

FAMILY MEMBERS' EXPERIENCES OF A CRITICAL CARE EPISODE

by

Teresa M. Lee

**Submitted in partial fulfillment of the requirements
for the degree Master of Nursing**

at

**Dalhousie University
Halifax, Nova Scotia
August 2000**

© Copyright by Teresa M. Lee, 2000



National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file *Votre référence*

Our file *Notre référence*

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-57239-0

Canada

This thesis is dedicated to my family, for 'being there', my husband, Pat and my children, Curtis, Tom, and Marie. And to my mother, Carmel, who encouraged me to be true to myself because in the end that is the greatest lesson to give to one's children.

TABLE OF CONTENTS

ABSTRACT	viii
ACKNOWLEDGEMENTS	ix
CHAPTER 1: INTRODUCTION	1
Background	1
Purpose	3
Definition of Terms	4
Relevance	6
CHAPTER TWO: LITERATURE CRITIQUE	8
Family Care	8
Family Support	11
Family Needs	14
Summary	17
CHAPTER THREE: METHODOLOGY	21
Research Perspective	21
Feminist Research	23
Thematic Method	25
Rigour and Credibility	26
Setting	27
Selection of Participants	28
Profiles of Participants	29
Data Collection	33
Ethical Considerations	35
CHAPTER FOUR: PRESENTATION OF FINDINGS	37
Overview	37
Role Definition	39
Need for Information	43
Need for Provider Consistency	50
Negative Interactions	52
Helping Relationships	55
Summary	59

CHAPTER FIVE: ANALYSIS	60
Overview	60
Role Definition	62
Need for Information	66
Need for Provider Consistency	68
Helping Relationships and Negative Interactions	69
Summary	73
CHAPTER SIX: CONCLUSIONS	74
Discussion	74
Implications for Nursing Practice	78
Implications for Education	81
Implications for Policy	82
Limitations	82
Suggested Future Research	84
Conclusions	85
APPENDICES	
APPENDIX A: Semi-Structured Interview Guide	86
APPENDIX B: Introduction Letter	87
APPENDIX C: Consent	88
REFERENCES	89

TABLE OF FIGURES

Figure 1. Illustrating the Key Themes	38
Figure 2. Model of Nurses' Caring Behaviours	77

ABSTRACT

He was calling for me, so she (the nurse) came and got me. He was in pain for a long time after, but he grabbed hold of my hand and he was hanging on, just me being there helped him a lot and it helped me feel better too.

The preceding passage reveals the significance of a family member's role to a critically ill patient in an adult critical care setting. This study was undertaken to give family members of critically ill adults a voice. Utilizing a feminist research perspective and thematic analysis, the participant's stories revealed five key themes. The five key themes which emerged from the participants narratives of their lived experiences were role definition, need for information, need for provider consistency, negative interactions, and helping relationships. Research has demonstrated that family members of critically ill patients need assurance, proximity, information, comfort, and support (Leske, 1991; Molter, 1979; Titler, Bombei, & Schutte, 1995). As the key themes materialized from the data, these needs were central but not inclusive of my findings. The need for information was the only one of these needs which emerged as a key theme. Although the need for access to the patient was prominent in their stories, the participants defined this as a need to 'be there' for their ill family member. Within the key themes negative interactions and helping relationships, the participants further revealed their need for information, reassurance and support. The findings of this study gave evidence of family nursing but that it was inconsistently applied, perhaps due to varying levels of expertise among the nurses. A number of implications for practice, education, policy and research were identified. To address the varying levels of skill acquisition among critical care nurses, managers and administrators must provide support to those nurses not yet expert in critical care nursing, to ensure the provision of family care for all patients and their families. Critical care nurses must have adequate academic preparation in the provision of family care in order to operationalize this concept. Development of specific policy requirements regarding the practice of family care would promote an expectation of its provision and enhance cultural changes at the unit level to promote this philosophy in a consistent manner by all nursing staff. An ethnographical study of a critical care unit would uncover nuances in health care provision that remain hidden today. Although the participants in this study give voice to individual family members, the voices of the critically ill patient and other members of the family grouping are silent. These are major limitations of the research. The critically ill patient must also be heard in order to fully understand the impact of social and family supports on his/her recovery from a critical illness. Other limitations included the homogeneity of the participants recruited since all the patients were admitted to the same small regional hospital unto the same unit, the vulnerability of both the patients and family members due to the physiological crisis being experienced by the patient; and time limitations of the researcher. This study uncovered the voices of five family members of critically ill adults. The most significant message they delivered was that their role involved physically 'being there' for their ill family member. No health care provider can replace that role.

ACKNOWLEDGEMENTS

I would like to thank my friends and colleagues who believed in me and encouraged me in my efforts to complete this body of work. I would like to thank my thesis advisor, Barbara Keddy, and Barbara Downe-Wamboldt and Carol Smillie, members of my thesis committee, for their patience, guidance and support.

CHAPTER 1

INTRODUCTION

Background

Having lived the role of critical care-nurse, nurse manager, and patient, I have experienced and observed a variety of patient and family approaches. I have listened to family members of critically ill adult patients describing the inconsistent support provided by critical care nurses. Their dialogue has revolved around their perception of the individual nurse's ability or inability to recognize and/or address their family needs.

Astrom, Norberg, and Hallberg (1995) in their exploration of nurses' experiences of caring discovered that "nurses thought it took from 1 to 3 years before they dared to think about more than the routines and the technical tasks" (p. 113). Benner (1984) in her study of skill acquisition by practising nurses, found that a nurse attains a competent level of practice only after two to three years in a new clinical setting. This phenomenon is consistent in non-critical care areas of nursing but is especially significant when providing care to patients in life and death physiological struggles. Chelsa (1996) found that "critical care nurses show variable skill in negotiating the concerns that arise when they engage in lifesaving functions while at the same time attending to the broader needs of patients and families" (p. 199). This variability of skill in the practice of family care is especially significant in critical care nursing since "we are now considering that the more serious the patient's condition, the more intense the need for the family to remain close and visit" (Dracup, 1993, p. 8).

Positivism asserts that any given phenomenon can be measured, quantified, reduced and replicated (Denzin & Lincoln, 1994; Maquire, 1987; Streubert & Carpenter, 1995). It has been my experience that health care providers in critical care units often approach patients and families from this positivistic, mechanistic point of view. Due to the nature of critical care units as inventions of the medical-industrial complex (Waitzkin, 1989), the focus of care often becomes the technology or machinery rather than the patient (Chelsa, 1996; Harvey, 1992). While machines are inanimate objects which lend themselves to quantification, the same cannot be said of human emotions in spite of repeated attempts to do so. This positivistic perspective also promotes a paternalistic approach by health care providers towards critically ill patients and family members. Critically ill patients and their families are in an extremely vulnerable position due to the nature of the illness or injury being life threatening. They can become marginalized groups within the positivistic, paternalistic paradigm of the critical care setting.

As a novice critical care nurse my focus in the provision of care was based upon a positivist view of the patient and his/her family. I depended upon objective data, such as a heart rate, a cardiac output, or a urine output, as the only reliable representation of the patient's condition. I considered his/her role in the family and the community of minimal significance in relationship to the circumstance of their role as patient. As I have grown personally and professionally I have come to value the significance of family to the individual's overall well being. Nursing researchers have documented this professional growth among nurses. "The nurses investigated described how their working focus had changed, in the beginning the technical issues had been their problem and their main

focus” (Astrom, Norberg, & Hallberg, 1995).

Scholars in the discipline of nursing have begun to discuss and write about the significance of the family to the health and well-being of individual family members (Johnson, Jeppson, & Redburn, 1992; Kristjanson, & Chalmers, 1991; Shelton, Jeppson & Johnson, 1987; Wright & Leahey, 1994). In the 1940's a British physician, Richardson, lobbied for research of the family as a unit (Dracup, 1993; Woolley, 1990). In the 1970's and 1980's family nursing became core to the curricula in many baccalaureate nursing programs (Wright & Leahey, 1994). Today care of family members of critically ill patients is considered a cornerstone in critical care post graduate nursing programs (Aslpach, 1998; Holloway, 1988; Ruppert, 1996). This is also the focus within the standards of practice for critical care nurses (Canadian Association of Critical Care Nurses, 1992). The connection between nurses and families and their relationships “have profound effect on how the patient and their family manage an illness and how nurses enhance their professional self-esteem” (Leahey, Harper-Jaques, Stout, & Levac, 1995, p. 224). This is especially significant for critical care nurses. “Health care professionals have begun to view the family as an integral part of the healing process and the patient’s well-being. While the patient experiences physiologic crisis, the family may be in a state of psychologic crisis” (Warren, 1993, p. 56).

Purpose

The purpose of this study was to explore experiences of family members of critically ill adults during their stay in a critical care unit. The underlying goal of this study

was to give family members a voice.

Critical care nurses are challenged to understand and respect the role of the patient within society and their social environment (ie. their individual family) and accept that despite the intensity of this illness experience, for the patient and his/her immediate family members, the stay in a critical care unit is time limited and brief (Chelsa, 1996). Other researchers propose that the critical illness itself has a lasting impact upon the family's history and affects its future to such an extent that critical nurses have a responsibility to utilize a family systems perspective in the provision of care (McClowry, 1992; Titler, Bombei, & Schutte, 1995).

Competing with the urgency of the patient and family's needs, for the individual nurse's attention is the complexity of the work environment itself. Despite this difficulty for nurses, family members of critically ill individuals must be given a voice. While health care providers struggle to maintain the life of one individual, the rights of that person's family members' to be involved in this life and death crisis must not only be recognized but valued and incorporated into the ongoing care of the patient. Family care is an aspect of adult critical care nursing practice which impacts positively upon family and patient outcomes. Assimilation of the concept of family care is imperative to allow critical care nurses to meet the needs of their adult patients' and their families.

Definition of Terms

I believe the reader would be assisted in reviewing this document by a clear understanding of how I am using key terms in my discussion of the phenomenon. The

word family historically refers to “a group of people related by blood, e.g. children and their parents, their cousins, their aunts and uncles” (Lexicon, 1988, p. 340). For the purposes of this study, however, family “means not just blood relatives but all those who care about and nurture the patient” (Holloway, 1979, p. 436). Like Robinson (1995) I define a family member broadly as any individual identified by the patient or other family members to be significant to the critically ill person. Warren (1993) defined a critically ill patient as an individual experiencing life threatening illness or injury, for the purposes of this study I utilized the same definition.

An expert nurse “with an enormous background of experience, now has an intuitive grasp of each situation and zeroes in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions” (Benner, 1984, p. 32). Within the context of this document an expert critical care nurse is one who has assimilated the coaching of other experts and her personal clinical experiences in a manner which enables her to practice family nursing at an individual and interpersonal level.

A thorough discussion of family care is provided within the literature critique. Simply, family care is demonstrated by the critical care nurse who sees the family as the unit of care. Family nursing is a concept which suggests that nursing is practiced on three levels: individual, interpersonal and family system (Friedemann, 1979). “Family systems nursing focusses on interaction and reciprocity, emphasizing the family as the unit of care” (Wright, 1994, p. 325). The complex practice of family systems nursing requires graduate level preparation (Robinson, 1995; Wright, 1994; Wright & Leahey, 1994).

Since the purpose of my research was to give family members a voice by exploring their lived experience I believed this could best be accomplished utilizing a grounded theory approach. Specifically, the “term *grounded* means based on the actual, concrete realities of people as they live through their experiences. Coupled with the word *theory*, grounded theory, then refers to theory that is constructed from a base of observations of the world as it is lived by people” (LoBiondo-Wood, 1990, p. 190). In analysing the data I used a modification of the constant comparative method, rather than searching for one main theme or core variable of the participants in this setting I utilized thematic analysis to uncover or eidetically intuit key themes within the data.

Thematic analysis is a process of encoding qualitative information in order to sense themes. Thematic analysis of the data reflects the eidetic intuiting or probing of the phenomena for typical structures or essence and for the essential relations within and among them (Spiegelberg, 1975). Eidetic intuiting refers to process of by which the researcher provides a detailed picture or understanding of a phenomena previously seen or imagined. Thus I hoped to be able to describe clearly the lived experiences of family members of critically ill patients which many critical care nurses have seen but have not necessarily understood.

Relevance

Research exploring the lived experience of family member’s of critically ill adults is important for several reasons. We need to hear how these family members feel, to understand what we do that helps them or does not help them, and to know how the

illness and the critical care experience affects both the patient and other family members. It is important that we allow patients and families to define how we practice family care since numerous studies have shown that nurses perceive that family needs have been addressed while family members do not share that perception (Reider, 1994; Titler, Bombei, & Schutte, 1995). A research approach which is qualitative in nature can illuminate the subjective reality of individuals directly involved in a family member's critical illness. It is my hope that this study will add to the developing knowledge base of family care in adult critical care units and result in a greater understanding and an improved implementation of this practice by critical care nurses.

CHAPTER TWO

LITERATURE CRITIQUE

Family Care

One of the most confusing aspects of the study of family care is the variety of terms and concepts being used to describe this phenomenon. Family-focussed, holistic and family care, are being used interchangeably with family-centred care to express the same or highly similar ideas and thus may be considered surrogate terms (Rodgers & Knafle, 1993). Family-centred care is a concept that is being utilized and studied in nurses' exploration of the care of families and is being employed in many different clinical settings.

The pediatric literature utilizes the term family-centred care when discussing optimization of the care provided to families of ill children or infants (Ahmann, 1994a; Nethercott, 1993; Johnson, Jeppson, & Redburn, 1992; Rushton, 1990; Shelton, Jeppson & Johnson, 1987). The dynamic relationships of family members and the importance of these relationships to the health status of an ill child are the basis of pediatric family-centred care. The Association for the Care of Children's Health defines family-centred care as a:

philosophy of care that recognizes and respects the pivotal role of the family in the experience of special health needs. It is a philosophy that strives to support families in their natural care giving roles by building upon their unique strengths as individuals and as families. It is a philosophy that views parents and professionals as equals in a partnership committed to

excellence at all levels of health care. (Shelton, Jeppson, & Johnson, 1987, p.2)

Although the concept, family-centred care, was first explored in pediatric settings it has had significant investigation in adult critical care settings during the 1990's (Chelsa, 1996; Crawford, 1998; Matheson, 1995). Family-centred care embraces the belief that families are deeply caring and nurturing, but diverse in structure, culture, choices, strengths, and needs (Ahmann, 1994a; Bond, Phillips, & Rollins, 1994; Darbyshire, 1995). Family-centred care is not thought to be static but rather a creative process involving interchange between nurses and family members which address its dynamic nature and interactive attributes (Ahmann, 1994b). Attributes of family-centred care describe a dynamic, flexible and interactive process in which the family is viewed as a system. The family is recognized as the constant factor in the patient's social context. In family-centred care the unit of care is the family and not only the individual; the biopsychosocial needs of all individuals within the family unit are considered.

Some researchers in adult acute care settings refer to family-focussed care of ill adult family members (Engli, & Kirsivali-Farmer, 1993; Titler, Bombei, & Schutte, 1995). 'Family-focussed care' is seen as broadening the patient-focussed concept by shifting the nurse's perspective from a linear cause and effect perspective to one of systemic or circular proportions (Grandine, 1995).

'Holistic care' is another term being used in relation to meeting patients' and family's needs in adult critical care units (Bouley, von Hofe, & Blatt, 1994; Rushton, 1990; Woolley, 1990). Lopez-Fagin (1995) utilizes the terms holistic and family-centred care in

describing how critical care nurses focus holistically upon the ill patient and their family. The practice of holistic care involves the establishment of a trusting relationship between the nurse and the critically ill patient's family (Bouley, von Hofe, & Blatt, 1994; Woolley, 1990). In the provision of holistic care “nurses cannot separate the needs of patients from those of patients’ families” (Curry, 1995, p. 19).

Others exploring the role of family in adult critical care utilize the term ‘family care’ (Chelsa, 1996; Crawford, 1998). Nurses who practise family care "recognize and reinforce the family's preeminent position in a patient's world. They acknowledge that for most patients, the illness and hospital stay are intense but relatively brief experiences, while family life constitutes the patient's sustained existence" (Chelsa, 1996, p. 201). The practice of family care is demonstrated by the critical care nurse who sees the family as the unit of care. The nurse respects the family members’ needs of proximity to, and need for current information about the patient, while recognizing the benefit to the patient of family support and encouragement. An individual nurse’s ability to provide family care is dependent not only upon her belief system, knowledge level, and professional experience but also upon organizational culture and institutional practices.

Friedemann’s (1989) concept of family nursing is practiced on three levels: individual, interpersonal and family system requiring different levels of nursing skills and expertise. Different nursing practices are required for each level. When the family functions well the nurse aims to ensure well-being of each individual; at the interpersonal level the nurse addresses conflict resolution or concerns about nursing care utilizing communication techniques; and at the family systems level the nurse intervenes to address

family dysfunction using advanced knowledge of family development and other theories (Nethercott, 1993). Friedemann (1989) suggests that the practice of family nursing is dependent upon the nurses level of preparation and expertise. As suggested previously advanced academic and practical preparation is required by nurses' practising family systems nursing.

It is important to distinguish the practice of family care during a life threatening physiological crisis of one family member from the practice of family system nursing in family dysfunction or pathology. Wright and Leahey (1994) view family systems nursing as the integration of four theoretical foundations: systems theory, cybernetics theory, communication theory, and change theory. "Family systems nursing focusses on interaction and reciprocity, emphasizing the family as the unit of care" (Wright, 1994, p. 325). The focus on the individual in the context of the family rather than family as the unit of care differentiates the nursing of families from family systems nursing (Wright & Leahey, 1990).

Family Support

Nursing in the home for the most part is carried out by females in the care giver role to family members (Wright & Leahey, 1994). Donohue (1996) in her exploration of the origin of nursing disputes nursing as a gender specific role but accepts the initial role of nursing as mother nurturer. "The role of the nurse gradually expanded from that of a mother whose biological function included the nourishing of infants and the nurturing of young children to one with a much broader scope . . . With the development of early

civilizations, slaves and servants of households and estates also received care and nursing began to be performed outside the home (Donahue, 1996, p. 5).

With industrialization and the growth of the medical industrial model, families have been further and further removed from the care of ill family members in Western society (Meleis, 1991; Wright & Leahey, 1994). Demands of family members to be reinvolved in dramatic life events such as child birth, critical illness or injury, and death are major forces promoting recognition of the role of family and need for family care (Ahmann, 1994b; Chelsa, 1996; Darbyshire, 1995; Marsden, 1992; Midmer, 1992; Rushton, 1990; Wright & Leahey, 1994). This recognition has also come from researchers who have identified better biopsychosocial outcomes for their clients when care is provided within the social context of family (Grandine, 1995; National Forum on Health, 1997; Rushton, 1990; Wright & Leahey, 1994).

With increasing demands by family members to be involved and with professionals accepting an a advocacy role, a subtle shift in power from the professional to the family is occurring (Humphry & Geissinger, 1993; Midmer, 1992; National Forum on Health, 1997). The practice of family care recognizes individual family member roles and member/professional equality. For family care to be practiced the nurse must not see nursing as a source of power but view family members and the patient as equals. To ensure that the process is one of equality and of interactivity information pertinent to the ill individual must be shared in an unbiased manner.

Crawford (1998) offers cost effectiveness, as another compelling reason for the practice of family focussed care in critical settings. She suggests that as length of stays are

reduced and families are being increasingly responsible for care in the home, they will require early intervention in critical care settings to ensure that they have the physical and emotional resources to provide that care. Tapp (2000) reflects upon this trend toward increased responsibility of family members. "During the management of chronic illness and after discharge from hospital, family members are providing physical care, emotional support and even technical care" (Tapp, 2000, p. 29).

As family members struggle to provide the psychosocial support required by a seriously ill family member, their ability to cope and adapt are affected by prognosis uncertainties, disruptions in family functioning and problematic interactions with health care providers perceived to be uncaring and insensitive (Davis & Cox, 1995). The degree of family involvement and the response of family members to the patient's critical illness could affect the individual's recovery (Warren, 1993). Family care promotes family support and the family's ability to cope and adapt in a crisis situation. A number of research methodologies have been utilized to examine the family's role as social support to an individual during a critical illness or injury. Grounded theory (Jezewski, 1994; Warren, 1994) has been useful in explicating the role of family in critical care settings while family systems theory (Engli & Kirsivali-Farmer, 1993) has been a useful conceptual framework.

Adequate social and family supports are seen as determinants of health as outlined by advisory groups to the Federal Government in the National Forum on Health (1997). Family support is perceived as significant for individual health and well being on the macro level. Similarly family support on a micro level has been shown to have a positive impact upon intervention outcomes in the acutely ill patient. "Health care providers are becoming

aware of the enormous influence a person's family holds on that individual's health and use of the health care system" (Thomas, 1990, p. 244).

The experience of a critical illness is an entire family's concern rather than an individual matter and thus care must be provided to all family members (Gaglione, 1984; Lopez-Fagin, 1995). Tapp (2000) reminds us that "Just as the illness has an influence on each family member, each person in the family also has an influence on the illness" (p. 31). Warren (1994) found that family involvement and individual family member response to a patient's critical illness could reduce the patient's anxiety and could affect his/her recovery. A positive relationship between family satisfaction and patient outcomes in critical care has been identified by Bouley, von Hofe, and Blatt, 1994; Holl, 1993; and Warren, 1993, 1994.

Family Needs

The literature suggests that whether we discuss pediatric or adult acute critical care settings, the needs of family members remain constant. Needs are requirements of family members that, if not met, become demands that can produce distress in the family members (Warren, 1993). Numerous studies have categorized and prioritized the needs of family members of critically ill adults (Curry, 1995; Molter, 1979; Molter, 1994; Page & Boeing, 1994; Titler, Bombei, & Schutte, 1995; Warren, 1993).

Empirically, the needs of family members of the critically ill have been identified, quantified, reduced and replicated since the 1970's. Molter (1979) in an exploratory descriptive study of relatives of critically ill patients ranked their following ten needs as

most important: to feel there is hope; to feel that health care providers care about the patient; to have the waiting room near the patient; to be called regarding changes in the patient's condition; to know the prognosis; to have questions answered honestly; to know about the patient's progress; to receive information once a day; to be given understandable explanations; and to see the patient frequently.

The Critical Care Family Needs Assessment Inventory (CCFNI) and the Needs Met Inventory (NMI) first developed by Molter (1979) has been refined and replicated in numerous quantitative studies (Davis-Martin, 1994; Dracup & Clark, 1992; Engli & Kirsivali-Farmer, 1993; Leske, 1986; Leske, 1991; Lopez-Fagin, 1995; Molter, 1994; Norheim, 1989; Warren, 1993; Warren, 1994). When the study was replicated by Leske (1986) the top nine needs identified were consistent with those reported by Molter (1979). Leske (1991) and Norheim (1989) determined the tools' validity and reliability.

Interrelationships among the responses to the forty-five item lists have been grouped into five domains: support; comfort; proximity; information; and assurance (Curry, 1995; Leske, 1986; Lopez-Fagin, 1995; Warren, 1993). The findings of numerous critical care family needs' studies have indicated that "at all these different family populations-young families, old families, children, spouses, elderly spouses-family members wanted reassurance, access, and information (Dracup, 1993, p. 5).

The positive effects of family support on patient outcomes during a life threatening illness or injury have been documented by a number of researchers (Bouley, von Hofe, & Blatt, 1994; Davis & Cox, 1995; Engli & Kirsivali-Farmer, 1993; Titler, Bombei, & Schutte, 1995; Warren, 1994). When the needs of the family members are not met there is

a decrease in their provision of emotional support which negatively impacts upon the patient (Bouley, et al., 1994; Titler, et al., 1995). Despite acknowledgment of the positive impact of family care for critically ill patients, there is research to suggest that family needs are not consistently recognized or addressed by critical care nurses (Bouley, von Hofe, & Blatt, 1994; Curry, 1995; Engli & Kirsivali-Farmer, 1993; Long & Greeneich, 1994; Molter, 1994; Reider, 1994). An extensive literature review of the intensive and critical care nursing literature by Wesson (1997) supports that the informational, psychosocial and emotional needs of patients and families are not always adequately met. Critical care family member anxiety, stress, adaptation, satisfaction and needs, all of which are qualitative characteristics, have been quantitatively examined by many researchers. Anxiety during critical illness of a family member was studied using the T-Double ABCX Model of family adjustment and adaptation (Reider, 1994). The Nursing Taxonomy of Family Satisfaction model which emphasizes the importance of nurses promoting family satisfaction was used to evaluate family satisfaction in critical care units (Long & Greeneich, 1994). These reductionist tools do not allow the voices of the participants to be heard but rather represent family with the researcher's view of what they believe is needed.

Crawford (1998) utilized quantitative and qualitative methodology's to explore factors influencing critical care nurses' implementation of family care. Another study utilizing both quantitative and qualitative data collection techniques examined the "experiences of families with a relative in the intensive care unit" (Jamerson, Scheibmeir, Bott, Crighton, Hinton, & Cobb, 1996, p. 467). Findings of this study suggest that

“health care professionals can minimize the stress associated with hospitalization of relatives in the ICU by anticipating and addressing the family’s needs for information and resources” (Jamerson, Scheibmeir, Bott, Crighton, Hinton, & Cobb, 1996, p. 467).

Within the last ten years qualitative research approaches have begun to explore the subjective reality of critical care nurses, patients and their families. Walters (1994) explored the phenomenon of the comforting role of critical care nurses utilizing phenomenology methodology. In undertaking an interpretive phenomenology with 130 nurse participants, Chelsa & Stannard (1997) discovered five nursing approaches which limited family care-physically distancing patients from family; emotionally distancing themselves from patient and family; seeing the family’s perspective as pathological; dissipating responsibility for family care; and taking a narrow perspective rather than a broad one. Unfortunately these findings are usual. Another interpretive phenomenological study uncovered ranges in practice from one focussed on the biomedical management to one incorporating the family while addressing the complex needs of the critically ill patient (Chelsa, 1996). Expert critical care nurses incorporate family needs while providing complex physical and emotional care to seriously ill patients while a less skilled nurse generally focuses upon the technological aspects of the care required by the ill individual.

Summary

The trend of exploring the lived experiences of critical care nurses’ is encouraging. However, a gap still exists between their theoretical knowledge of family needs and their

ability to expertly incorporate that knowledge into the provision of the complex biopsychosocial care that a critically ill individual and his/her family requires. In one attempt to provoke discourse the practice of separating relatives from critically ill patients in the emergency department was explored and was examined utilizing Neuman's (1989) model to highlight family dynamics (Picton, 1995). This study highlighted health care providers' desire to reduce and control the phenomenon by having the care of the patient provided by one health care provider and the care of the family by another in a separate location. Once more, traditional paradigms attempt to reflect what is in the family's best interests without asking them directly.

Maquire (1987) in her discussion of paradigms noted that due to the lack of specialized language, or jargon, individuals may be judged to be inferior by themselves and by others. In qualitative research there are no subjects only participants. The researcher views these participants to be the experts in the area being explored. This belief opposes the accepted paradigm in which critical care providers are viewed by themselves and others to be superior and experts in all aspects of the critical illness experience. The prevailing paradigm is supported by families acceptance of limited access to their loved ones in critical care units due to stringent and restrictive visiting policies defined by health care providers to 'protect' the patient and themselves. This paradigm has been described in adult and pediatric literature.

The nurse, however, remains the expert who exercises control over the family's involvement, and participation is in the form of delegated tasks: the nurse may see him- or herself as the professional who 'knows best' in

all aspects of child care. Views of family involvement can be subjective, based on perceptions influenced by ethnic origin or social class.

(Nethercott, 1993, p. 794-795)

Simon, Phillips, Badalamenti, Ohlert, & Krumberger (1997) found that most nurses based visitation decisions upon patient and nurse needs while the needs of the family were ranked as less important. Visitation restriction, as a patient need, is not reflected in a review of current research. Simpson (1990) determined that patients find visits to be helpful and nonfatiguing and that they would prefer longer more flexible visiting times.

The outcomes of family nursing are improved patient outcomes and enhanced family functioning. Marsden (1992) describes the practice of family-centred critical care as an obligation, not an option for critical care nurses. Rushton (1990) suggests that despite awareness of the importance of family care that nurses have difficulty in developing deliberate plans of care for the family. Wright and Leahey (1994) believe the most significant variable that promotes or impedes family care is how a nurse conceptualizes problems. Others suggest that family care is not practiced due to lack of knowledge about its components and how to actualize them (DePompei, Whitford, & Beam, 1994). "Many nurses who perceive themselves as competent to care for a patient in "medical crisis . . . feel unqualified to provide family care" (Smith, Kupferschmid, Dawson & Briones, 1991, p. 211).

The practice of family care is demonstrated by the critical care nurse who sees the family as the unit of care. The nurse respects the family members' needs of proximity to,

and current information about the patient. She meets those needs by encouraging family presence. An individual nurse's ability to provide family care is dependent not only upon her belief system but also organizational culture and institutional practices.

Despite the evidence supporting family care in critical care settings there are still indications that the paradigm shift has not occurred and that the patient is cared for in relative isolation from his/her family. Nurses must hear and be involved in the dialogue of the patients and their families, in order to internalize and operationalize this important aspect of critical care nursing.

CHAPTER THREE

METHODOLOGY

Research Perspective

I have chosen qualitative research methodology to explore family members' experiences during a family member's stay in a critical care unit. Although my educational and professional socialization evolved from the scientific positivistic paradigm, I have come to appreciate the perspective of multiple realities of lived experiences. My interest in qualitative research was promoted by my desire to acknowledge and understand the subjective experience of family members of the critically ill patients to whom I provide care. Through this approach I hope to guard against what Hagell (1989) described as the loss of caring, "as nurses become more and more scientific they will lose what is essential to nursing i.e. caring itself, because science cannot conceptualize caring nor can caring be measured, only experienced" (p. 231).

There are significant problems with the dominant western positivist research paradigm. This paradigm minimizes or negates aspects of life that cannot be quantified and it assumes that individuals are subjectively unaware of a social world (Maquire, 1987). Many nurse scientists suggest that "human behaviours cannot be isolated and quantified and that the attempt to do so results in misleading and dehumanizing outcomes rather than in knowledge that is useful for nursing practice" (Campbell & Bunting, 1991, p. 2). As discussed previously the accepted paradigm in critical care settings is one of scientific, rational, objective actions undertaken by expert health care providers. Modern

philosophers (Madison, 1988; Spiegelberg, 1975) and nurse researchers (Anderson, 1991; Doering, 1992; Dzurec, 1989; Hagell, 1989; Streubert & Carpenter, 1995) suggest that science is only one way in which we interpret reality and that an openness to truth seeking through alternate methodologies must be accepted as legitimate.

Qualitative research seeks to describe and understand rather than to predict (Parse, Coyne & Smith, 1988). Unlike quantitative research which predetermines precisely the method of data collection, analysis and interpretation prior to data collection, qualitative inquiry embraces changes in these mandated by the nature of its analysis (Streubert & Carpenter, 1995). This aspect of uncovering or discovering the appropriate questions or method rather than fitting findings into a pre-existing framework reveals the inductive nature of qualitative research. Other principles of this inductive process include a belief in multiple realities, a commitment to participant involvement rather than study of subjects, researcher participation, and presentation of the phenomena in participants' own words.

These principles are consistent with all qualitative research approaches but especially interested me from a grounded theory perspective in that my research was based upon the "actual, concrete realities of people as they lived through their experiences" (LoBiondo-Wood, 1990, p. 190). Perspectives which guided the direction of my research were feminism and thematic analysis. The cyclical reflexive nature of these qualitative methods promoted the collection of rich, detailed information strengthening the research design. Grounded theory approaches give an opportunity to impact upon practice, it has been suggested that providing nurses with a fresh view or theory of a "situation often has immediate and direct implications for practice" (LoBiondo-Wood, 1990, p. 191).

Feminist Research

Like DuBois (1983), I believe that traditional research methods have been narrow and confining and that the application of basic feminist principles in my research will ensure a flexible and dynamic process as the study evolves. Feminist research has been described as “subjective, personal, experiential and non-hierarchical” (Keddy, 1992, p. 8).

The tenets of feminist research include the following:

- Identifying and overcoming oppression of females through studies by women for women (Hall & Stevens, 1991; Lather, 1991; Mies, 1983; Stanley & Wise, 1983; Webb, 1993)
- Inclusion of all participants’ viewpoints (Cook & Fonow, 1990; Lather, 1991; Stanley & Wise, 1983)
- The subjectivity of the researcher as a participant (DuBois, 1983)
- Awareness that knowledge is influenced by social factors and power structures and that this context must be considered in designing, conducting and interpreting the findings (Campbell & Bunting, 1991; Hall & Stevens, 1991)
- A desire for social change to relieve oppression through criticism and political action (Hall & Stevens, 1991)
- Making the invisible visible, bringing the margins to the centre, and making the insignificant or silenced, important (MacPherson, 1983).

While these principles guide feminist research, the recognition that researchers must look beyond women, to all marginalized groups is also significant in my endeavour to give voice to family members of critically ill adults. “Most health care institutions

operate as impersonal bureaucracies with rigid hierarchies and countless policies” (Valentine, 1992, p. 23). I believe the social structure of critical care units marginalize all family members irrespective of gender, class or culture. Through the process of internalized oppression as described by Radsma (1994), I believe critical care nurses maintain this dominant paradigm and support the invisibility of their care and the marginalization of families.

Utilization of feminist theory to address oppression of marginalized groups has been advanced by several researchers. Allen, Allman, and Powers (1991) promoted gender less feminist research as a mechanism to promote equality and justice. “Feminist research, along with active dissemination of results can act as a catalyst for the emancipation of women and other marginalized groups alike” (King, 1993, p. 19). Dublin (1996), stated “in my view many of the feminist principles can be employed with other marginalized groups as well as women” (p. 72).

Other axioms of feminist research which appeal to my personal research focus are the valuing of others as themselves, the subjectivity of the researcher and the empowerment of participants. The need to consider the context of any research situation and the subjectivity and multiple realities of knowledge are valued within the domain of feminist research. This perspective is especially significant for critical care practitioners in that all knowledge is valued equally with the knowledge of the lived experience being as valid as expert knowledge.

Thematic Method

Streubert and Carpenter (1995), noted that data analysis in qualitative research is an ongoing process beginning with data collection, progressing in a cyclical manner, resulting in clustering similar data as themes. Thematic analysis is a process of encoding qualitative information in order to sense themes. Significantly in thematic analysis participants' own wording is used and the common aspects are noted and interpreted (Benner, 1984; Carter, 1989; Leininger, 1985; Lincoln & Guba, 1985). Thematic analysis "focuses on identifiable themes and patterns of living and/or behaviour" (Aronson, 1994, para. 2). Thematic analysis of the data reflects the eidetic intuiting or probing of the phenomena for typical structures or essence and for the essential relations within and among them (Spiegelberg, 1975). With this eidetic intuiting there are no preconceived expectations and the researcher is not trying to defend or define any particular theoretical framework (Omery, 1983).

Aronson (1994) presented an outline for the process of thematic analysis which I have applied in my research while being true to the cyclical nature of qualitative and feminist research. My adoption of this format has provided me with a framework by which I can comfortably interpret the participants words and credibly build arguments for choosing the themes. Theme as defined by Walters (1990) describes the structure of the experience with thematic analysis referring to the process of insightful discovery of underlying meanings.

The steps identified by Aronson (1994) include the collection of data, transcription of conversations, listing of patterns of experiences, identification of all data related to the

patterns, cataloguing patterns into sub-themes, incorporating participant feed-back, and finally building a valid argument for choosing the themes. The challenge for the researcher in utilizing thematic analysis is how to determine what is important, “What is the theme?” (Love, 1994, para. 5). This process then becomes the creative, inductive aspect of the data analysis.

Rigour and Credibility

Whether one refers to trustworthiness, rigor, validity, worthwhileness, or credibility, qualitative and feminist research must at the end of the day be truthful and meaningful. Perhaps the most significant difference utilizing these research methodologies versus quantitative methods is that of researcher as instrument. Reviewers must be privy to the researcher’s background and perspectives (Boyd, 1990). Within the introductory chapter, my background and perspectives were presented. Throughout the data collection and analysis process I maintained a reflexive journal and field notes to assist me in acknowledging and minimizing my personal biases and to ensure the findings reflect the participants perspectives rather than my own.

To further ensure the rigor and credibility of my research methodology transcription of the interviews were validated with participants. Further sets of data and themes were identified and meanings corroborated with participants. The act of soliciting feed-back is a reflective process, which Noel (1996) suggests is integral to feminist research. Sensed themes were discussed with participants as a means of establishing confirmability and credibility (Magilvy, Congdon, & Martinez, 1994). This technique of

obtaining feed-back also called 'member checking' was critical to ensuring the credibility of the study. Lincoln and Guba (1985) consider member checking as the most crucial technique in establishing the trustworthiness of research. Credibility also refers to whether participants' experiences have been accurately presented (Webb, 1993). The participant's stories while not presented in their entirety were presented in the context of their lived experiences. Direct quotations provide descriptive data that will allow the reviewer to understand the data and draw their own interpretations. I have attempted to carefully describe my methodology and data collection process to ensure replicability and reliability.

Examining 'being in the world' as a family member of a critically ill patient and sharing this experience with critical care nurses will expose alternate realities and will add to body of knowledge of critical care nursing practice. By combining the principles of feminist research and thematic analysis I believe I had the flexibility needed to allow the research to give voice to family members of critically ill adults.

Setting

Participants were recruited from family members of patients admitted to the critical care area of a small regional hospital. The critical care area encompassed two separate units, one four-bed coronary care unit and one seven-bed intensive care unit. The units are located in the same geographic area but are physically separated by doors. Both units are managed by one nurse manager. Although the units are budgeted and are staffed as separate entities, patients in both units, are considered to have the same level of acuity and require specialized intensive care nursing. Some nursing staff work in both units

depending upon patient acuity and staffing requirements. All patients admitted to the coronary care unit have a cardiovascular diagnosis with the most responsible physician being an internist or cardiologist. Other physician specialty groups admit and provide care to patients in the intensive care unit.

Selection of Participants

Participants were family members of an individual who was or had been recently a patient in the critical care area of a small regional hospital. Often the most difficult aspect, when undertaking qualitative research is considered to be the recruitment of participants. Purposeful sampling was utilized to ensure participant selection based upon their first hand experience with the phenomena of interest (Streubert & Carpenter, 1995).

Due to the crisis aspect of any admission to a critical care unit, the family member's ability to make an informed consent and participate in any research at this time was a major area of concern. To ensure that family members understood the project and fully realized the volunteer aspect of participating. The head nurse of the unit provided my letter of introduction (Appendix A) to family members of patients in the critical care area. Exclusion criteria would exclude only those individuals who are unable to speak English. The head nurse introduced me to those family members expressing an interest in participating in the project.

I was also concerned that a participant might become emotionally upset while recalling their experiences during the interview. Thus prior to beginning all interviews, I reviewed the voluntary aspect of participation and that the participant could terminate the

interview at any time or refuse to answer any question they chose. I utilized sensitivity in determining an individual's continuing ability to participate in the interview. Although no participant became distressed during the interview process, I was prepared to provide support and gently terminate the interview. Pastoral care personnel and medical support were available, on call, to support the participants if they had become emotionally distraught during the interview.

Profiles of Participants

I believe it is important for readers to have some background about each of the participants when reading and interpreting these qualitative results. Each participant was given a pseudonym to maintain confidentiality. As stated previously to protect patient confidentiality I did not discuss patient or family care with members of the health care team. I had no contact with the patient during their hospital stay and no knowledge of the severity of any patient's condition. For the purpose of this study only one member of the family group was interviewed. However, each participant did share information about their family member's illness, and the makeup of their individual family grouping.

I utilized the broad definition of family as meaning a group of individuals "not just blood relatives but all those who care about and nurture the patient" (Holloway, 1979, p. 436). Five family members were recruited to participate in this research. Four of the participants were spouses of, and one was the adult child of the critically ill patient. Although it was not an inclusion criteria, all of the participants identified themselves as the next of kin, of the family member admitted to the critical care area of the hospital. All of

the volunteers were family members of an individual who was or had been a patient in the critical care area during the recruiting time period. I interviewed three women and two men. The participants ranged in age from 38 to 59.

Three of the interviews were conducted in the quiet room of the hospital while the critically ill individual was still in the hospital. Two of the interviews were conducted in a private area of the family members' homes after the critically ill individual had been discharged home.

Elizabeth

The first person I interviewed was Elizabeth. Elizabeth's husband had been a patient in the critical care area for four days during our first interview. Her husband experienced chest pain at home and was subsequently admitted with a diagnosis of myocardial infarction.

Elizabeth and her husband have been married thirty-two years. Elizabeth is fifty-two years of age. They have five adult children, four living in the immediate vicinity and one son still living at home. Elizabeth describes her family as close and during our conversation it became clear that she perceived that her adult children respected her as, and expected her to be, the significant other for their father during his critical illness.

A few years ago Elizabeth obtained employment outside the home as a nursing assistant at a nearby senior's complex. Elizabeth's husband works as a miner. About one year ago after being out of work for several years, her husband began to travel in his work necessitating that Elizabeth obtain her driver's license. Her husband returned home one month before his hospitalization, from an out of province work site. While he is at home

due to her evening work, Elizabeth's husband has assumed more of the household chores.

Irene

Irene was the second family member who volunteered to participate in this study. Irene's husband had been a patient in the critical care area for nineteen days at the time of our first interview. Like Elizabeth's husband, Irene's husband began having chest pain at home and was admitted while experiencing a myocardial infarction. Irene's husband subsequently experienced a cerebral vascular accident.

Irene and her husband have been married thirty years. They have two grown children, a son and a daughter, both of whom live in the immediate area. Irene is a secretary in a local general goods store. Her husband has been retired for several years. Like Elizabeth, Irene describes her family as close, and she refers to a sister-in-law, a nurse in the facility as another significant family member. Irene is seen by health care providers and other family members as her husband's next of kin or significant other. Irene is employed outside the home full-time, and although she has children in the area none live at home with her. Irene is fifty-two years of age.

George

George was the third person I interviewed. George's wife had been a patient in the critical care area for eighteen days following a myocardial infarction. She had been discharged home for one week at the time of our first interview. George and his wife have been married eleven years and have two young daughters. Their immediate family group includes George's mother-in-law who now lives with them. George described a large extended family, including grandparents and aunts, many of these family members

demonstrated their caring and nurturing of his wife by providing child care for the couple's two children during his wife's hospitalization.

George works full-time outside the home as a floor manager of a nearby store. His wife normally performs the majority of the child care activities. George is forty-eight years of age.

Ronald

The next participant that I interviewed was Ronald. Ronald's wife was also home at the time of my first interview with her husband. She has a long cardiovascular history, with numerous previous critical care admissions. She had been a patient in the critical care area for 10 days prior to our interview.

Ronald and his wife have been married thirty-five years. They have two adult children, both of whom live in the province but not in the local area. Although Ronald describes his family as close the geographical distance makes it difficult for them to offer concrete support to their parents. Ronald described an extended family of brothers and sisters but as with the other spouses in this study he was the family member perceived by himself and by other family members and health care providers, as his wife's significant other.

Ronald was a welder but is retired on a disability pension for several years. He is at home full time. Ronald is 59 years old.

Lorraine

The last participant interviewed was Lorraine. Lorraine is thirty-eight years old. Lorraine's mother, at sixty-seven years old, has a long cardiovascular history and has had

numerous admissions to the hospital and critical care area. Lorraine's mother had been a patient in the critical care area on and off for the last sixty days during our first interview.

Lorraine is married with a young family (three children) and also works full-time outside the home as a secretary. Lorraine defined herself as her mother's next of kin. Lorraine has one brother who while concerned about his mother does not actively participate in her care during her hospitalizations. Her mother and father were separated seven years ago and have no contact. Lorraine at times finds it difficult to juggle the needs of her young family with those of her ill parent but she visits daily and struggles to remain actively involved in her mother's treatment plan.

Data Collection

The data collection process was based on feminist principles of subjectivity with the researcher as an interacting participant. Each family member was invited to participate in a face to face semi-structured interview. The interview with the family member participant was structured around open-ended questions (Appendix B). These open-ended questions defined the area to be explored but allowed myself or the interviewee to diverge in order to pursue an idea in more detail (Britten, 1995). I encouraged the participant to talk about their experience in their own way and in their own words. Reinharz (1992) suggested that unstructured interviewing promotes a trusting personal relationship and enables participants to express their thoughts in their own words rather than those of the researcher. As a trusting relationship developed between us, the participant was able to express his/her personal experiences and feelings.

By creating a trusting open relationship with each participant and by seeking confirmation of my perceptions of their words ensured a flexible and dynamic process as the study evolved further supporting the feminist aspect of the process. I attempted throughout the data collection and analysis process to create a non-hierarchical relationship while recognizing that research in and of itself does involve some degree of inequality (Webb, 1993).

The cyclical nature of this process made it essential for me to maintain a reflexive journal and field notes to capture my thoughts and allow for reflection of my observations and analyses decisions. Prior to conducting the interviews I documented my perspectives and thoughts in the journal. Each interview was audio-taped. Field notes were recorded during and after each interview, documenting my observations about the interview itself, where it occurred, how the participant reacted to the interview, observations about my own role and other comments to establish a context for interpretation of the data.

The interviews were transcribed verbatim and sent to the participants for feedback. One week after mailing the transcripts the participants were contacted by telephone. The participants were asked to provide feedback and confirm my interpretation of our dialogue. The cyclical aspect of data analysis occurring concurrently with data collection provided additional information with which to further explore issues. Throughout the analysis process the participants were contacted by telephone when clarification or interpretation of their dialogue was required. The identification of the five key themes was shared with each participant in telephone conversations with clarification and interpretation occurring even during the final phases of preparation of this document.

The transcriptions from interviews, the documentation of feedback and clarification, my reflexive journal, and field notes formed the raw data for the ongoing analysis.

Kirby and McKenna (1989) consider that saturation occurs when further information no longer reveals new understanding about relations or abstractions. Data collection and analysis continued until saturation of the emerging themes occurred.

Ethical Considerations

Prior to conducting the interview, each participant signed a consent to ensure their participation was informed and not overly influenced by the crisis aspect of their family member's illness. Participants were advised from the outset that their participation was entirely voluntary and that they could withdraw at any time. Participants were assured that participation or withdrawal would not influence the care of their family member in any manner. To protect patient confidentiality I did not discuss patient or family care with the doctors and/or nurses caring for the patient. I had no contact with the patient during their hospital stay and had no knowledge of the severity of any patient's condition. The study participants were not identified to the nursing or medical staff during the data collection process or in any reports of this research. Each participant was provided with a synonym to ensure confidentiality in the final document. Synonyms, audio tapes, transcripts not given to the participants and field notes will be kept in a secure area only available to the researcher during the study, and these will be destroyed upon completion of the project. Study findings will be provided to the participant upon request.

The family member admitted to the critical care area was not interviewed nor did

any discussion, regarding the patient or family, occur between me and the health care team. I did not have access to any hospital documentation regarding the patient and/or the family members. The purpose of my research was to gain an in depth understanding of family members' experiences with health care providers and the critical care environment while their family member was a patient in a coronary or intensive care unit. I did not have any contact with the doctors and/or nurses directly caring for the patient.

Prior to conducting this research ethical approval was obtained from the Human Ethics Review Committee, Dalhousie University and from the hospital's ethics committee. After ethical approval participants were solicited for this study, as described previously. An explanation of the study, the purpose, and data collection method was provided in writing to all potential participants. Each participant signified their agreement and informed consent in writing.

CHAPTER FOUR

PRESENTATION OF FINDINGS

Overview

In this chapter, I present the themes extrapolated from the data. The stories of five family members who participated in this study are shared. Guided by the principles of feminist research I interpreted the patterns of the participants' experiences while uncovering similarities and differences. These patterns were at first listed and all data related to the patterns catalogued into sub-themes and finally into key themes. The cyclical nature of qualitative research guided my clustering of the themes. As I catalogued the data into sub-themes, the more prominent key themes slowly emerged. Five key themes emerged which reflect the eidetic intuiting of the phenomena for typical structures and for the essential relations within and among them. Through this process the five key themes uncovered were role definition, need for information, need for provider consistency, negative interactions, and helping relationships. The lived experience of the participants as presented through their own words will support the identification of these key themes.

The central tenet of the participants' stories was their vision of their role and of its significance to the critically ill individual and to other family members. The participants defined their role through their stories as they discussed: their need for information about their ill family member; their need for provider consistency; and interactions with health care providers they perceived to be either negative or helpful (Figure 1).

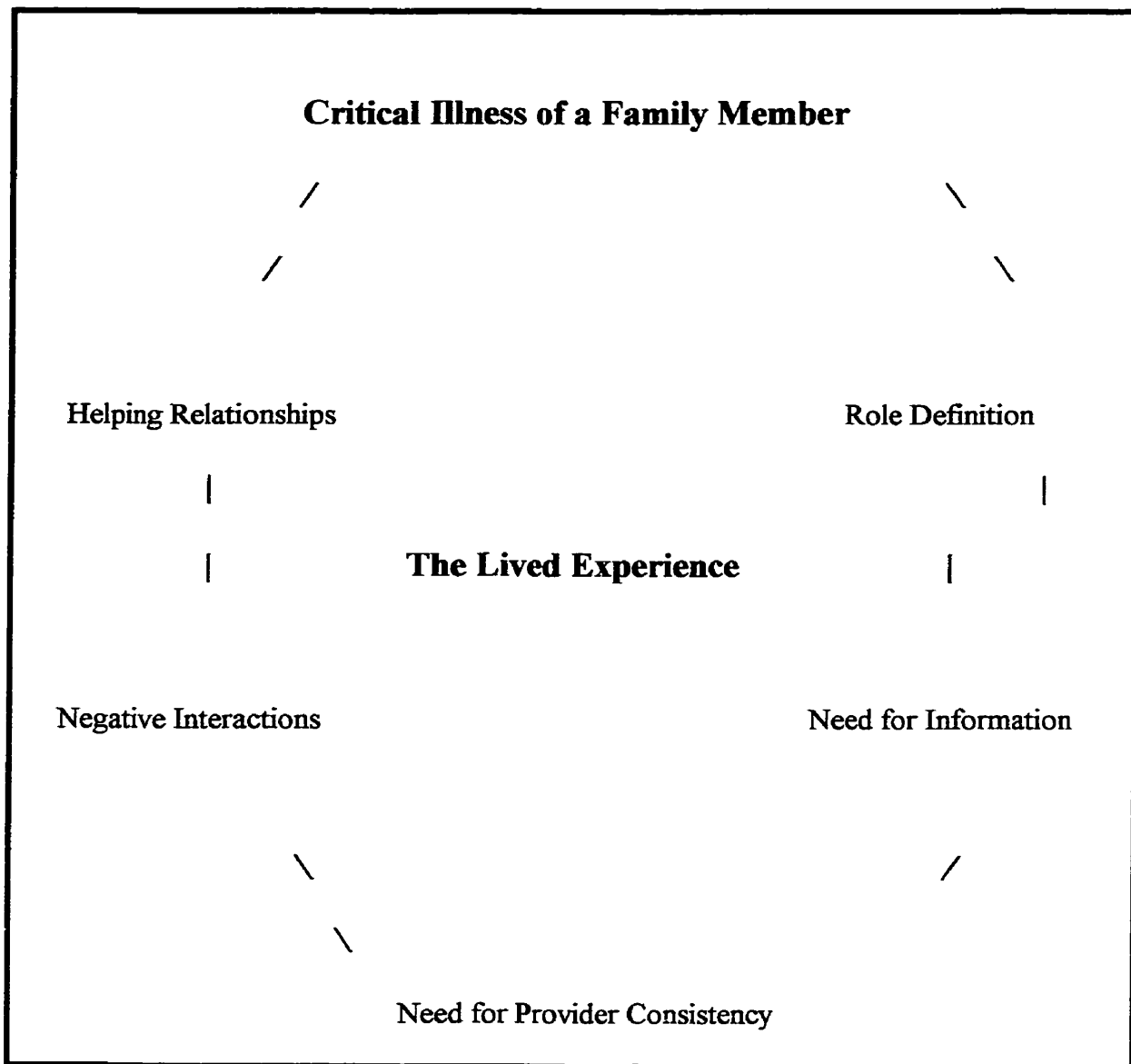


Figure 1 - Illustrating the Key Themes

Role Definition

The key themes emerged from the participants stories in a cyclical manner. As I explored the narratives the significance of these individuals role in the health and welfare of the critically ill family member became more clear. The participants described their role from different perspectives but the consistent undercurrent in all their narratives was that of physically ‘being there’ for their ill family member. The need for access to their ill family member is articulated within the key themes of role definition, but was presented by the participants as a need to ‘be there’ for their family member. The data which uncovers this need includes statements such as

Actually my day was long. I would come home from work, pick up the kids, take them to the hospital . . . (George)

You know, you hate to be separated from them, in a case like that, when you don't know where they are and case something drastic happened (Elizabeth)

Just me being there helped him a lot and it helped me feel better too . . . (Elizabeth)

You see, we have always done everything together and now we are apart and I feel that whatever happens to him, is happening to me and he feels the same. (Irene)

I don't know when they would have come to get me. I finally got mad . . . (Irene)

The wife just went through hell, it'd be nice to be there when she wakes up and talk to her. (Ronald)

Elizabeth considered her most significant role during her husband's stay in ICU/CCU as ‘being there’.

He was calling for me, so she (the nurse) came and got me. He was in

pain for a long time after, but he grabbed hold of my hand and he was hanging on, just me being there helped him a lot and it helped me feel better too.

Throughout his stay in critical care, Elizabeth strove to ‘be there’ for her husband. She was very concerned that he would minimize any chest pain he did experience and that she would need to inform health care providers about the pain.

That’s what I’m saying, he just passes things off. He doesn’t think it’s macho to be hurting, you know what I mean. I don’t think he’s going to tell them if he has pain. I’ve seen a couple of times when he’s twinged but he says oh that’s nothing. I don’t think he’ll tell if he gets another pain.

Elizabeth was also concerned that her husband not be alone to lie there and think, so part of her role was to distract and occupy his mind until he was well enough to deal with the impact of this illness on his life.

I think he needs me a lot right now, just to be there. I try to think of things to keep his mind off things.

She explained tearfully;

I think sitting around thinking is bad. He’s not feeling any pain so he thinks he’s good. So he’s just thinking, when I’m not there, he’s just lying in bed thinking.

Elizabeth elaborated on her role and its significance to her husband’s well being.

I try to keep up his spirits, I find he’s getting very, very depressed, actually me coming in at ten was probably good. When I got here, he was in tears. The doctor had just told him he wouldn’t be driving for six months or stuff like that, I guess that upset him. He’s not going . . . I mean he probably won’t even mention anything to anybody outside of me. I mean when I came in I knew if one of the nurses had walked in he would have been nonchalant, I don’t care about a thing, which isn’t true.

Irene also discussed the need to ‘be there’ for her husband. On admission Irene and her family were very concerned about her husband. The option of thrombolytic

therapy to treat the myocardial infarction was carefully discussed with them, including the risks of haemorrhage and/or stroke. Irene explained how everything seemed to be working well.

So we watched really, really carefully and he did really, really well and so I thought I would just run home and change my clothes. She (the nurse) said it wasn't hardly any time after I left that she noticed his speech was a little off.

Unfortunately Irene's husband did experience a cardiovascular accident. Irene shared her guilt for leaving her husband at that time.

Of course, I regretted doing that afterwards, but I couldn't have done anything anyway. I was nervous to go home after that because I was afraid that I would just get home and they would call me again.

Irene expanded upon her need to be there for her husband.

You see, we have always done everything together and now we are apart and I feel that whatever happens to him, is happening to me and he feels the same.

Lorraine describes herself as her mother's primary care giver whose role it is to provide support, encouragement and to 'be there' for her mother.

I must say at times it's hard to be encouraging when you don't see a lot of relief for her. It is very hard, but just to be supportive and to be there.

Ronald also used the term 'being there' is his description of his lived experience when his wife was a patient in critical care. He described his attempt to be there for his wife at the tertiary care hospital.

The wife just went through hell, it'd be nice to be there when she wakes up and talk to her, but no 'You'll have to leave!' says the nurse.

Ronald articulated why he needed to 'be there' for his wife very clearly;

I mean she was going up the next day, you know, she was scared, she needed someone to talk too.

George saw his role as one of care giver to his young children and also to his mother-in-law. George was there for his wife and ensured through his care giving role that other members of their family were also there for her. George talked about remaining calm but admitted that

I had a time when I was sort of water eyed! Not totally upset but just a strong feeling . . . Initially I am very calm. I'll carry something through and think about it more after.

George threw himself into his role as care giver in what appears to have been a coping strategy.

I didn't have a lot of time to dwell on the experience, my days were busy, busy, busy.

Although George did not directly articulate his role as advocate and protector it becomes evident when he shares his wife's experience at the tertiary care centre as part of her critical care admission. His expectation that he was to 'be there' for and to act as her protector and advocate is also evident in his efforts to go to the city with his young children to be with her in that setting..

Irene demonstrated her protective role in her family during her husband's admission to the critical care area.

I don't know when they would have come to get me. I finally got mad and both my sons were with me and they were taking this very hard. Tom was so upset and he finally broke down, and I said never mind. I would go down and find out what was going on.

Irene believed her current role was to be her husband's voice and advocate and shared her difficulty in performing that role in this circumstance.

Right now, all I feel that I can do for him is to try to protect him as much as I can, be there when he needs me, try to get him as much help as I can to improve his quality of life and get him home. There is nothing I wouldn't do for him if I could and sometimes you feel so helpless . . .

Elizabeth described her role as protector of the family. When asked about her support systems she indicated that there were

just the kids and I don't want to burden them with it.

She further demonstrated this role,

I mean I do have a son at home, he's worried, and he feels like he has to take on a lot . . . I made him go back to work yesterday, there's nothing really going on. There's no need for us both to be here, I'd call him if there was any need.

The day Elizabeth found her husband in tears, caused her to consider the change of his role within the family and as a husband.

It might not be important to me if they told me I couldn't drive, it wouldn't bother me but he feels that's his role, as a husband, that's what he's supposed to do, he takes his role quite seriously.

Elizabeth also expressed her fear of her changing role in her family caused by her husband's critical illness.

I just got my licence last year, I go get groceries, even driving around town scares the daylight out of me. I'd go to the airport to pick him up, that's about the extent of it. Now if the driving falls back on me that kind of scares me.

Need for Information

The need for information is such a common thread for family members of critically ill patients that the participants in this study were seen by other family members' as the providers of information. George faced the most direct questions regarding his wife's

condition, when his daughter asked “*Is Mommy going to die?*” His belief in keeping his children aware of what was happening ensured that he did not minimize their concerns and he answered their questions directly.

I never left them out of the picture. I basically told them mostly everything, everything they needed to know and I didn't hide anything from them.

Elizabeth had to explain treatment plans to her children even as she struggled to deal with the frustration of changes that she did not understand.

I was okay with it and I explained it to the kids, “Your dad is going to be going to the city, he's going to have the dye test, to see what damage was done and what further could be done”. I came in here yesterday and they told me now they're not taking him to the city. So I said why, one day you tell me it's important and the next day you say he doesn't need to go, and I have to try to explain this to the kids. They said it was important because they can't do it here, so it made me think well why did they change their mind.

Lorraine, the adult child of a critically ill parent, is her family's contact person when her mother is in the critical care unit. She is the one who calls for updates on her mother's condition and lets her sibling know what is going on. Her brother looked to her for information.

Family member's need for specific information about what is happening with their loved one is often frustrated by health care providers intentional vagueness in relation to patient response to treatment and resource availability for tests. Elizabeth shared

to have some kind of an idea at least. The doctor said she'd give him a stress test sometime next week, but does that mean Monday, Tuesday, or Friday.

Participants' words revealed the lack of information sharing by health care

providers about the admission procedure and that family members are expected to wait without knowledge of what may be happening to their family member.

I'm used to it, for an average person it might seem long. I suppose the first time it did seem like a long time. Now I know the routine, so I know what has to be done, and that they'll come and get me when they are ready. (Lorraine)

They told me downstairs to come up here and wait in the Family Room and they would come right down and get me when he was comfortable. A little over an hour later, I'm thinking there's got to be something else wrong. I was in there thinking that he had another heart attack. Finally, I couldn't take it any longer and I went down and I walked right in and I said, 'I don't know what's going on, but I need to know.' I was asked 'Didn't somebody go get you?' I told them, 'Thanks a lot. I just spent the worst hour of my life.' They all apologized. I wasn't mad when I went down because I thought there was something wrong. When I went down, he was lying up in bed and they were asking him questions and stuff and they had forgotten all about the family. So, I told them, I don't think that was a very good thing to do. I have two sons down there that are very, very upset. (Irene)

Elizabeth was frightened during the three quarters of an hour she waited to see her husband upon his transfer from the emergency department to the critical care unit. She stated

you know, you hate to be separated from them, in a case like that, when you don't know where they are and case something drastic happened.

Despite Irene's outward confidence and assertiveness in demanding information, she shared her concerns about her inability to speak for her husband and her inability to advocate for him.

I think I'm just overwhelmed because it's my husband maybe, but I felt the same concern when it was my mother-in-law, but I could express myself more. You know what I mean? But with this, I don't know. I sort of lose it. I go to ask something and I forget what I wanted to ask to start with. Maybe I'm just confused. I don't know.

Irene's distress about obtaining information was partially based upon her difficulty accessing the physicians and/or obtaining current information in a timely way.

If I get in here tomorrow morning and I can get a hold of one of those doctors, maybe I can put some questions to them, but by the time that he's moved out on to the floor, it's going to be different altogether again. I am worried about that. He has had one seizure. What's to say he won't have another one? It might not be today. It might be tomorrow and if he isn't monitored, and it dropped really drastically really fast. Are they going to have a chance to do anything for him or am I going to get a call at work? . . . I have so many questions that still need answers. They must have seen patients like this before. Roughly, how long would he be in rehab? I still have a lot of things to think about. How long will he be out on the floor? Do they want me to take him home for a period before he goes to rehab? I have a lot of getting ready to do if anything like that happens. If I have to take him home before he goes to rehab, I probably am going to have to end up quitting my job. I have been there for fifteen years and I wouldn't want to, but eventually it might happen anyway.

Later in our conversation, Irene identified further knowledge gaps she needed to have addressed.

This is another thing that I would like to find out. Is anyone going to test him to see if he does have brain damage and in what areas. It's to find out how you go about this.

Irene had previous experience with the facility and when she was unable to get information she looked for other resources who had advocated for her in the past. In relation to her need for information, Irene started to investigate her rights and how to stand up for herself and address her needs.

I was really upset I couldn't get any answers as to why this was happening or what they were doing. I could see the names of drugs but that didn't really mean a lot to me. Anyway, the next day I contacted the social worker and my daughter-in-law (a nurse) and we had a chat with her. I can't find out why he had his heart attack. I can't find out why he had his seizures. I can't find out how much damage has been done to his heart. All of these questions and nobody will tell me. They keep beating around

the bush. So, she came up with me and we had a little chat with one of the doctors.

Irene eloquently defined the need for communication between the health care team and the family members of critically ill patients.

If I can't be here when the doctor is coming in, could the doctor not tell the nurse or leave me a message or something because I can't be in there at that time and that is the only time of day that the doctor is going to be there. Can't you leave me a little communication either with the nurse or something to let me know where I stand or my husband stands, or both of us stands? It would be really good if the doctors could communicate with the nurses and give them permission, or whatever they have to do, to relay to the family, "I'm sorry I missed you. I couldn't see you, but this is what's happening today." You know, it would clear the air. It would just make the families feel so much better to know. Then they will think, well that doctor really cares because he is leaving this message and he trusts his nurse. He is leaving a message. It would. I think that is one of the biggest things that they could actually do . . . I don't know how much the nurses are allowed to tell me. That's another thing. I know they are not allowed to diagnose my husband or anything like that, but how much are they allowed to tell me as to what the doctor has done that day or if they have changed medications. Are they allowed to tell me that? That is one thing that I don't know. I have been doing a lot of thinking this time around and like some of them will just volunteer information, which is really appreciated. It really helps, but then others are really closed about it. So, then you get thinking, what happened today? You're not telling me anything. What happened today?

Rather than going back to work right away, Elizabeth decided for her it was better to have the time right away, to be there for her husband. To address her need for information, Elizabeth also looked for a resource external to the critical care setting, her husband's family doctor.

His doctor, his personal doctor has been coming in to see him too. What I had thought was maybe I could call his doctor's office, he doesn't even know me, we don't have a family doctor, it's so scary nowadays, and maybe talk to him right, ask him, I didn't know if that would be the right thing to do.

George had a different perspective. He felt any lack of information rested in a misunderstanding of the level of care the regional hospital could provide versus that of a tertiary care institution.

I think that one thing dealing with heart patients is that should outright be told, this is a stabilizing hospital not to fix your problem and a lot of people are expecting somebody here to tell them what the problem is. The answer isn't out here. If you don't go to the city to get that test, you don't know. That should be brought right to their attention, we're here to do the best we can to stabilize and see where we go from here, don't expect them to give you big answers. I never felt that I didn't understand after a day or two or three when I picked up that they were a stabilizing unit . . . A lot of people maybe aren't aggressive enough to ask questions or medically don't understand.

Ronald's experience at the regional centre was positive.

The regional hospital was good, if I asked a question no problem, or if I called. I used to call every morning at 7 o'clock, every morning, I'd ask what kind of night she had. When I went in, it was 'Hi, Mr. Ronald!

The difficulty accessing members of the health care team away from their family member's bedside was also a concern expressed by the participants.

Sometimes I find it difficult because you might like to ask the nurse or doctor something but the answers may not be what you want your loved one to hear. It's hard to get one on one with the nurse or physician when you are visiting your loved one. But the phone is the only way you can do it really. And I find some nurses are more willing to sit down and give you information, I know they're busy and what not. (Lorraine)

I could just say so much in front of him. (Elizabeth)

The doctors don't have the courtesy to sit down and talk with you. It was in the city that I couldn't get any information. I'd call the nurses up and I couldn't get any satisfaction, so I went and stayed right there. I've never seen a doctor in there yet, and this is going on pretty near a year, no doctor has sat down and talked to me yet. (Ronald)

Irene decided to go back to work after her husband's condition had stabilized a bit.

She based her decision on the uncertainty of his prognosis outcome, the fact that he was being well cared for in ICU, and that he would really need her when he was transferred to the rehabilitation centre.

I was really concerned about that because I kept trying to get information through the nurses. I had no contact with these doctors anymore because I went back to work. They come in the morning. I'm working and there has not been one, I thought for sure one of them would leave me a note or something to tell me how they think my husband is progressing, but no, I haven't gotten anything. I thought well maybe I'll place a note in his chart to have somebody leave me a note to tell me how my husband is progressing.

Lack of access to health care providers away from the patient's bedside was a sub-theme within the key theme of need for information. Lack of access to health care providers and lack of information overlapped into the key theme-negative interactions.

Some of the comments which revealed this insight were:

Sometimes I find it difficult because you might like to ask the nurse or doctor something but the answers may not be what you want your loved one to hear. It's hard to get one on one with the nurse or physician when you are visiting your loved one. (Lorraine)

The doctors don't have the courtesy to sit down and talk with you. It was in the city that I couldn't get any information. (Ronald)

Can't you leave me a little communication either with the nurse or something to let me know where I stand or my husband stands, or both of us stands? It would be really good if the doctors could communicate with the nurses and give them permission, or whatever they have to do, to relay to the family, "I'm sorry I missed you. I couldn't see you, but this is what's happening today." You know, it would clear the air. It would just make the families feel so much better to know. (Irene)

I have so many questions that still need answers. They must have seen patients like this before. Roughly, how long would he be in rehab? I still have a lot of things to think about. How long will he be out on the floor? Do they want me to take him home for a period before he goes to rehab? I

have a lot of getting ready to do if anything like that happens. If I have to take him home before he goes to rehab, I probably am going to have to end up quitting my job. (Irene)

I never felt that I didn't understand after a day or two or three when I picked up that they were a stabilizing unit . . . A lot of people maybe aren't aggressive enough to ask questions or medically don't understand. (George)

It would be really beneficial, if they could have a case conference or a meeting with the family, to say this is the scenario, this is what's going on, this is what we're going to do. (Lorraine)

Need for Provider Consistency

The participants expressed concern about the lack of consistency in health care providers (especially medical and nursing) in both tertiary and regional hospitals. This lack of consistency in health care providers increased some participants sense of a lack of control over the situation.

When she goes into the hospital, why don't they refer her to the doctor who took care of her the last time. They have some very nice nurses don't get me wrong! There's no consistency. (Ronald)

I know that I can't control the situation but I think it could be organized a little better so that I didn't have to have all this worry. Really, when you get right down to it, I think that between the doctor and the nurses and myself, I don't see why there couldn't have been better control. It's just a matter of communication. It's to get the right communication, I guess. I feel like if there was one doctor looking after him, I would have half a chance, but with four, and they are coming and going all the time. You never know which one is going to be looking after him and at what time. It is hard to get the situation under control and I know that the doctors like to talk to the people concerned. (Irene)

I don't feel as comfortable with the newer ones coming on, you don't build up the same rapport, is there some way you could maybe have the same nurse. Where I work we find that consistency pays off, you get a lot better

results. I realize you can't with 12 hour shifts, you can't nurse one person through. If you had that same nurse for a longer period, if she started at the beginning and she knows what you're like at the beginning, she could maybe pick up on something you know a little farther down the road, that maybe you're not admitting to, you know what I mean. Where she's seen you at your most vulnerable she could maybe pick it up later. (Elizabeth)

While her mother was a patient at the tertiary care hospital Lorraine found the lack of consistency among nursing staff to especially difficult.

Because I wasn't there all the time it was hard for me to keep tabs on people and to know who was who. Mother expressed a concern, people would come in and she wouldn't know if they were a doctor or an intern or nurse or nurse's assistant. It was really mind boggling. You never really saw the same person twice, and a lot of different people coming in and asking questions . . . It was not as personal a touch as it is in a smaller hospital . . . You'd be very surprised to see the same nurse two days in a row (at the tertiary centre). There might have been a nurse that she really liked but she'd never see her again. It would be nice if they could keep the same nurse with the same patient the whole time. (Lorraine)

Although she talked about the personal touch of a smaller hospital, and seeing nurses on a more regular basis, the lack of consistency in medical care providers was very frustrating for Lorraine at the smaller regional centre.

One thing I do find frustrating in this area is with the three internists, I believe that they are all very good but one person may have a different opinion than another. And it's frustrating, because she's on her last day with Dr. X., he's been with her three days, he will not be here and somebody else will come. They may or may not have a different opinion. It would be nice if one internist stuck with her case, I find that frustrating . . . Well if I happen to be here when they visit I can talk to them but I don't have any separate time away from Mom with them. I was thinking about that today that it would be really beneficial, if they could have a case conference or a meeting with the family, to say this is the scenario, this is what's going on, this is what we're going to do. (Lorraine)

Elizabeth also referred to the number of physicians providing care for her husband and how it was difficult to relate to so many different individuals.

Now, see there's been three different doctors, the one who saw him when he came and did the initial care and told me what was going on, then Dr. X., who I really felt alienated from, who was over there and I couldn't talk to him and then this Dr. Y. who is really nice.

Irene looked for reassurance that her husband would receive consistent care even when she was not with him but she did not expect the same care giver to be there all the time.

I could ask the one that is looking after him right now, but does it stay there, does it go to all the ones that are looking after him? I know that they have to go. I could tell one that I'm worried about this and while I'm there she could say, "I'll hook him up for you". But I need to know he's being looked after like that when I'm not there.

Negative Interactions

Ronald discussed his frustration with mixed messages that he and his wife received between the regional and tertiary hospital.

But you know when they got to the city, they're not communicating back and forth, the right way. They said, oh no, we can't do that, you're too young. I've never heard of that, I've heard of people 18, 19 years old having ah, ah, clogged veins or whatever they call it. But why wouldn't the doctors sit down and say now here's your options. (Ronald)

Lorraine was quite clear about her role as supporter and encourager but also recognized her personal lack of support from her mother's health care providers.

Although she was very quick to praise the support provided by the nurses to her mother she did not experience that support directly.

I am supportive but it is hard, I have a family. As far as medically I have no real support. It might be kind of nice to have a liaison that you could work between the family and the medical staff. You know, you worry about your family, you worry about your mother, but you don't put a lot of

emphasis on your own needs. (Lorraine).

Well, I guess I'm an exception to the rule in that I know all the nurses by name because Mother has been here so long. The only reason I know their name is that I say to Mom, who is your nurse today, and she'll tell me and point her out. No, I don't think I've ever had a nurse come over and say to me "Hi, I'm so and so, and I'm your mother's nurse today". I've never had that. (Lorraine)

After a physiological crisis when she had been called to the hospital due to the seriousness of the incident Irene described her disappointment that the attending physician did not speak to her about her husband's condition,

(B)ut the doctor, I was so disappointed. I thought, I can't imagine he was there . . . he could have said to me, well I think maybe there is a seizure going on here and explain what a seizure was and take some of the worry off me, but no. He never even came near me. So, you can imagine how much respect I have for this doctor . . . He never came near me. He never looked sideways. That made it a lot harder. (Irene)

Irene found another incident bothersome. When her husband had first received Ativan, he was so drowsy for two days that there was concern that he had a second cerebral vascular accident. It was decided at that time that the dose was too high for him and he did not receive it for several days. However one night, after Irene had overheard the nurses' talking about being short staffed for the shift, he was given the drug again.

The nurse was a little worried because she couldn't get him awake, and I said 'Well, we already went through this once. Why would they do it again?' He hasn't had it again, but it did upset me. It really did.

Irene insisted that her husband not receive the same dose of Ativan again.

Perhaps the most negative interaction experienced by Irene was with one individual. She shared that

There is one nurse that I did not take to. I didn't like her attitude and I didn't take to her but I had not said anything because she was giving my husband good care. She comes along and she is working with in CCU and she sees my husband and she is walking by and she comes over and she said, "Hi. How are you tonight? I bet I can get a reaction out of you." Why she did this, I don't know. She uplifts the covers takes his left foot, which is paralysed. She took her pen and she just dug that up the bottom of his foot as hard as she could and the look on my husband's face. I mean I was just speechless and he just glared at her. You knew that had to hurt and I just turned around and I said to her, "If that ever happens again, it won't be him that's going to feel it. It will be you, trust me. If he can't do it, I can." And I left it at that and she quietly left. That I did not like and far as I know, she has never stopped to see him again, which suits me fine. There was just no need of that. That was just not called for.

Ronald had very positive experiences with nursing staff at the Regional Hospital except for one incident in the Emergency Department.

No, here has been no problems, there's just that one nurse in emergency, who doesn't think that privacy is important . . . last Monday when my wife went in to Emergency the nurse said "Well, the last time you came here you had no medication are you sure you have some now?" Wow, were we embarrassed, it was right in front of everybody, in a really loud voice.

The most distressing experiences described by the participants involved their interface with health care providers at the tertiary care centre. Participants shared negative interactions they or their family member experienced during their stay at the tertiary care centre.

But the city, phew, they didn't care! That was the attitude I picked up. They were boss and that was it! She went up and had the test done, I went over to the hospital at 11 o'clock, she went up at a quarter to twelve, I waited around, she never came back, well it was during quiet time. The nurse said to me, well you can go in for about a second, you'll have to leave. I said 'Big deal! The wife just went through hell, it'd be nice to be there when she wakes up and talk to her! No, no you'll have to leave now, you're allowed in for a minute and you'll have to leave! (Ronald)

Actually my mom said one day a man came in with a heart attack, and his

wife came in and it was rest time and the nurses asked her to leave. My Mom felt kinda bad, because I think she came in from the country. She was just sitting there with him very quietly, it didn't sound like it would be a problem. So it seems like they are pretty strict with there rules, they stick to their guns. (Lorraine)

That was quite a major trauma! When you get to the city, you're into the work farm! Where you're just a patient and you're there to get something done, and you conform to their rules . . . So, no it wasn't pleasant down there, she couldn't get the medicine she wanted, she couldn't get this . . . they had some reasoning why! I mean any med they gave her after that brought her heart rate down. Um, some nurse . . . when a patient is upset like that, stay there for a while, talk with her, tell her the situation. Just say these are the rules, this is the rule and this is why we have to do it, and that it can't change. The bedside manner was terrible. The nurses barely came around, they're busy I suppose, but they barely came around and she was making noise, I'd think they'd come to her just to cut down on the noise, just to keep her quieter. Obviously, the experience isn't a nice one! The only thing I would have liked to have happened differently out of the whole thing is the night in the city. Other than that it was inevitable and it was going to happen. But that night was torture! It was the ultimate torture. I'm usually pretty good at handling things but that night was the limit. (George)

Helping Relationships

Several participants described verbal support and compassion they or their family member received from nursing staff and/or physicians. The need for reassurance is a sub-theme within the key theme of helping relationships in these narratives. The helping relationships described assisted the participants live their role.

Irene made a decision to go back to work until her husband was transferred to the rehabilitation centre where she felt he would need more assistance from her. One of the nurses acknowledged that decision which validated Irene and reaffirmed her decision making abilities.

It was about a week later and one of the nurses was coming by, and she said, "You know, I've never told you this, but I should have, and I'm going to stop and tell you now. You've really got it together because you thought about every bit of it instead of just thinking, I've got to be here right now. You really thought that out. We really admire you for that.

Lorraine's mother required readmission to the Regional Hospital shortly after discharge from the tertiary care centre. This readmission was disappointing to both the patient and her family but the compassion shown to them, by nurses and doctors, was considered very helpful.

I feel they are really doing everything they can do with her medical problems. And yesterday, one of the nurses' said, and it was kind of nice to hear this, she said, "we all felt so bad when your mother was back, we were hoping you would have some relief after this." It is nice to feel that compassion, and even the physician has expressed lately how bad he feels. It's just nice to know that there is a human side, you know. They have a job to do but it's nice that they have compassion, I think that means a lot. Actually Mom said last night, one of the nurses from coronary care came down and sat with her for 15 minutes or so, you know just talking. She didn't have to do that, it was her choice to do that. I thought that it was very nice. There is support.

Irene had similar experiences,

They might just come over to the bed and say hi to him and touch his hand, you know.

Elizabeth was surprised by the nurses' attitudes

I find them very cheerful, I really didn't think it would be like that in a critical care area. I feel that is probably good because it's uplifting.

On his transfer from the Emergency Department, Elizabeth's husband was experiencing chest pain, she was very frightened waiting to see him.

They told me I'd have to wait until they got the pain settled. It seemed like forever it was about three quarter's of an hour or more and they couldn't get it settled but he'd been calling for me, so she came down and got me

she thought maybe if I was there it might help. It really helped him and me!

Irene experienced many positive interactions with health care providers. Her initial contacts with the physicians were positive. She was especially grateful to the physician who assessed her husband for a code status and to one nurse who involved her in her husband's care and reaffirmed her need 'to be there' for him.

Dr. X explained everything right to me . . . But you know, after he did that, like you know, he took me in and we had this chat and everything. He explained everything right out to me which I really appreciated and I felt better knowing that if anything did happen, he could have the paddles and there was a chance, but after he (the doctor) did that I still say that's what brought him (her husband) out of this.

The nurse made me feel, yes, she made me feel like I was involved . . . but she made me feel good. The nurse did because she came by every 10 minutes while his blood pressure was being taken. She explained to me how the medication was being given to him. The whole bit and every once in a while she would say, "Yes." That's a good one, I think. She said, "Yes. We're getting it and it's coming up." Then the next one would drop a little and she would say, "Now don't worry about that because this medication we can't give it to him fast." She explained the whole thing out to me . . . She did her job and actually more than her job because she made me feel that I was even helping . . .

Irene's anxiety about her ability to obtain information and what she considered a positive response to that need is reflected by the following statements.

I had no idea they were going to start him on another antibiotic but the nurse said to me, "I just want you to know Mrs. Irene, before you go home, that we have started . . ." She offered. I didn't have to go to her.

The day that he was going from CCU into ICU they called me and they told me that they would like to move my husband from CCU because he was well enough to go to ICU and would it be ok. I mean, they didn't even have to do that. They were nice enough to do it. So, when I came in that night I knew exactly where to find my husband. Just go in there. I have had the experience before of coming in and the bed is made up and flat

and that gives you the feeling of death, right there. So, I didn't have to go through that this time.

Unlike Ronald, Lorraine's family had a more positive experience with relation to visiting hours at the tertiary care centre. It is interesting, however, to note the differentiation that Lorraine makes between the critical care area and the ward at the tertiary care centre.

At the tertiary care centre it was nice because we could go and could stay however long. And that was nice especially when we were out of town. Initially when she was in intensive care there were times but after no. It was nice being from out of town, we could just go quietly and sit in the room, as long as she was happy they had no problem with it. (Lorraine)

Lorraine experienced the different approaches of nurses in both settings. She found those willing to share and to communicate to be most helpful.

And I find some nurses are more willing to sit down and give you information, I know they're busy and what not. But some certainly don't mind taking the time to try and explain the best that they can what's happening.

George described one nurse's advocacy role for his wife.

I believe that one of the nurses' looked at the age of our kids and her age, you know, and she said well, maybe we could try and get you a little priority because you have young kids at home. So she talked to one of the doctors and the priority maybe became a little better.

Unlike the other participants Ronald did not experience difficulty accessing or talking with the doctor about his wife's condition at the regional centre. It was the physicians' at the tertiary care centre who were unavailable to Ronald. Ronald and his wife share the same family physician and have also had several encounters with physicians in the regional hospital's emergency department and coronary care unit which perhaps

increased Ronald's comfort level with the process for accessing the physician at the Regional Centre.

If I wanted to see the doctor or talk to the doctor, oh yes by all means. If I want to see our family doctor, I just make an appointment in his office and I go see him. If he saw me down in the emergency, he'd come over and talk to me.

Summary

The goal of this chapter was to present the family members' lived experience of a critical care in the participants' own voices. The participant's stories illustrate their perception of their role during this episode in their family's life. Through this interpretive process the key theme role definition was explored as the key themes: need for information; need for provider consistency were uncovered. The lived experience of the participants as presented through their own words supports the identification of these key themes and the impact of care givers helping relationships and/or negative interactions upon the participants' ability to meet their needs for information and consistency in fulfilling their role as the family member of a critically ill adult.

CHAPTER FIVE

ANALYSIS

Overview

This study was undertaken to give family members' of critically ill adults a voice. In the presentation of the findings I focussed on the participants' interpretations of their experiences with critical care health care providers and the critical care environment. In this chapter I present my analysis of the findings. Participants in this study unanimously described the regional hospital's critical care nurses as "great". Their dialogue supports that statement however as I listened and reviewed their stories over and over again, and began to explore the narrative's similarities and differences I was able to categorize their words into the key themes.

As indicated previously, my analysis began as data was being collected and as I transcribed the conversations. During the transcription of the conversations I had the opportunity to listen and re-listen to each participants style of conversation allowing me a more accurate understanding of their lived experience. An integral element of my analysis of the data was contemplation of and reflection upon my personal and professional experiences of family care in critical care settings. These experiences included advocating for a wife to sit quietly at her husband's bedside all night after his admission to coronary care following a myocardial infarct; soothing adult children wanting to see their mother during a resuscitation attempt; and holding a young woman's hand as she watched her husband being intubated. These and similar experiences have evoked in me empathy for

the family members of critically ill patients. Personally I have experienced a family member's frustration of being isolated from and excluded from my father's bedside during the insertion of a thermodilution catheter. I can also remember my feelings of reassurance and peace when my husband arrived and sat with me during the traumatic premature delivery of our daughter. My personal experiences as critically ill patient, family member and nurse helped me to achieve closeness to the lived experience of the participants.

I listed patterns of experiences among the five participants and identified all data related to the patterns. The patterns that I identified were their experiences upon arrival at the emergency department, waiting to see their family member after admission to the critical care unit, ongoing care, communications with providers, and transfer to and care provided at the tertiary care centre. The patterns were then catalogued into sub-themes and the five key themes finally emerged from the participants narratives of their lived experiences. The five key themes which emerged were role definition, need for information, need for provider consistency, negative interactions, and helping relationships.

Research has demonstrated that family members of critically ill family members need assurance, proximity, information, comfort, and support (Leske, 1991; Titler, Bombei, & Schutte, 1995). As the key themes materialized these needs were central but not inclusive of my findings. The need for information was the only one of these needs which emerged as a key theme, with access to the physician as a sub-theme within this context. Although the need for access to the patient was prominent in their stories, the participants defined this as a need to 'be there' for their ill family member. Within the key

themes negative interactions and helping relationships, the participants further revealed their need for information, reassurance and support. Previous researchers had found family members connected the need for proximity with physical comfort while waiting and discussed location of waiting rooms, washroom facilities, and sleep areas as of being significant to family members (Leske, 1991; Titler, Bombei, & Schutte, 1995). The findings of this study did not reflect the need for comfort as a sub or key theme.

Role Definition

Most significantly the participants struggled to fulfil their new role in relation to their family members changed health status. Being there for their family member was a pivotal domain in the participants definition of their role. The importance of this acknowledgement and validation of the family member's role by the nurse, is reflected by the following statements.

The nurse made me feel, yes, she made me feel like I was involved . . . she made me feel good.

He was calling for me, so she (the nurse) came and got me.

Despite being worried, anxious and confused the participants in this study had a very clear vision of their role. They revealed that their primary role was to 'be there' for their ill family member. Although critical illness of a family member is a traumatic and overwhelming experience, 'being there' allowed the participants to support, to protect and to advocate for their ill family member. My findings suggest that the health care providers who interfaced with the participants did not consistently demonstrate an acceptance of

and/or an ability to operationalize this vision of the role of families in relation to the critically ill family member. This lack of consistent family care experienced by the participants is highlighted by statements such as

I am supportive but it is hard, I have a family. As far as medically I have no real support. It might be kind of nice to have a liaison that you could work between the family and the medical staff. You know, you worry about your family, you worry about your mother, but you don't put a lot of emphasis on your own needs.

Well, I guess I'm an exception to the rule in that I know all the nurses by name because Mother has been here so long. The only reason I know their name is that I say to Mom, who is your nurse today, and she'll tell me and point her out. No, I don't think I've ever had a nurse come over and say to me "Hi, I'm so and so, and I'm your mother's nurse today".

They have some very nice nurses don't get me wrong! There's no consistency.

He could have said to me, well I think maybe there is a seizure going on here and explain what a seizure was and take some of the worry off me, but no. He never even came near me.

Although family members were very clear about their role, they had more difficulty determining the roles of the various health care providers who came in contact with their critically ill family member. "Role expectations are the assumptions a person makes about the actions, behaviours, or attitudes of another. Families have expectations about how nurses should act and about what will happen to them and the patient. When role expectations are not met by the way the other person enacts a role, role conflict occurs" (Long & Greeneich, 1994 , p. 105).

I don't know how much the nurses are allowed to tell me. That's another thing. I know they are not allowed to diagnose my husband or anything like that, but how much are they allowed to tell me as to what the doctor has done that day or if they have changed medications. Are they allowed

to tell me that?

My findings support Valentine's (1992) perspective that male physicians and administrators hold the power. The bureaucracy of getting the work done (i.e. the medical interventions) still marginalizes patients, families and those nurses who attempt to provide care based upon their moral obligations. Bowie (1982) described 'role' as a moral concept.

To fully understand any of the roles in health care, one must be acquainted with all three of the key role elements - the customary, the legal, and the moral. This understanding will increase one's appreciation of some of the role conflicts which often occur in health care. The nurse has a moral obligation to treat newly admitted patient with dignity, respect, and compassion for the patient's affliction. Yet the admittance procedures of many hospitals, which constitute in part the legal element of her role, undercut the moral obligation to treat newly admitted patients with dignity, respect, and compassion (Bowie, 1982, p. 58).

The participants' experienced delays and isolation from their ill family member during the admission process and the concept of protecting patients from visitors by restrictive visiting practices was also evident. Ronald's anger at being banned from his wife's bedside at the tertiary care centre is consistent with other research findings. Improved patient outcomes have been found in relation to flexible, patient and family controlled visiting practices. Flexible visiting hours allows families to meet their need for access to the critically ill patient, to attend to their personal activities of daily living while

providing emotional support to the patient (Davis-Martin, 1994; Titler, Bombei, & Schutte, 1995). My findings also concur, Ronald articulated trust and support for health care providers in the regional centre where he had more control over when he visited. “We have found families to be less hostile and apprehensive and to have more trust for health care providers when their presence at the bedside is controlled by the patient and family rather than the nurse” (Titler, Bombei & Schutte, 1995, p. 377).

The findings support that the need for access or proximity to the ill family member is crucial. Family members perceive that ‘being there’ provides the patient with a connection to life, gives them something or someone to hang on to. Even when logically a family member knows they could not prevent an adverse event, they feel guilt when they were not there with the patient during the event. Conversely they feel less helpless when they are with the patient during the event. Yates (1995) found that spousal social support was most effective for minimizing depressive symptoms related to short term recovery outcomes in men with coronary heart disease. This is consistent with my findings as evidenced by the following comments.

You know, you hate to be separated from them, in a case like that, when you don't know where they are and case something drastic happened

Just me being there helped him a lot and it helped me feel better too . . .

The wife just went through hell, it'd be nice to be there when she wakes up and talk to her.

I think he needs me a lot right now, just to be there.

I try to keep up his spirits, I find he's getting very, very depressed, actually me coming in at ten was probably good. When I got here, he was in tears.

Need for Information

My findings concur with those of other researchers, in that the need for information was clearly articulated by every participant. Participants described helpful relationships when the need for information was addressed by health care providers and negative interactions when this need was overlooked. My findings suggest that family members experienced anxiety and frustration when their need for information was not addressed by health care providers in the critical care setting.

An additional method to build a feeling of acceptance for family members is to provide information in understandable terms as often as family members request it. Medical jargon is usually overwhelming to patients and they are embarrassed or afraid to ask for clarification. Sensitivity to this issue will engender the confidence and support of family members. (Davis-Martin, 1994, p. 518)

Data which supported the theme of helping relationships in relation to information provision included the following statements;

Dr. X explained everything right to me . . . which I really appreciated and I felt better knowing .

And I find some nurses are more willing to sit down and give you information, I know they're busy and what not. But some certainly don't mind taking the time to try and explain the best that they can what's happening.

If I wanted to see the doctor or talk to the doctor, oh yes by all means.

Negative interactions as a key theme was especially significant when the need for information was not addressed. Data which supports this perspective includes

So, you can imagine how much respect I have for this doctor . . . He never came near me. He never looked sideways. That made it a lot harder.

Dr. X., who I really felt alienated from, who was over there and I couldn't talk to him.

But why wouldn't the doctors sit down and say now here's your options.

I have been doing a lot of thinking this time around and like some of them will just volunteer information, which is really appreciated. It really helps, but then others are really closed about it. So, then you get thinking, what happened today? You're not telling me anything. What happened today?

And I find some nurses are more willing to sit down and give you information, I know they're busy and what not.

My findings suggest that not only is the need for information significant to family members of critically ill adults, but also the environment where they receive that information is of concern. My findings indicate that family members not only want timely information but to be given the opportunity to receive it away from their family member's bedside in case it is bad news. They also want the opportunity to talk with the nurse or physician away from the patient's bedside if they have difficult or potentially upsetting questions to ask.

Sometimes I find it difficult because you might like to ask the nurse or doctor something but the answers may not be what you want your loved one to hear. It's hard to get one on one with the nurse or physician when you are visiting.

I could just say so much in front of him.

The doctors don't have the courtesy to sit down and talk with you. It was in the city that I couldn't get any information.

Can't you leave me a little communication either with the nurse or something to let me know where I stand or my husband stands, or both of

us stands? It would be really good if the doctors could communicate with the nurses and give them permission, or whatever they have to do, to relay to the family, "I'm sorry I missed you. I couldn't see you, but this is what's happening today." You know, it would clear the air. It would just make the families feel so much better to know.

Need for Provider Consistency

Another key theme extrapolated from the data was the need for consistent care givers. This theme overlapped with the need for information in that participants searched for some sense of control over the situation. Their lack of control was heightened by the number of personnel with whom they and their family member had to interface and was perceived as a stressor. This pattern was similar to that within the key theme of negative interactions. The lack of provider consistency was revealed by statements such as

I feel like if there was one doctor looking after him, I would have half a chance, but with four, and they are coming and going all the time.

I don't feel as comfortable with the newer ones coming on, you don't build up the same rapport, is there some way you could maybe have the same nurse.

When she goes into the hospital, why don't they refer her to the doctor who took care of her the last time.

It has been discovered that "Introductions to all personnel the family observes providing care are very helpful" (Davis-Martin, 1994, p. 517). My findings identified that when this did not occur the need for provider consistency became even more significant to family members.

No, I don't think I've ever had a nurse come over and say to me "Hi, I'm so and so, and I'm your mother's nurse today". I've never had that.

My findings support that when provider consistency is achieved the participants perceived

a helping relationship but that when it was not family member stress was increased. The impact of this lack of consistency enhanced the family members' need to 'be there' for their ill family member.

Because I wasn't there all the time it was hard for me to keep tabs on people and to know who was who. Mother expressed a concern, people would come in and she wouldn't know if they were a doctor or an intern or nurse or nurse's assistant. It was really mind boggling. You never really saw the same person twice, and a lot of different people coming in and asking questions . . . It was not as personal a touch as it is in a smaller hospital . . .

And it's frustrating, because she's on her last day with Dr. X., he's been with her three days, he will not be here and somebody else will come. They may or may not have a different opinion. It would be nice if one internist stuck with her case, I find that frustrating . . .

Now, see there's been three different doctors, the one who saw him when he came and did the initial care and told me what was going on, then Dr. X., who I really felt alienated from, who was over there and I couldn't talk to him.

I could tell one that I'm worried about this and while I'm there she could say, "I'll hook him up for you". But I need to know he's being looked after like that when I'm not there.

Helping Relationships and Negative Interactions

The participants' discussions of helping relationships and negative interactions revealed these both as key themes. Any analysis of these themes is more relevant when one can be seen as a foil for the other. The significance of helping relationships can best be described by comparing it to the negative interactions which were uncovered. Indeed in this discussion the circular, overlapping nature of the data is most apparent. Not only do the key themes overlap but it is in the participants perception of negative interactions and helping relationship in relation to the needs for access, information and reassurance

which highlight the importance of addressing these needs in the clinical setting.

Astrom, Norberg, and Hallberg (1995) found that “for the nurse in medical care, caring meant seeing a human being in her or his social context and trying to understand the way in which the patient needs care when he or she is ill” (p. 112). My findings suggest that this is a considered practice, it is not necessarily inherent in the provision of nursing care, and does not consistently occur. George would have liked to see a nurse sit and talk with his wife when she was experiencing great discomfort after a cardiac catheterization. That intervention might have decreased both his and her anxiety and provided a sense of dignity and respect in the relationship between the nurse, patient and family member.

So, no it wasn't pleasant down there, she couldn't get the medicine she wanted, she couldn't get this . . . they had some reasoning why! I mean any med they gave her after that brought her heart rate down. Um, some nurse . . . when a patient is upset like that, stay there for a while, talk with her, tell her the situation.

Reider (1994) describes a similar stressful situation, the resolution of which was not time consuming and did not require extensive educational preparation on the part of the nurse.

The family had repeated requests regarding the patient's care. When one nurse sat with the family for a few minutes in an undisturbed room outside of the Critical Care Unit, the family revealed that they most distressed about the visiting hours and the resultant inability of all of the immediate family to see the patient each day. (Reider, 1994, p. 278).

The pattern of the data supports the cataloguing of the sub-themes, need for reassurance and the need for families to feel that hospital personnel care about their ill family member within the key theme of negative interactions and as identified in the

literature (Davis-Martin, 1994; Molter, 1994). This is reflected by George's experience during his wife's recovery from the cardiac catheterization procedure, and by Irene's reaction to the nurse's neurological testing of her husband.

In addressing the family member's needs to be reassured and to be assured that the health care providers care for the critically ill patient Davis-Martin (1994) found that "the most important approach is for them to observe excellent care being provided in a caring manner (p. 517). The findings of this study support that statement. The findings reflect helping relationships when nurses attended to the provision of care in a caring manner.

It's just nice to know that there is a human side, you know. They have a job to do but it's nice that they have compassion, I think that means a lot.

She explained the whole thing out to me . . . She did her job and actually more than her job because she made me feel that I was even helping.

The positive impact of helping relationships on patients and family members has been compared to an energy infusion from the nurse while negative interactions with a nurse drain a patient's energy (Dracup, 1993). When nurses acknowledged and validated the family member's role, as when the nurse affirmed the helpfulness of the family member, the relationship with the nurse was seen by the participant as helpful. When doctors or nurses did not approach family members from this perspective the interactions were viewed as negative.

My findings indicated that health care providers who attended to family member needs in helping relationships enhanced individual family member's coping strategies. Lazarus (1993) suggests that helping people through crisis enhances individual and family coping mechanisms. Conversely, negative interactions increase stress and anxiety levels

resulting in decreased family member problem solving abilities. “The ability of the family to use coping strategies is associated with lower anxiety levels” (Reider, 1994, p. 277). This is also important for minor children of critically ill patients. The welcoming of George’s young children at his wife’s bedside supported his desire to keep them informed and able to deal with their mother’s illness. This finding is consistent with current research (Titler, Bombei, & Shcutte, 1995).

My findings support that “when significant family members are incorporated into the patients care, anxiety is decreased in critically ill patients” (Warren, 1994, p. 67). As evidenced when participants felt most valued in helping relationships with health care providers, decreased anxiety levels for both patients and family members were achieved. Such positive outcomes for the patient when family care is provided has been identified by many other researchers (Chelsa, 1996; Reider, 1994; Titler, Bombei, & Schutte, 1995).

The nurse, she came by every 10 minutes while his blood pressure was being taken. She explained to me how the medication was being given to him. The whole bit and every once in a while she would say, “Yes.” That’s a good one, I think. She said, “Yes. We’re getting it and it’s coming up.” Then the next one would drop a little and she would say, “Now don’t worry about that because this medication we can’t give it to him fast.” She explained the whole thing out to me . . . She did her job and actually more than her job because she made me feel that I was even helping

I don’t think he’s going to tell them if he has pain. I’ve seen a couple of times when he’s twinged but he says oh that’s nothing. I don’t think he’ll tell if he gets another pain.

Just me being there helped him a lot and it helped me feel better too.

I must say at times it’s hard to be encouraging when you don’t see a lot of relief for her. It is very hard, but just to be supportive and to be there.

I believe that one of the nurses' looked at the age of our kids and her age, you know, and she said well, maybe we could try and get you a little priority because you have young kids at home. So she talked to one of the doctors and the priority maybe became a little better.

The findings of this study also reflected how not being incorporated into the patient's care increased patient and family anxiety.

I don't know when they would have come to get me. I finally got mad.

I mean she was going up the next day, you know, she was scared.

Summary

It becomes obvious that the five key themes that have emerged from the data overlap and impact upon one another. Elizabeth's ability to be with her husband when he was having pain helped her, Irene being valued during her husband's physiological crisis, and George's ability to have his children at his wife's bedside in the critical care supported these family members and promoted and enhanced their ability to cope with their family member's illness. The significance of a family member's role is perhaps most clearly revealed by the following passage.

He was calling for me, so she (the nurse) came and got me. He was in pain for a long time after, but he grabbed hold of my hand and he was hanging on, just me being there helped him a lot and it helped me feel better too.

CHAPTER SIX

CONCLUSIONS

Discussion

Experienced critical care nurses have a very clear understanding of what family members need. As this study demonstrates despite this understanding, our ability to meet those needs continues to occur inconsistently. Critical care nurses must have the skills necessary to practice competent critical physiological and family care. For the benefit of the patient, critical care nurses must internalize the concept of family nursing as the basis of their practice. Methods of optimizing the transition from competent to expert practitioners in critical care nursing must be explored since it is generally accepted that expert critical care nurses provide family care.

My findings reflect the practice of family nursing as described by Friedemann, (1989) at the individual level. Occasionally the participants experienced the practice of family nursing at the second or interpersonal level but rarely at the third or family systems level. The voices of the participants in this study called for nurses to provide helping relationships, at the interpersonal level, to enable them to fulfill their role, to obtain information, to address their need for provider consistency, and to be supported and reassured through positive rather than negative interactions.

The challenge when we do hear the voices of family members is how to respond to those voices in a therapeutic manner. The participants in this study told me that their most important role during a family member's stay in a critical care unit was to 'be there' for

their family member. The family member's perceived that the ill person required them to 'be there' to support, advocate, and at times protect them. Nurses who facilitated this role were seen as helpful, those health care providers who did not facilitate this role increased family and patient anxiety.

Warren (1994) has developed a conceptual framework that promotes incorporation of the family member into critically ill patient care by nurses who display caring behaviours (Figure 2). To ensure the consistent practice of family nursing in adult critical care units, a multi disciplinary approach must be implemented with the philosophy and operationalization of the concept clearly understood and accepted by all members of the team. Utilization of Warren's (1994) conceptual framework of nursing's caring behaviours in critical care settings will provide the format to operationalize family nursing for critically ill patients and their families.

This framework supports my findings in the context of the concept of family nursing (Friedemann, 1989). The data exposed many nurses practising interpersonal level family nursing demonstrated in their caring behaviours in helping relationships. Warren (1994) described four caring behaviours: informing, spiriting, touching, and enhancing.

Informing

The findings reflect informing behaviours in the subcategories-orienting, sharing, encouraging, allowing, and dialoguing (Warren, 1994). The need for information emerged as a key theme from the data and is consistently documented in the literature as a priority need for family members of critically ill adults (Davis-Martin, 1994; Dracup & Clark, 1992; Engli & Kirsivali-Farmer, 1993; Leske, 1986; Leske, 1991; Lopez-Fagin, 1995;

Molter, 1994; Norheim, 1989; Warren, 1993; Warren, 1994). The findings of this study are consistent with this perspective.

When it did occur informing was revealed as helping relationships in the data especially when family members were allowed to 'be there' for the patient. Conversely when participants were not allowed, experienced delays seeing or isolation from their ill family members the caring behaviour of informing did not occur. Sharing and encouraging were perceived as caring behaviours by the participants in this study, but when information and/or access to health care providers was not readily available it was perceived negatively.

Spiriting

Warren (1994) describes the caring behaviour of spiriting as "extending healing power, enhancing subjectivity, and intuiting" (p. 70). This behaviour was experienced in an inconsistent manner by the participants in this study. The data showed that when nurses involved family members in patient care that extending healing power was evident, for example the husband 'hanging on to his wife's hand' and the wife 'being with' her husband throughout a hypotensive crisis.

Touching

The data do not reflect touching as being physically experienced by the participants in this study. However the data are consistent with this tenet in relation to the caring perceived by the family members for their ill relative. When the nurse patted or caressed the patient, the participants revealed these as helping interactions or relationships. This is consistent with findings from the literature which identified that family members' need to

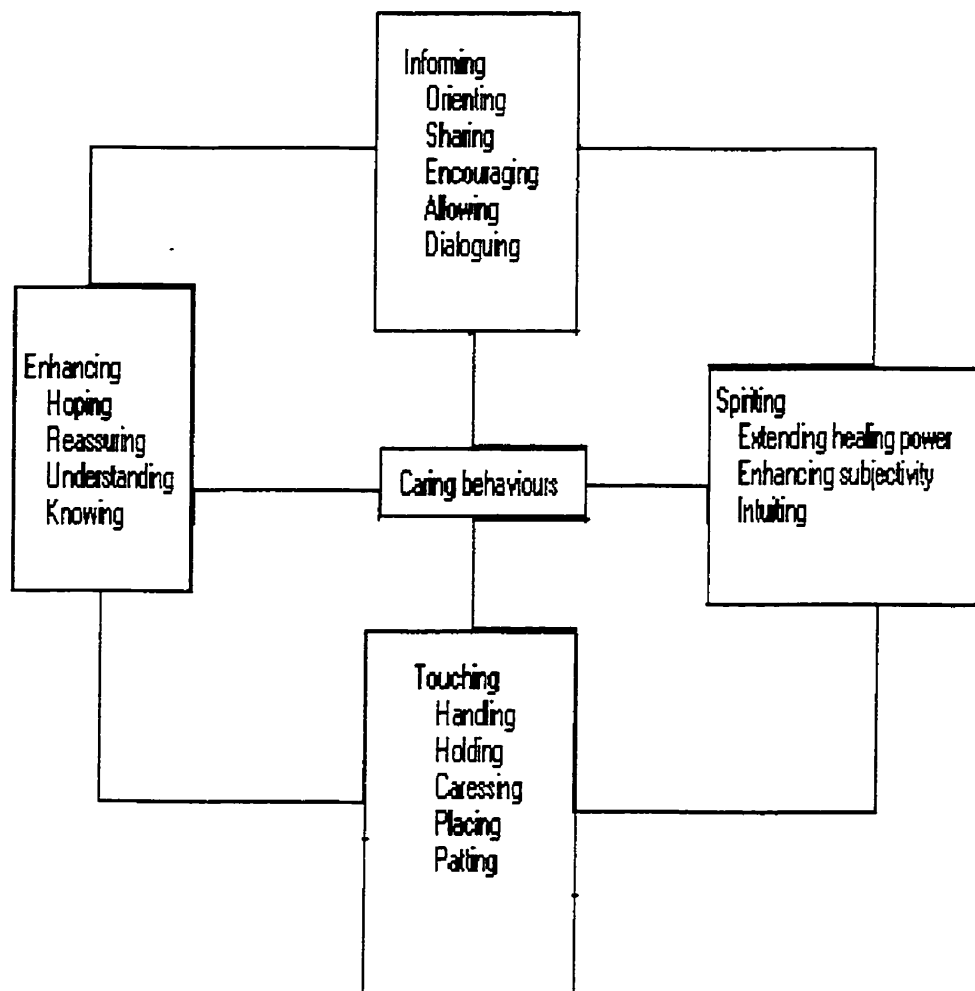


Figure 2. Model of nurses' caring behaviours. (Warren, 1994, p. 70)

feel that health care providers care about the critically ill patient (Molter, 1979).

Enhancing

Nurses demonstrated the caring behaviour of enhancement by encouraging a sense of hope, and demonstrating reassurance, understanding, and knowing (Warren, 1994). The need for reassurance has been identified in the literature as significant to family members of critically ill adults (Curry, 1995; Leske, 1986; Lopez-Fagin, 1995; Warren, 1993). This study reflects that the participants perceived the interactions as helpful when this behaviour was demonstrated but negative when not. The data reflected the inconsistency with which the participants experienced this caring behaviour.

Implications for Nursing Practice

The findings of this study revealed evidence of family nursing at the individual and interpersonal levels as described by Friedemann (1989) but that family nursing was being inconsistently practiced. I believe that expert nurses and managers that espouse the principles of family nursing must coach and mentor new learners and novice level nurses not only in the physical care required of critically ill adults but also in the family care required. As Chelsa (1996) suggests there is growing evidence that nurses with expertise in family systems theory should be introduced into critical care settings as consultants or educators to mentor and coach critical care nurses in the provision of family nursing.

Recognition and facilitation of 'being there' by family members must occur consistently in all critical care areas independent of the level of skill acquisition of the bedside nurse caring for the ill patient. Nursing researchers agree that comprehensive

family care in critical care settings requires the skills, knowledge and experience of an expert nurse (Benner, 1984; Chelsa, 1996; Titler, Bombei, & Schutte, 1995). “Expert nursing knowledge is acquired through formal and informal learning, coupled with extensive experience within a specific area (domain)” (Fonteyn & Grobe, 1994, p. 80).

To address the varying levels of skill acquisition among critical care nurses, managers and administrators must provide support to those nurses not yet expert in the provision of family care in a critical care setting. The concept of leadership and its role in nursing has been extensively studied. Value-driven leaders set key values and then allow others in the organization to implement them, effectiveness is determined by how well these values are maintained over time (Nyberg, 1993). Astrom, Norberg and Hallberg (1995) cite numerous studies that “emphasize that the ward sister is an important model for learners and other nurses and has a significant influence on the work situation and climate” (p. 116). One would expect that in units where the nurse managers espouse family care for critically ill patients that there would be a strong culture for support of the concept. Nurse managers must recognize that culture fills the gap between formal rules and the way things really work and guides and shapes practice (Freund, 1988). Culture “can restrain innovation when there is conflict between the culture and the innovation” (Van Ess Coeling & Simms, 1993, p. 13). This reflects the discrepancy between the acceptance of the concept of family care and its consistent clinical application in critical care settings.

The patient’s right to confidentiality must always be a consideration of health care providers. Rushton (1994) suggests that critical care nurses are in a unique position as

patient advocates to address this concern. “Advocacy can, therefore, be enhanced by developing trusting, therapeutic relationships with patients and families and by fostering a care delivery model that supports continuity” (Rushton, 1994, p. 106).

Titler, Bombei, and Schutte (1995) suggested an approach to the provision of family-focussed care in a busy critical unit that meets patient and family members needs without taking the nurse away from the bedside.

Even with a very unstable patient, the family can come to the bedside and observe all that is being done for their loved one while the nurse updates the family about the patient’s condition. This approach actually saves time because the nurse can talk with the family while delivering care rather than trying to find time to leave the patient’s bedside to explain the equipment and condition to family members in the waiting room. Family members develop a deep appreciation and understanding of what is being done for their loved one when they can observe, firsthand, the care they are receiving, accompanied by explanations from the nurse. It is our experience that families who are welcomed at the bedside rather than restricted to waiting rooms, provide emotional encouragement and support to the patient. (Titler, Bombei, & Schutte, 1995, p. 377)

Critical care nurses need to examine their practice to ensure that policies such as restrictive visiting are truly patient driven and not provider focussed. “Once the patient’s condition has been stabilized, families should be offered the opportunity to play some part in the nursing care and not be made to feel as if they are intruding in matters which do not

concern them” (Woolley, 1990, p. 1406).

My findings also suggest that family members access to physician’s must be planned and coordinated at the bedside by the primary nurse. Neither physicians nor nurses can realistically expect family members to ask life and death questions in front of their critically ill family member. Thus the bedside nurse must provide significant family members with regular opportunities to discuss concerns and questions in a private area separate from the patient.

Implications for Education

The findings of this study support that critical care nurses need to be exposed to educational programs that address methods of providing family care consistently in critical care settings. Many researchers have discovered that critical care nurses believe that families provide emotional support for the patient, but that as nurses, they do not have the required knowledge or skill to meet the psychosocial and emotional needs of families (Crawford, 1998; Hickey & Lewandowski, 1988; Wright & Leahey, 1994). Not surprisingly then is the extensive research that indicates that critical care family needs are not consistently recognized or addressed by critical care nurses (Bouley, von Hofe, & Blatt, 1994; Crawford, 1998; Curry, 1995; Engli & Kirsivali-Farmer, 1993; Reider, 1994). A number of explanations for the discrepancy between belief and application have been proposed, among them lack of time by, and emotional exhaustion of, the nurse (Crawford, 1998; Curry, 1995; Titler, Bombei, & Schutte, 1995). Other investigators suggest that nurses perceive that not only is family care exhausting but that families are

dysfunctional and liabilities in the provision of patient care, this perspective must be disputed (Tapp, 2000). Educational endeavours need to focus on the context of each family situation and help individual nurses develop strategies to engage with family members in efficient ways. Family members themselves should be the focus of educational endeavours to promote understanding of the critical illness, their rights in the situation, and the significance of their role for the patient and his/her recovery.

Implications for Policy

The findings of this study suggest a number of areas in which unit and hospital policy development would enhance family care of critically ill patient's families. As the data demonstrated family members identified and were concerned about the lack of provider consistency both among nursing and medical health care providers.

Policy statements and development by facility administration regarding the priority of family care would strengthen the nurse manager's and individual nurses' ability to coach and promote this as a standard of practice within the unit by all nursing staff. Medical staff should be encouraged to explore their manner of practice to reduce frequent changeover of critically ill patients.

Limitations

The most significant limitation of this study is that it presents the 'voice' of only one family member. The participants define themselves as next of kin but I have not been able to corroborate that with the critically ill patient or other family members. The voice

of the critically ill patient must also be heard in order to fully understand the impact of social and family supports on his/her recovery from a critical illness.

All of the participants were family members of critically ill patients admitted to a small regional hospital in a relatively rural setting. The findings in a large urban setting might be significantly different from this study.

The homogeneity of the participant group is another limitation to the study. Since all of the participants were white, Anglo-Saxon rural inhabitants it is suggested that research with others from diverse populations be under taken. The presentation of the experiences of visible minorities, of poor, of non-white, of gay/lesbian, or of other marginalized groups would be beneficial. In addition it is suggested that there are groups of people who should be specifically identified according to gender, such as older women whose needs would probably differ than those of older men.

Replication of the study to include family members of patients with a diagnosis other than cardiovascular disease would provide another perspective as well. In retrospect a larger sample size encompassing a more diverse population would have yielded further rich data.

A significant limitation to any study of critically ill patients and their family members is the vulnerability of this population due the crisis aspect of their situation. Concern about protection of family members from intrusion during this stressful life event limited access, as did researcher time commitments both factors then becoming limitations to the research.

Suggested Future Research

The limitations identified suggest that thematic analysis principles which guided this research might not have been the most appropriate. To fully explore a family's experience with the critical care environment all members of that group need to be invited to participate. An ethnographical study of a critical care unit would uncover nuances in health care provision that remain hidden today. The challenge of course is the ethical implications of doing such research in an environment where not all the participants can give informed consent (i.e. the critically ill or injured adult patients). The nature of critical care units is one of a multi- and inter-disciplinary environment. The impact of various environmental organizational and interactional processes upon critically ill patients and their family members should also be uncovered.

The introduction of consultants and/or clinical nurses specialists with advanced academic preparation in family systems nursing needs to be explored. While the literature suggests this strategy (Chelsa , 1996) no evidence of its impact upon patient and family outcomes has been documented.

The application of Warren's conceptual model of caring and its impact upon patient and family outcomes needs further exploration. Interventional studies would promote application of successful strategies from one setting to another. Although much work has been done we must continue to explore family care in adult critical care settings to optimize the care of these patients.

Conclusions

Within the subspecialty of critical care nursing we must promote and make visible the need for family care. Unless the practice of family care becomes visible and thus valued we will continue to provide inconsistent and at times ineffectual family care and compromise the outcomes for our critically ill patients. “Today more than ever, families are compelled to be directly involved in the care of their ill family members. During the management of chronic illness and after discharge from hospital, family members are providing physical care, emotional support and even technical care. Families need more, not less, support and information from nurses to prepare them for the demands that accompany recovery from acute illness” (Tapp, 2000, p.29).

This study uncovered the voices of five family members of critically ill adults. The key themes they shared were how they defined their role, their need for information, their need for provider consistency, negative interactions with health care providers, and the helping relationship they experienced with health care providers. The most significant message they delivered was that their role is important to their ill family member. No health care provider can replace that role. Our critically ill patients need their family members support and presence to ensure that we nurses can provide the best possible care.

Appendix A

Semi-Structured Interview Guide

I am interested in exploring with you, your experience of care when your family member was critically ill. In order to do this I would like to hear about your experiences during your family member's stay in the intensive/coronary care unit. Listed below are some questions which I may ask to help you to explore your experience. Please feel free to ask any questions or to refuse to answer any of my questions.

- Can you tell me about how you learned your family member was in the ICU?
- Could you explain your relationship with the person you visited in the ICU?
- Describe your thoughts and feelings while you waited to visit your family member after they were admitted to the ICU.
- Can you describe your experiences with the nurses looking after your family member in the ICU?
- Describe your thoughts and feelings waiting to and visiting your family member while they were in the ICU?
- Describe how you received information about your family member while they were in the ICU.
- Tell me how you felt you could help your family member during his/her stay in the ICU?
- Would you like to share anything else about your experience with me?

Appendix B

Introduction Letter

HELLO:

My name is Teresa Lee. I am a graduate student of Dalhousie University currently working on my thesis as part of the degree requirements toward a Masters of Nursing degree. My thesis is a research study of family members' experiences when their family member was a patient in a critical care unit. I am providing you with this introductory letter in hope that you will be interested in participating in this study.

This research study developed as a result of my experience as a critical care-bedside nurse, nurse manager, and patient. I have experienced and observed a variety of nursing care practices. The purpose of my research is to gain an in depth understanding of family members' experiences with health care providers and the intensive care environment while their family member is a patient in a critical care unit. I will not discuss patient or family care with the doctors and nurses caring for your family member and I will also have no contact with your family member. This study will explore your experience and not that of your ill or injured family member. Your choice whether or not to participate will in no way affect the care being provided to your family member.

Your participation would involve an audio taped interview with me of about forty minutes. You would have an opportunity to review the transcript of your interview and to confirm my interpretation of your statements in person or over the telephone as you prefer.

You will be asked to sign a written consent form that indicates your willingness to be involved in this study. You will not be identified as a study participant during the interview process or in any reports of this research. You will be provided with a code name to ensure confidentiality in the final document. Code names, audio tapes, transcripts not provided to you and field notes will be kept in a secure area only available to the researcher during the study and will be destroyed at the completion of the research. You are free to withdraw from the study at any time. Study findings will be provided to you upon request.

Thank you for considering this request for assistance in contributing to the knowledge base of the experience of family care in adult critical care settings. If you are interested in participating in this project please let the nurse manager in ICU/CCU know and she will introduce us.

Yours truly,

Teresa Lee

Appendix C
Consent

Study Title- FAMILY MEMBERS' EXPERIENCES OF A CRITICAL CARE EPISODE

Principle Investigator Teresa Mary Lee, BScN, RN
 Masters Student
 School of Nursing
 Dalhousie University

Introduction

I have been invited to take part in a research study at the Colchester Regional Hospital. I have read and understand several general principles that apply to all who take part in this study: (a) taking part in the study is entirely voluntary. Whether I participate or not, the quality of medical care provided will be the same; (b) personal benefit may not result from taking part in this study, but knowledge may be gained that will benefit many others; (c) I may withdraw from the study at any time without loss of any benefits to which I am otherwise entitled. This study is described below. The description includes information about the risks, as well as any inconvenience or discomfort which I may experience. I have been urged to discuss any questions I have about this study with the researcher, Mrs. Lee.

Purpose

The purpose of this study is to explore care experiences of family members of critically ill adults. I understand that I will be asked to participate in an audio-taped interview, lasting forty minutes. I will be asked to spend another twenty minutes to review and comment on a transcription of that interview as interpreted by the researcher.

Participants

I understand that any English speaking visitor in the ICU/CCU waiting area may participate in this study.

Risks and Discomforts

I understand that discussing my thoughts and feelings about the time my loved one was in the ICU/CCU may cause me to relive the experience and/or have strong emotions related to that time.

Possible Benefits

I understand that reviewing the experience and/or emotions may assist me to put them into perspective and achieve a greater understanding of the experience.

Compensation

There will be no costs to me for participation in this study. I will not be charged for telephone calls, audio tapes or transcripts. In the event that I become ill or injured while participating in this research study, necessary medical treatment will be made available to me. None of my legal rights are waived. The investigator and involved institutions are not released from their legal and professional responsibilities.

Confidentiality

All information provided will be confidential and results will be anonymous. The researcher will be the only individual with access to participants' names. Tapes and transcriptions not provided to me, will be destroyed at the end of the study. A copy of the study results will be made available to me upon request. I am aware the study is a thesis component of the Masters of Nursing Program at Dalhousie University and the results will be shared with the researcher's thesis committee and may be used for publication in the future.

Questions or Problems

If I have any questions about the study, I can contact, at any time: Teresa Lee, 35 Deer Brooke Drive, Cole Harbour, Nova Scotia, 902-434-7967.

I have been given an opportunity to ask questions and all questions have been answered to my satisfaction. I agree to participate in this study.

Participant Signature _____

Date _____

Researcher Signature _____

Date _____

REFERENCES

Ahmann, E. (1994a). Family-centred care: Shifting orientation. *Pediatric Nursing*, *20*(2), 113-117.

Ahmann, E. (1994b). Family-centred care: The time has come. *Pediatric Nursing*, *20*(1), 52-53.

Allen, D.G., Maeda, K.K., & Powers, P. (1991). Feminist nursing research without gender. *Advances in Nursing Science*, *13*(3), 49-58.

Alspach, J.G. (Ed). (1998). *Core curriculum for critical care nursing*. (5th ed.). Philadelphia: Saunders.

Anderson, J.M. (1991). Current directions in nursing research: Toward a poststructuralist and feminist epistemology. *Canadian Journal of Nursing Research*, *23*(3), 1-3.

Aronson, J. (1994, Spring). A pragmatic view of thematic analysis [10 paragraphs]. *The Qualitative Report* [On-Line]. Available: <http://www.nova.edu/ssss/QR/BackIssues/QR2-1/aronson.html>

Astrom, G., Norberg, A., & Hallberg, I.R. (1995). Skilled nurses' experiences of caring. *Journal of Professional Nursing*, *11*(2), 110-118.

Benner, P. (1984). *From novice to expert*. Menlo Park, CA: Addison-Wesley.

Bond, N., Phillips, P., & Rollins, J.A. (1994). Family-centred care at home for families with children who are technology dependent. *Pediatric Nursing*, *20*(2), 123-130.

Bouley, G., von Hofe, K., & Blatt, L. (1994). Holistic care of the critically ill: Meeting both patient and family needs. *Dimensions of Critical Care Nursing*, *13*(4), 218-223.

Bowie, N.E. (1982). 'Role' as a moral concept in health care. *The Journal of Medicine & Philosophy*, *7*(1), 57-63.

Boyd, C.O. (1990). Qualitative approaches to research. In G. LoBiondo-Wood & J. Harber, (Ed.), *Nursing research methods, critical appraisal, and utilization*, (2nd Ed), (pp. 181-208). St. Louis: Mosby.

Britten, N. (1995). Qualitative research: Qualitative interviews in medical research. *British Medical Journal*, *311*(6999), 102-107.

Canadian Association of Critical Care Nurses. (1992). Standards for critical care nursing practice. London, Ontario: CACCN.

Campbell, J.C., & Bunting, S. (1991). Voices and paradigms: Perspectives on critical and feminist theory in nursing. Advances in Nursing Science, 13(3), 1-15.

Carter, S.L. (1989). Themes of grief. Nursing Research, 38(6), 354-358.

Chelsa, C.A. (1996). Reconciling technologic and family care in critical-care nursing. Image: Journal of Nursing Scholarship, 28(3), 199-203.

Chelsa, C.A., & Stannard, D. (1997). Breakdown in the nursing care of families in ICU. American Journal of Critical Care, 6(1), 64-71.

Clark, S. (1993). Helping patients and families cope. Critical Care Nurse, Supplement, 9(4), 14-22.

Cook, J.A., & Fonow, M.M. (1990). Knowledge and women's interests: Issues of epistemology and methodology in feminist sociological research. In J. McCail Neilsen (Ed.), Feminist research methods: Exemplary readings in the methods (pp. 69-93). Boulder: Westville Press.

Crawford, T. (1998). Factors influencing critical care nurses' involvement with families in the intensive care unit. Unpublished master's thesis, Dalhousie University, Halifax, Nova Scotia, Canada.

Curry, S. (1995). Identifying family needs and stresses in the intensive care unit. British Journal of Nursing, 4(1), 15-20.

Darbyshire, P. (1995). Family-centred care with contemporary British paediatric nursing. British Journal of Nursing, 4(1), 31-33.

Davis, L.L., & Cox, R.P. (1995). Using interventive questions to empower family decision making. Dimensions of Critical Care Nursing, 14(1), 48-55.

Denzin, N.K., & Lincoln, Y.S. (1994). Introduction: Entering the field of qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), Handbook of qualitative research (pp. 1-17). Thousand Oaks, CA: Sage.

DePompei, P.M., Whitford, K.M., & Beam, P.H. (1994). One institution's effort to implement family-centred care. Pediatric Nursing, 20(2), 119-121. 204.

- Doering, L. (1992). Power and knowledge in nursing: A feminist poststructuralist view. Advances in Nursing Science, 14(4), 24-33.
- Donahue, M.P. (1996). Nursing the finest art (2nd ed.). Mosby: St. Louis.
- Dracup, K. (1993). Helping patients and families cope. Critical Care Nurse, Supplement, 9(4), 3-13.
- Dublin, S.D. (1996). Mothers' experiences as caregivers for children with severe neuromuscular disorders. Unpublished master's thesis, Dalhousie University, Halifax, Nova Scotia, Canada.
- DuBois, B. (1983). Passionate scholarship: Notes on values, knowing, and method in feminist social science. In G. Bowles & R.D. Klein (Eds.), Theories of womens' studies (pp. 105-116). London: Routledge.
- Dzurec, L.C. (1989). The necessity for and evolution of multiple paradigms for nursing research: A poststructuralist perspective. Advances in Nursing Science, 11(4), 69-77.
- Engli, M., & Kirsivali-Farmer, K. (1993). Needs of family members of critically ill patients with and without acute brain injury. Journal of Neuroscience Nursing, 25(2), 78-85.
- Fonteyn, M.E., & Grobe, S.J. (1994). Expert system development in nursing: Implications for critical care nursing practice. Heart & Lung, 23(1), 80-87.
- Forchuk, C., & Park, D.J. (1995). Hildegard Peplau meets family systems nursing: innovations in theory-based practice. Journal of Advanced Nursing, 21(1), 110-115.
- Friedemann, M. (1989). The concept of family nursing. Journal of Advance Nursing, 14(3), 211-216.
- Freund, C.M. (1988). Decision-making styles managerial application of the MBTI and type theory. In M.J. Ward & S.A. Price (Eds.), Issues in nursing administration selected readings (pp. 163-170). St. Louis: Mosby.
- Gaglione, R.M. (1984). Assessing and intervening with families of CCU patients. Nursing Clinics of North America, 19(3), 427-432.
- Grandine, J. (1995). Embracing the family. Canadian-Nurse, 91(9), 31-36.

Hagell, E.I. (1989). Nursing knowledge: Women's knowledge. A sociological perspective. Journal of Advanced Nursing, 14(3), 226-233.

Hall, J., & Stevens, P. (1991). Rigor in feminist research. Advances in Nursing Science, 13(3), 16-29.

Harvey, M.G. (1992). Humanizing the intensive care unit experience. NAACOGS-Clinical Issues in Perinatal Womens Health, 3(3), 369-376.

Hickey, M., & Lewandowski, L. (1988). Critical care nurses' role with families: A descriptive study. Heart and Lung, 17(6 Pt 1), 670-676.

Holl, R.M. (1993). Role-modelled visiting compared with restricted visiting on surgical cardiac patients and family members. Critical Care Nursing Quarterly, 16(2), 70-82.

Holloway, N.M. (1979). Nursing the critical ill adult. Menlo Park, California: Addison-Wesley.

Holloway, N.M. (1988). Nursing the critically ill adult. (3rd ed.). Menlo Park, California: Addison-Wesley.

Humphry, R., and Geissinger, S. (1993). Issues in early intervention: Measuring attitudes about family-centred services. Occupational Therapy Journal of Research, 13(3), 147-162.

Jamerson, P.A., Scheibmeir, M., Bott, M.J., Crighton, R., Hinton, R.H., & Cobb, A.K. (1996). Experiences in the ICU. The experiences of families with a relative in the intensive care unit. Heart & Lung Journal of Acute & Critical Care, 25(6), 467-474.

Jezewski, M.A. (1994). Do-not-resuscitate status: Conflict and culture brokering in critical care units. Heart & Lung, 23(6), 458-465.

Johnson, B., Jeppson, E.S., & Redburn, L. (1992). Caring for children and families: Guidelines for hospitals. Bethesda, MA: Association for the Care of Children's Health.

Johnson, S.K., Craft, M., Titler, M, Halm, M., Kleiber, C., Montgomery, L.A., Megivern, K., Nicholson, A, & Buckwalter, K. (1995). Perceived changes in adult family members' roles and responsibilities during critical illness. Image Journal Nursing Scholarship, 27(3), 238-243.

Keddy, B. (1992). The coming of age of feminist research in Canadian nursing. The Canadian Journal of Nursing Research, 24(2), 5-10.

King, K.E. (1994). Method and methodology in feminist research: What is the difference? Journal of Advanced Nursing, 20(1), 19-22.

Kirby, S., & McKenna, K. (1989). Experience research social change methods from the margins. Toronto: Garamond Press.

Kristjanson, L.J., & Chalmers, K.J. (1991). Preventive work with families: Issues facing public health nurses. Journal of Advanced Nursing, 16(2), 147-153.

Lather, P. (1991). Getting smart: Feminist research and pedagogy within the postmodern. London: Routledge.

Lazarus, R.S. (1993). Coping theory and research: Past, present, and future. Psychosomatic Medicine, 55(3), 234-247.

Leahey, M., Harper-Jaques, S., Stout, L., & Levac, M. (1995). The impact of a family systems nursing approach: Nurses' perceptions. The Journal of Continuing Education in Nursing, 26(5), 219-225.

Leininger, M. (1985). Qualitative research methods in nursing. Orlando, Florida: Grune & Stratton, Inc.

Leske, J.S. (1986). The needs of relatives of critically ill patients: A follow up. Heart & Lung, 15(2), 189-193.

Leske, J.S. (1991). Internal psychometric properties of the critical care family needs inventory. Heart & Lung, 20(3), 236-244.

Lexicon Publications, Inc. (1988). The new lexicon Webster's encyclopaedic dictionary of the English language (Canadian Ed.). New York: Authors.

Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.

Long, C.O., & Greeneich, D.S. (1994). Family satisfaction techniques: Meeting family expectations. Dimensions of Critical Care Nursing, 13(2), 104-111.

Lopez-Fagin, L. (1995). Critical care family needs inventory: A cognitive research utilization approach. Critical Care Nurse, 15(4), 21, 23-26.

Love, J.G. (1994, Spring). The hermeneutics of transcript analysis [11 paragraphs]. The Qualitative Report [On-Line]. Available: <http://www.nova.edu/ssss/QR/BackIssues/QR2-1/love.html>

- MacPherson, K.I. (1983). Feminist methods: A new paradigm for nursing research. Advances in Nursing Science, 5(2), 17-25.
- Madison, G.B. (1988). The hermeneutics of postmodernity. Bloomington: Indiana University Press.
- Magilvy, J.K., Congdon, J.G., & Martinez, R. (1994). Circles of care: Home care and community support for rural older adults. Advances in Nursing science, 16(3), 22-33.
- Marsden, C. (1992). Family-centred critical care: an option or obligation? American Journal of Critical Care, 1(3), 115-117.
- Matheson, S.D. (1995). Current practice and perceptions of the role of nurses in caring for families in the critical care unit: A Canadian perspective. Unpublished master's thesis, Dalhousie University, Halifax, Nova Scotia.
- Maquire, P. (1987). Doing participatory research: A feminist approach. Maine: University of Maine.
- McClowry, S.G. (1992). Family functioning during a critical illness: a systems theory perspective. Critical Care Nursing Clinics of North America, 4(4), 559-564.
- Meleis, A.I. (1991). Theoretical nursing: Development and progress (2nd ed.). Philadelphia: Lippincott.
- Midmer, D.K. (1992). Does family-centred maternity care empower women: The development of the woman-centred childbirth model. Family Medicine, 24(3), 216-221.
- Mies, M. (1983). Towards a methodology for feminist research. In G. Bowles & R.D. Klein (Eds.), Theories of womens' studies (pp. 117-119). London: Routledge.
- Molter, N.C. (1979). Needs of relatives of critically ill patients: A descriptive study. Heart & Lung, 8(2), 332-339.
- Molter, N.C. (1994). Families are not visitors in the critical care unit. Dimensions of Critical Care Nursing, 13(1), 2-3.
- National Forum on Health. (1997). Canada health action: Building on the legacy. Ottawa, Ontario: Author.
- Nethercott, S. (1993). A concept for all the family: Family-centred care: A concept analysis. Professional Nurse, 8(12), 794-797.

Neuman, B. (1989). The Neuman systems model (2nd ed.). Norwalk: Appleton & Lange.

Noel, J. (1996). Voices on health care: Afro-Caribbean women's experiences. Unpublished Master's thesis, Dalhousie University, Halifax, Nova Scotia.

Norheim, C. (1989). Family needs of patients having coronary artery bypass graft surgery during the intraoperative period. Heart & Lung, 18(6), 622-626.

Omery, A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 5(2), 49-62.

Page, N.E., & Boeing, N.M. (1994). Visitation in the pediatric intensive care unit: controversy and compromise. American Association Critical Nursing-Clinical Issues, 5(3), 289-295.

Parse, R., Coyne, A.B., & Smith, M.J. (1988). Nursing research: Qualitative methods (2nd ed.). Bowie, MD: Brady Communications.

Picton, C.E. (1995). An exploration of family-centred care in Neuman's model with regard to the care of the critically ill adult in an accident and emergency setting. Accident and Emergency Nursing, 3(1), 33-37.

Powers, P.H., Goldstein, C., Plank, G., Thomas, K., & Cankright, L. (2000). The value of patient- and family-centred care. American Journal of Nursing, 100(5), 84-88.

Radsma, J. (1994). Caring and nursing: a dilemma. Journal of Advanced Nursing, 20(), 444-449.

Reider, J.A. (1994). Anxiety during critical illness of a family member. Dimensions of Critical Care Nursing, 13(5), 272-279.

Reinharz, S. (1992). Feminist methods in social research. New York: Oxford University.

Robinson, C.A. (1995). Beyond dichotomies in the nursing of persons and families. IMAGE: Journal of Nursing Scholarship, 27(2), 116-120.

Rodgers, B.R., & Knafle, K.A. (1993). Concept development in nursing. Philadelphia: Saunders.

Ruppert, S.D., Kernicki, J.G., & Dolan, J.T. (Eds.). (1996). Dolan's critical care nursing: Clinical management through the nursing process (2nd ed.). Philadelphia: F.A. Davis.

Rushton, C.H. (1990). Strategies for family-centred care in the critical care setting. Pediatric Nursing, 16(2), 195-199.

Rushton, C.H. (1994). The critical care nurse as patient advocate. Critical Care Nurse, 14(3), 102-106.

Shelton, T., Jeppson, E., & Johnson, B. (1987). Family-centred care for children with special health care needs Bethesda, MD: Association for the Care of Children's Health.

Simon, S.K., Philips, K., Badalamenti, S., Ohlert, J., & Krumberger, J. (1997). Current practices regarding visitation policies in critical care units. American Journal of Critical Care, 6(3), 210-217.

Simpson, T. (1990). Cardiovascular responses to family visits in coronary care unit patients. Heart & Lung, 19(4), 344-351.

Smith, K., Kupferschmid, B.J., Dawson, C., & Briones, T.L. (1991). A family-centred critical care unit. American Association of Critical Nursing-Clinical Issues Critical Care Nursing, 2(2), 258-269.

Spielgelberg, H. (1975). Doing phenomenology. The Hague: Martinus Nijhoff.

Stanley, L., & Wise, S. (1983). Back into the personal or: Our attempt to construct feminist research. In G. Bowles & R.D. Klein (Eds.), Theories of womens' studies (pp. 192-209). London: Routledge.

Streubert, H.J., & Carpenter, D.R. (1995). Qualitative research in nursing Advancing the humanistic imperative. Philadelphia: J.B. Lippincott.

Tapp, D.M. (2000). Therapeutic conversations that count. Canadian Nurse, 96(6), 29-32.

Tanner, J.L. (1995). Training for family-oriented pediatric care. Pediatric Clinics of North America, 42(1), 193-207.

Thomas, R.B. (1990). Research commentary A foundation for clinical assessment. Children's Health Care, 19(4), 244-250.

Titler, M.G., Bombei, C., & Schutte, D.L. (1995). Developing family-focussed care. Critical Care Nursing Clinics of North America, 7(2), 375-385.

Valentine, P. (1992). Feminism a four-letter word? The Canadian Nurse, 88(11), 20-23.

Van Ess Coeling, H., & Simms, L.M. (1993). Facilitating innovation at the unit level through cultural assessment, part 2: Adapting managerial ideas to the unit work group. Journal of Nursing Administration, 23(5), 13-20.

Waitzkin, H. (1989). Marxist perspectives in social medicine. Social Science Medicine, 28(11), 1099-1101.

Walters, A.J. (1994). The comforting role in critical care nursing practice: A phenomenological interpretation. International Journal of Nursing Studies, 31(6), 607-616.

Warren, N.A. (1993). Perceived needs of the family members in the critical care waiting room. Critical Care Nursing Quarterly, 16(3), 56-63.

Warren, N.A. (1994). The phenomena of nurses' caring behaviours as perceived by the critical care family. Critical Care Nursing Quarterly, 17(3), 67-72.

Webb, C. (1993). Feminist research: Definitions, methodology, methods and evaluation. Journal of Advanced Nursing, 18(3), 416-423.

Wesson, J.C. (1997). Meeting the informational, psychosocial and emotional needs of leach ICU patient and family. Intensive & Critical Care Nursing, 13(2), 111-118.

Woolley, N. (1990). Crisis theory: A paradigm of effective intervention with families of critically ill people. Journal of Advanced Nursing, 15(12), 1402-1408.

Wright, L.M. (1994). Live supervision: Developing therapeutic competence in family systems nursing. Journal of Nursing Education, 33(7), 325-327.

Wright, L.M., & Leahey, M. (1990). Trends in the nursing of families. Journal of Advanced Nursing, 15(2), 148-154.

Wright, L.M., & Leahey, M. (1994). Nurses and families A guide to family assessment and intervention (2nd ed.). Philadelphia: Davis.

Yates, B.C. (1995). The relationships among social support and short- and long-term recovery outcomes in men with coronary heart disease. Research in Nursing & Health, 18(11), 193-203.