if necessary these patients transferred to a level 3 unit. This transfer may impact on the family members' experience because of the potential disruption in care. The family member may also have had different experiences depending on the seriousness of their relative's illness.

Lam and Beaulieu (2004) suggest that family members whose relative was admitted to ICU for a short period of time, that is 2 days, may have different experiences from those whose family members are in ICU for longer periods of time.

Another possible limitation of this study was the fact that one of the participants was visiting their relative during the study and the other was recalling an experience that had occurred 6-8 months previously. Although this may not have impacted on the experience, it may have had an influence on the family members' recall of the experience

Furthermore, types of relationships and gender may also be a factor in influencing the experience. In this study the participants were either spouse or parent and both were female. Although identified as 'not

statistically significant, Rukholm et al., (1991) noted that anxiety levels were higher for women than for men when visiting an ICU. Finally, the participants in this study were visiting relatives who had been admitted unexpectedly to ICU. This raises questions about how the experience might differ for those visiting relatives whose admission had been planned.

Yet, there seemed to be aspects of the experience that could be common to both. Which leads me to ask: Are there some fundamental aspects of human experience that are shared? If so, does this phenomenon transcend the Intensive Care Unit? Do family members have similar experiences on general wards or other areas of the health care service?

Recommendations for Further Research

Clearly, this study needs to be extended in terms of its size and location. A greater number of stories need to be collected and interpreted phenomenologically so that a more substantial glimpse of what it is like to have an ill relative suddenly admitted to an ICU is provided.

I believe that to benefit families in the long term, other qualitative approaches such as hermeneutic phenomenology could provide further insights into the life world of family members. For example, family members' experience of coping with a relative in ICU or descriptive studies about the impact on family members when their needs have not been met. Quantitative studies in the past have provided useful information about how to meet the needs of the family members, whilst other quantitative studies have identified incongruities between family perceptions of what is important and nursing perceptions. Fuller understanding of families' experiences will assist nurses to meet the needs of family members and reduce their dissatisfaction.

Conclusion

This small study explored and described the experience of having a close relative in an ICU. Using data analysis methods outlined by Colaizzi (1973, 1978), themes were identified by clustering significant statements and meanings from the stories of two participants. A fundamental description of the phenomenon and its structure was then provided.

Recommendations have been made for practice, education and further research. Asking the family members about their experience is essential in order to gain a better understanding of their experience from their perspective.

For the participants in this study, having a close relative in ICU was a cruel and life changing experience that was made more difficult by a lack of information and lack of trust in the medical and nursing staff.

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MEMORANDUM



Academic Registry - Academic Services

To: Deb Spence
From: **Madeline Banda**
Date: 10 November 2001
Subject: 01/105 The lived experience of having a 'close' relative in an intensive care unit

Dear Deb

Thank you for providing amendment of your ethics application as requested by AUTECH.

Your application is approved for a period of two years until **November 2003**.

You are required to submit the following to AUTECH:

- A brief annual progress report indicating compliance with the ethical approval given.
- A brief statement on the status of the project at the end of the period of approval or on completion of the project, whichever comes sooner.
- A request for renewal of approval if the project has not been completed by the end of the period of approval.

Please note that the Committee grants ethical approval only. If management approval from an institution/organisation is required, it is your responsibility to obtain this.

The Committee wishes you well with your research.

Please include the application number and study title in all correspondence and telephone queries.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Madeline Banda'.

Madeline Banda
Executive Secretary
AUTECH

From the desk of ...
Madeline Banda
Academic Services

Private Bag 92006, Auckland 1020
New Zealand
E-mail: madeline.banda@aut.ac.nz

Tel: 64 9 917 9999
ext 8044
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Auckland Ethics Committees

Delivery Address:
C/O Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92522
Wellesley Street
Auckland
Phone (09) 580 9105
Fax (09) 580 9001
Email: pat_chainey@moh.govt.nz

Please include the reference no. and study title in all correspondence/telephone calls.

26 September 2001

Ms Mandy J. Williams
2/20 Valecrest Pl
Glkenfield
Auckland

Dear Mandy,

2001/150 The lived experience of having a 'close' relative in an intensive care unit

Thank you for your amendments – received today.

We are pleased to inform you that this study has received ethical approval until 30 July 2002, at which time a final summarised report/ abstract is required to be presented to the committee for consideration. It is certified as not being conducted principally for the benefit of the manufacturer and will be considered for coverage under ACC.

Please note that the Committee grants ethical approval only. If management approval from the institution/organisation is required, it is your responsibility to obtain this.

TA progress report is required by 26 September 2002. A form should come off our data base two months prior to this date for submission to the Ethics Committee one month before the expiry date. However, it is your responsibility to ensure that the progress report is submitted to the Ethics Committee, or the End of Study Report.

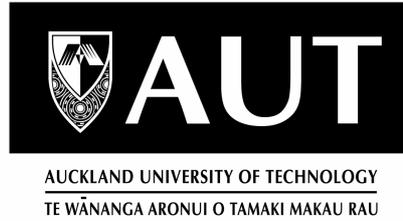
The Committee wishes you well with your research.

Yours sincerely,



**Pat Chainey
Administrator**

Cc: Waitemata ADHB



The Lived Experience of Having a 'Close' Relative in an Intensive Care Unit

My name is Mandy Williams and I am a registered nurse with 15 years clinical experience, most of which has been within an Intensive Care Unit (ICU).

I am currently employed as a lecturer at Auckland University of Technology where I am also enrolled as a student in the Masters in Health Science Programme.

I am about to embark on research study to gain an insight into the feelings, perceptions and fears experienced by you, the relative of a patient in the ICU. It is hoped that the awareness developed from this study will enhance the ability for the nursing staff to meet your needs more effectively.

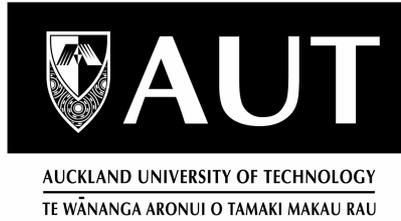
You are invited to participate in 2 tape-recorded interviews lasting approximately 1 hour.

If you are interested, please contact either the nurse looking after your relative, or the unit coordinator. Alternatively you may contact me directly on 917-9999 extn 7127 or 025-593-893.

With thanks

Mandy Williams RN.

Post Grad Cert Critical Care



Participation Information Sheet

Project Title: Relatives Experience of Having a Close Family Member in the Intensive Care Unit (ICU).

Introduction.

You are invited to participate in this study, which explores the feelings, perceptions and fears experienced by a close family member of a patient in the Intensive Care Unit.

The aim of this study is to develop an insight into this experience, thereby gaining greater awareness of what this experience means. It is hoped that this will aid nursing staff to meet the needs of future relatives more effectively.

Who I am.

My name is Mandy Williams. I am a registered nurse with 15 years clinical experience, most of which has been within an Intensive Care Unit. I am currently employed as a lecturer at Auckland University of Technology where I am also a Masters in Health Science student.

How are Participants Chosen.

If you wish to participate, please inform the nurse looking after your family or the Unit coordinator. You may also wish to contact me, Mandy Williams directly on 09-917-9999 extn. 7127 or 025-593-893. We will arrange a convenient time to meet. This meeting will be to discuss any queries you may have about the study and supply you with any further information you may require.

What Happens in the Study?

The study involves participation in a tape-recorded interview at a time and place convenient for you. The interview will take approximately 1 hour, or as long as you feel is needed to describe your experience. You will not be required to divulge any health information about your relative and you should not volunteer this information.

I will be responsible for the transcribing the interviews and storing of all information securely. A follow-up interview will be required for you to confirm my interpretation of your experiences.

Participation in this study will not affect the treatment of your relative in any way. If preferred, the interview can take place *after* your family member has been discharged from the Intensive Care Unit.

What are the Benefits?

Whilst there may be no direct benefit to you as a participant of the study, it is hoped that the insights developed will be useful for relatives of future patients.

What are the Discomforts/Risks?

The purpose of the interview is for you to talk about your experiences. Due to the nature of the experience, this may cause some emotional distress. If you feel that the interview is becoming too difficult to deal with you may stop it. Conversely, if I feel that the interview is becoming too difficult for you, I will give you the option of a break or stopping the interview.

You may bring a support person with you if you wish, or the services of a hospital chaplain, counsellor or Social Worker can be arranged.

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this trial.

How is Your Privacy Protected?

To safeguard your identity, a pseudonym will be used on all recordings and documents. The tapes and notes will be secured in a locked cabinet. Your consent form will be stored separately from this. At the conclusion, your audiotape and transcripts will be offered back to you or destroyed, which ever you prefer.

If you have any further questions about the study or would like to participate, please feel free to contact me.

Ph 917-9999 extn. 7127

Mob 025-593-893

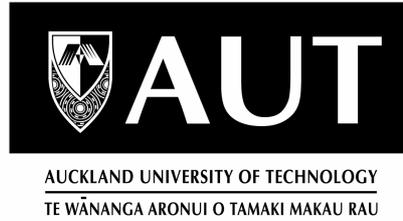
Email mandy.williams@aut.ac.nz

Any concerns regarding the conduct of the research should notified in the first instance to the Project Supervisor, Dr Deb Spence, deb.spence@aut.ac.nz, or 09-917-9999 extn 7844 Concerns

regarding the conduct of the research should be notified to Jocelyn Peach, Ethics Committee peachj@whl.co.nz, or 09-418-1491 or the Executive Secretary AUTEK, Madeline Banda, madeline.banda@aut.ac.nz, or 09-917-9999 extn 8044

If you have any concerns regarding your rights as a participant in this study, you may wish to contact the Health Advocates Trust 0800 555 050 Northland to Franklin.

This research study has received ethical approval from the Auckland Ethics Committee and from the Auckland University of Technology Ethics Committee.



Consent to Participate in Research

Title of Research Project Relatives' experience of having a close family member in an Intensive Care Unit.

Project Supervisor: Dr Deb Spence

Principal Investigator: Mandy Williams

- I have read and understood the information provided about this research project
- I have had an opportunity to ask questions and to have them answered
- I understand that the interview will be audio-taped and transcribed
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way. If I withdraw, I understand that all relevant tapes and transcripts, or parts thereof, will be destroyed
- I agree to take part in this research

Participants
signature:.....

Participants
name:.....

Project Supervisor contact details:
Dr D. Spence,
Principal Lecturer,
Auckland University of Technology.
Phone: 917-9999 ext. 7844.

