I am part of the sun as my eye is part of me. That I am part of the earth my feet know perfectly, and my blood is part of the sea. My soul knows that I am part of the human race, my soul is an organic part of the great human race, as my spirit is part of my nation. In my very own self, I am part of my family.

D. H. Lawrence (cited in Beck, 1980, p. 790)

UNIVERSITY of ALBERTA

DELINEATING THE PROCESS OF NURSING SUPPORT WITH FAMILY MEMBERS OF THE CRITICALLY ILL ADULT

By

Virginia Vandall-Walker ©

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in partial fulfillment of the requirements for
the degree of Doctor of Philosophy

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DEDICATION

This dissertation is humbly and lovingly dedicated to the memory of my parents, Professor Paul Ernest Vandall and Eleanore Mary Grantier Vandall who together, instilled in me a thirst for knowledge, an intense independence, a relentless spirit of inquiry, a compulsion for adventure and risk-taking, and a determination to persevere against all odds.

Additionally, I wish to dedicate this thesis to those resilient and loving family members who were unswervingly present at the bedside of their ill relatives and who so graciously agreed to take part in this study. They were a source of inspiration for me, and at times, their pain was a source of deep sorrow. Ultimately, they are the reason why this dissertation had to be written.

ABSTRACT

Critical illness constitutes a crisis for both the patient and family. Research about family members of the critically ill adult has identified their perceived needs, explored their overall experiences, and investigated interventions. However, there is a lack of knowledge regarding the process nurses are involved in to support family members. The purpose of this study was to delineate the process of nursing support from the perspective of family members. A grounded theory was developed from 27 taped interviews with 20 individuals from 14 families. Results indicate that family members are initiated into a cycle of '*work*' in an effort to meet their perceived responsibilities in order to '*get through*' the experience. Their '*work*' was interpreted to be analogous to '*carrying a heavy load*'. When family members perceive that nurses engage in the process of *LIGHTENING OUR LOAD*, which involves three interconnected and cyclical phases, the negative effects of the critical care experience is mitigated. In the first phase, *ENGAGING WITH US*, nurses begins to develop relationships with the family by *Letting Us In*, *Getting Acquainted With Us*, and *Respecting Us*. During the second phase nurses are *SUSTAINING US* for the duration of the critical care experience by *Reassuring Us*, *Involving Us*, and *Advocating For Us*. The third phase, *DISENGAGING FROM US,* includes nurses *Facilitating Us Moving On* and *Easing Our Departure* in response to the transitions involved in the experience. No research has yet identified the '*work*' of family members of critically ill adult patients, the steps taken to gain the respect and acceptance of nurses, and the significance to family members of nurses *Welcoming us* and *Saying goodbye*. *LIGHTENING OUR LOAD* extends the understanding of nursing support beyond current theories of family needs, caring, comfort, supportive care, social support, and professional support.

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CHAPTER 1

INTRODUCTION

During times of stress, family members assume the responsibility to support and comfort their members. However, when events necessitate a family member's admission to a critical care unit, the family and patient yield responsibility for the physical well-being of the patient to professionals (Heater, 1985; Krapohl, 1995; McClowry, 1992). Notwithstanding, it is documented that family remain very significant in supporting emotional well-being (Geary, Tringali, & George, 1997; Hickey & Lewandowski, 1988; Hupcey & Zimmerman, 2000; Kirchhoff, Pugh, Calame, & Reynolds, 1993; Simpson, 1991; Simpson et al., 1996), and physiological well-being (Kupferschmid, Briones, & Dawson, 1991) of the patient. Patient length-of-stay has also been shown to decrease when family members are involved with the patient (Heater). Indeed family has been considered crucial to patient survival (Cobb, 1976; Medina, 2005). Further, morbidity in family members increased with critical care hospitalization of a relative in terms of physical (LaMontagne, Hepworth, Johnson, & Deshpande, 1994) and psychological symptoms (Perez-San Gregorio, Blanco-Picabia, Dominguez-Roldan, Sanchez, & Nunez-Roldan, 1992). However these symptoms were mitigated by family members' perceptions that nurses helped them meet their needs for information, proximity, support, and assurance (Dorn, 1989). As a result, critical care professionals have increasingly come to realize the interrelatedness of family and patient (Hodovanic, Reardon, Reese, & Hedges, 1984; Olsen, 1970; O'Malley et al., 1991). Caring for the critical care patient not only requires an understanding and appreciation of the patient's family (Doherty, 1985; Feetham, 1984; Hymovich, 1974), and possibly consideration of the family as the unit of care (Bozett, 1987; Fleury & Moore, 1999), but as well, consideration of family members as partners in the care of the patient (Hupcey, 1998b). Families are not just visitors (Molter, 1994). In fact, family members are usually those with whom critical care nurses first communicate (Gavaghan & Carroll, 2002; Hupcey). "When nurses and families work in partnership, patients, families, and nurses all benefit" (Hupcey, p. 180).

In their Illness Constellation Model, Morse and Johnson (1991) labeled the crisis point in the illness trajectory, the "Stage of Disruption" and Leske (1992c) in turn called this the period of "Certain Uncertainty", during which family members of the critically ill hover, become vigilant, suffer with the patient, and assume additional roles. A pervading sense of powerlessness and lack of control augments family member uncertainty. Anxiety mounts and can become debilitating. Many nursing studies have demonstrated the negative effects of the critical care experience on family members and on the family as a whole (Breu & Dracup, 1978; Johnson et al., 1995; Kupferschmid et al., 1991). These effects can last long past the acute stage (Artinian, 1989; Breu & Dracup; Cohen, Craft, & Titler, 1988; Daley, 1984; Dhooper, 1983; Titler, Cohen, & Craft, 1991). Feelings of helplessness and hopelessness have been demonstrated to be associated with suppression of the family member's immune system (Shelby, Sullivan, Groussman, Gray, & Saffle, 1992; Stewart, 1993); family members being unable to provide emotional support to their critically ill relative (Krantz, 1980); feelings of intense emotional distress (Hilbert, 1996); and a diagnosis of post-traumatic stress disorder after the relative's death or discharge (Azoulay et al., 2005). Therefore family members of the critically ill adult are in need of support. However, what constitutes this support from nurses?

Historically, it has been assumed that providing support to patients is an essential component of nursing practice (Gardner, 1979). More recently this assumption has been broadened to include supporting the patient's family as well (Bozett, 1987; Ellers, 1993; Henderson, 1980, 1997). Indeed, nursing support is considered by some to be fundamental to the practice of nursing (Davies & Oberle, 1990; Millar, 1989; Oberle & Davies, 1992; Wheeler & Gardner, 1987). Despite this, a review of the literature revealed that the concept of nursing support has received minimal attention. As well, the root term *support* has been loosely, imprecisely, and contradictorily referred to in the nursing literature. In addition, nursing support is enmeshed with the concepts of care and social support (Gardner & Wheeler, 1987; Hupcey & Morse, 1997; Oberle & Davies). When defined as a form of social support, nursing support has been demonstrated to be essential to helping family members of critically ill adults (Caine, 1991; Heater, 1985; Johnson et al., 1999; Krapohl, 1995; Kupferschmid et al., 1991; McShane, 1991). Nonetheless, the confusion and imprecision in the use of the term *support* indicate the need to seek greater conceptual clarity.

Research with families of the critically ill adult has focussed primarily on three interactional concerns of the nurse-family-patient triad: exploring the family members' experiences; identifying family members' needs, assessing if needs have been met and as a result, family members' satisfaction with care; and evaluating nurse interventions on behalf of family. In the area of family needs, significant quantitatively-derived knowledge has been established, based principally on the classic work of Molter (1979) who with Leske developed the Critical Care Family Needs Inventory (CCFNI©, 1983). An analysis of 27 studies using the CCFNI© suggested that there are five categories of needs perceived by family members as important: assurance, proximity, information, comfort, and support (Leske, 1992b). These categories have been further validated by Wasser and Matchett (2001b) and were included in their Critical Care Family Satisfaction Survey. Family members of the critically ill adult have consistently identified five categories of needs independent of most family demographics: assurance, proximity, information, comfort, and support (Hunsucker, Frank, & Flannery, 1999; Price, Forrester, Murphy, & Monaghan, 1991). More recently, Verhaeghe, Defloor, Van Zuuren, Duijnstee, and Grypdonck (2005) proposed an alternative categorization of these same needs: cognitive, emotional, social, and practical. Whichever way needs are categorized, a growing body of qualitative research has supported and extended the knowledge about family needs (Coulter, 1989; McGaughey & Harrison, 1994a; Rasie, 1980; Reeder, 1991; Wilkinson, 1995).

Qualitative studies have been conducted to gain an understanding of family members' experiences with critical care in terms of: (a) their response to the overall critical care situation (Chesla & Stannard, 1997; Cohen, Titler, et al., 1988; Jamerson et al., 1996; Johnson et al., 1995; Kleiber et al., 1994; Leavitt, 1990; McRae & Chapman, 1991; Titler et al., 1991); (b) their perceptions of nurse caring behaviours (Rosenthal, 1992; Warren, 1994); and (c) their identification of nurse supportive behaviours (Kleiber, 1995) or nurse helping behaviours (Johnson et al., 1999). In particular, anxiety and stress experienced by family members, and the coping mechanisms they employ to alleviate stress, have been investigated (Artinian, 1989; Caplin & Sexton, 1988; Coulter, 1989; Jamerson et al.; Leavitt; Nyamathi, Jacoby, Constancia, & Ruvevich, 1992; Twibell, 1998).

Additionally, intervention research has been conducted which has addressed: (a) family assessment (Lynn-McHale & Smith, 1991); (b) family member visiting (Clarke, 2000; Friesmuth, 1986; Henneman, McKenzie, & Dewa, 1992; Krapohl, 1995; Simpson et al., 1996); (c) informational support for family members (Bunn & Clarke, 1979; Chavez & Faber, 1987; Cray, 1989; Giuliano, Giuliano, Bloniasz, Quirk, & Wood, 2000; Lopez-Fagin, 1995); (d) emotional support for family members (Bunn and Clarke; Holub, Eklund, & Keenan, 1975; Thompson, 1989); and (e) volunteers in the waiting room to help families meet their needs (Appleyard et al., 2000).

Despite this body of research to inform nurses about family members and the critical illness of a relative, other studies have identified a disparity between critical care nurses' and family members' perceptions. Cohen, Titler, et al. (1988) noted that the nurse interviewed in their case study had minimal appreciation of the family members' appraisal of the critical care event as earth-shattering, and as a result family members' fears led to silence between themselves and the nurse. Further, nurses rated the importance of specific family member needs differently from family members (Forrester, Murphy, Price, & Monahan, 1990; Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Kleinpell & Powers, 1992; Lynn-McHale & Bellinger, 1988; O'Malley et al., 1991), being accurate only half the time (Forrester et al.; Jacono et al.). Differences existed as well between nurses' and physicians' perceptions of the needs of families dealing with critical care (Takman & Severinsson, 2005). While family members most frequently identified critical care nurses as the individuals they looked to for support, the majority of nurses reported not feeling adequately prepared to provide support to family members (Curry, 1995; Hickey & Lewandowski, 1988), beyond providing information and explanations (Fox & Jeffrey, 1997). Indeed, they perceived that it was their responsibility to restrict visiting and family member involvement in care, despite evidence challenging this perception (Heater, 1985). In light of this disparity, it comes as no surprise, that when family members look to healthcare providers to augment their indigenous supports so that their ability to support the ill person is not depleted, their expectations are frequently unmet (Chesla & Stannard, 1997; Halm, 1990; Leske, 1992a; Mathis, 1984; Mendonca & Warren, 1998; Waters, 1999), and they report dissatisfaction with care (Auerbach et al., 2005; Eagleton & Goldman, 1997; Heyland et al., 2002; Leske & Pelczynski, 1999;

Malacrida, Bettelini, Degrate, Martinez, & Badia, 1998; Ramsey, Cathelyn, Gugliotta, & Glenn, 1999).

Nursing support most accurately corresponds with what it is that nurses do or should do, to help family members of the critically ill adult (Curry, 1995; Davies & Oberle, 1990; Kleiber et al., 1994; Millar, 1989; Oberle & Davies, 1992; Waters, 1999). Nonetheless, nursing support for these family members has been identified as a random and inconsistent occurrence, dependent upon such factors as the nurse's time, knowledge, experience, personality, attitude (Chesla, 1996; Chesla & Stannard; Murphy et al., 1992; Fox & Jeffrey, 1997; Rodgers, 1983), and affinity to the family (Hickey & Lewandowski, 1988). Additionally, Mandel (1981) has suggested that when nurses do not know how to be helpful, they experience confusion and feel frustrated. To date, no theoretical or empirically- based descriptions of the process that critical care nurses engage in which results in family members identifying that they are supported, have been proposed.

Purpose of the Study

The purpose of this study was to delineate the process of nursing support for families of critically ill adults, from family members' perspectives. The theoretical process was generated from an interpretation of the data provided by family member participants during the critical illness of an adult relative, within the context of a Western Canadian critical care hospital environment. The central question guiding this study was:

> *How do family members of the critically ill adult describe and explain nursing support for themselves and their family unit?*

Additional guiding questions included:

> *What do family members describe as helpful to them in dealing with the critical care experience?*
>
> *Do family members voluntarily use the term "support" to describe what was helpful?*
>
> *What do family members describe as unhelpful to them in dealing with the critical care experience?*
>
> *Who and what was most often regarded as being helpful and unhelpful?*

Over time, were there changes in family members' expectations and therefore changes in their perceptions of what was helpful and unhelpful in dealing with the critical care situation?

Significance of the Study

Over 15 years ago, three nurse scholars called for the humanizing of critical care nursing practice: Heater (1985) basing her arguments on research and the premise that the right to treat was a privilege granted by the patient and the family; Mathis (1984) who suggested that were professional nurses to meet the perceived needs of family members during the acute phase of illness, through interventions to reduce uncertainty and promote control, family adaptive coping and patient recovery might well be enhanced; and Millar (1989), who posited that the family's response to the critical care experience often hinged on the nursing support they received. In the intervening years since Heater's, Mathis', and Millar's comments, there has been considerable research with family members in critical care directed at identifying their needs and whether they have been met, from both the nurse and family perspective, and determining family members' satisfaction with the care provided. Family members' experiences have been explored and interventions to meet their perceived needs have been investigated (Leske, 1992a, 1992b). Some researchers have subsumed the helpful actions and behaviours of nurses with families of the critically ill under the broad label of nursing support (Curry, 1995; Gardner, 1978; Kleiber et al., 1994; Paladichuk, 1998; Waters, 1999), but have not adequately clarified what constitutes nursing support, referred to by Millar 17 years ago. This study investigated the process of nursing support for families of critically ill adults from family members' perspectives. Identification of this process may serve as one framework to guide critical care nurses in their practice with family members and could potentially influence the development and testing of interventions to promote the health and well-being of individual family members. Thus supported, family members might then be better positioned to collaborate with critical care staff to effectively provide support to the patient in either recovering or dying. Consequently, as Mathis suggested so many years ago, the family unit as a whole might benefit.

CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of this literature review is to demonstrate the importance of the current study and to provide preliminary background to aid in interpreting the findings (Strauss & Corbin, 1998). This review reveals on the one hand, that family members require nursing support when an adult family member is critically ill, but on the other hand, that few researchers have explored family members' perceptions of what constitutes nursing support. Taken as a whole, nursing support is inadequately explicated for any population, and suffers from a lack of conceptual clarification, enmeshed as it is with the concept of social support. There is research about what family members of the critically ill adult need, but not about how their needs can be met from their perspective: about what they have experienced, but little about how nurses provide support from the family's perspective. Consequently, no theoretical or research literature specifically addresses the question that drives the current study.

In this chapter, first, a dictionary definition of *support* is provided, followed by an overview of how the term *support* has been used in nursing literature. This includes a discussion about supportive care and nursing support with both critical and non-critical care populations. Then, the concept of social support is explored as well as the related concepts of professional support, objective support, surrogate support, and formal support. Next, literature addressing the experiences of family members of the critically ill adult is presented, followed by research about family members' perceived needs and their satisfaction with the care they have received. Intervention studies with these family members are then discussed. Finally, the ambiguity that prevents a clear understanding of what constitutes nursing support for family members of the critically ill adult is highlighted.

Dictionary Definition of Support

According to *Webster's New World Dictionary* (Neufeldt & Guralnik, 1991), the term *support* is derived from the Latin *sub* meaning *under* and *portare*, meaning *to carry,* and is defined as follows:

> *To carry or bear from underneath; bearing up or upholding; to keep from falling or sinking; to give courage, faith, or confidence to; to help or comfort; to give approval to or be in favor of; to maintain or provide for with money; to maintain, sustain; to hold up or serve as a foundation or prop for; to promote the interest or cause of; to advocate (p. 1345).*

This definition implies one-way help, rather than reciprocal help. It is interesting to note that synonyms such as "assist" and "aid" imply different hierarchical roles. The provider of *aid* is in a primary or superior role. The provider of *assistance* is in a secondary or subordinate role (Neufeldt & Guralnik).

Support in Nursing

A dominant theory of support in nursing has not yet been determined (Wheeler & Gardner, 1987; Hupcey, 1998a). However, the significance of the concept of support in nursing is reflected in the pervasive use of this term and concept in the nursing literature, either literally or by implication, beginning with Florence Nightingale. In her writings, Nightingale implied that the provision of psychological, informational, and social support were important aspects of nursing (1860). More recently, influenced by Maslow's (1968) theory about a hierarchy of needs, Henderson (1997) suggested the following definition of nursing:

> *The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or to its recovery (or to a peaceful death) that the person would perform unaided given the necessary strength, will, or knowledge (p. 22).*

The current focus on providing nursing care that is holistic and contextual includes family members as well as the ill individual, as necessary recipients of care. This shift in focus influenced Henderson (1980, 1997) to expand her definition of nursing to include health promotion activities with the family as a component of the provision of care to the individual. Henderson's definition, which formed a cornerstone of modern philosophical and theoretical understanding about professional nursing, speaks to the significance of the nurse's role in becoming involved only when there is a need or request, and only to the extent that the patient (or family) requires. Implied in Henderson's definition is a respect for the individual's strengths and capabilities. Her definition, using the key word *assistance*, a synonym of *support*, indicates that the nurse, involved with providing support, is in a secondary or subordinate role to the individual or family. The nursing interventions are therefore driven by what is important to the individual or family. Levine (1991) implied a different understanding of support. She wrote of nursing care as being either supportive or therapeutic, with supportive actions being those performed when nursing interventions cannot alter the outcome and that even the "best efforts can only maintain the status quo or fail to halt the downward course" (p. 243). Levine did not define *supportive.*

Overwhelmingly, nurse researchers, as well as nurses working with oncology patients and their families, and maternity patients, liberally use the term *support* or its derivatives. As a result, much of the research available investigating what is termed *supportive care* or *nursing support,* has focussed on these three populations: (a) oncology patients at varying stages of their illness, but predominantly towards the end-of-life when palliative care is required (Cuisinier, Van Iejk, Jonkers, & Dotker, 1986; Hanson, 1994; Hanson, McClement, & Kristjanson, 1995; Wiggers, Donovan, Redman, Sanson-Fisher, 1990); (b) the families of oncology patients (Hull, 1989; Irwin & Meier, 1973; Kerr, Harrison, Medves, & Tranmer, 2004); (c) or women during the perinatal period (Bryanton, Fraser-Davey, & Sullivan, 1994; Callister, 1993; Chang & Chen, 2000; Gale, Fothergill-Bourbonnais & Chamberlain, 2001) and initiating breastfeeding (Hong, Callister, & Schwartz, 2003). The focus of these studies attests to an understanding of support shared with Levine (1991), as consisting of interventions to be used when the outcome of the situation cannot be halted. Certainly this understanding is echoed by Cairns (2001) who identified support for patients as a goal and principle that together define the boundaries of practice for palliative care. He further identified support for the family of the dying patient before and after death, as a component in the definition proposed for palliative care. There is a significant body of research dealing with nursing support qualified by either the focus of support (e.g., breastfeeding support), or the recipient of support (e.g., parental support). As well, the literature about supportive care highlighted the fact that physicians as well, lay claim to providing supportive care, specifically at the end of life. This variation in how *support* is qualified or how it qualifies, adds to the imprecision and confusion that already exists about nursing support. As a result, for this discussion, only research that qualified support as nursing support, or care as supportive care and provided by nurses, was included.

Heslin and Bramwell (1989) explored the supportive role of the palliative care nurse, based on a definition of supportive nursing interventions for cancer patients proposed by Larson (1986). Larson's definition included management of pain and discomfort symptoms, provision of psychological support to both families and patients, and the provision of physical care. Heslin and Bramwell also included the aspect of encouraging independent function as a supportive nursing intervention. Irwin and Meier (1973) investigated families of terminally ill oncology patients identifying the following as supportive nursing behaviors: being honest, giving clear explanations and information about the patient’s condition, making the families and patients comfortable, and showing interest by answering questions. Hull (1989) conducted a review of the literature about family needs and supportive nursing behaviours during terminal cancer, and found that “families indicated their preferences for patient-centered information and the wish to focus attention away from their [the family's] emotional needs, especially when Hampe (1975) had found that spouses of the terminally ill did not expect nurses to be concerned with their difficulties but to demonstrate support by being courteous and friendly.

Supportive care was defined globally by Fitch (1994) as the provision of necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment and follow-up phases, encompassing issues of survivorship, palliative care, and bereavement. However, *supportive care* referred to in the research literature is seldom clearly defined. Supportive care for postoperative mastectomy patients was discussed by Lierman (1982) based on data from nurses, as consisting of the supportive actions of teaching, presencing, empathy, reassurance, encouragement, trust, and confidence. Thijs-Boer, de Kruif, and van de Wiel (1999) investigated nurses' perceptions of their involvement in the supportive care of newly diagnosed breast cancer patients in Holland. *Specialized nursing support* was identified as a criterion of optimal nursing care and resulted when nurses with postgraduate training systematically supported patients in terms of providing *emotional support*, and *educational support,* as well as interventional (physical) care. Davies and Oberle (1990) proposed the Supportive Care Model based on the care provided to oncology patients as reported by an expert nurse. Dimensions of the supportive care role that focussed on promoting patient adaptation and coping were explored and were determined to be: "valuing" as a contextual dimension, "connecting", "doing for", "empowering", and "finding meaning" as action dimensions; and "preserving integrity" as the core concept. This study is to date, the only one identified that goes beyond description to address the theoretical components of support from the perspective of the nurse. Most recently, Kerr et al. (2004) conducted a systematic review of 45 studies investigating the supportive care needs of parents of children with cancer. Kerr et al. defined supportive care according to Fitch (1994), who characterized supportive care as the necessary services defined by those living with or affected by cancer to meet their emotional, spiritual, psychosocial, informational, practical, and physical needs throughout the course of their disease. Kerr et al. listed the need categories hierarchically, according to the number of times each was cited in their review, beginning with informational needs as the most reported, followed by emotional, psychosocial, practical, spiritual, and finally, physical needs, as the least reported.

Callister (1993) analyzed interview data from new mothers. These women described nursing support as involving the nurse providing reassurance, encouragement, and comforting presence during the perinatal period. In another study, new mothers have indicated the importance of "feeling respected", "cared about as individuals" by maternity nurses, and of "reassuring touch", and "coaching" activities (Bryanton et al., 1994). Chang & Chen (2000) surveyed 117 mothers' about their perceptions of nursing support during labour and delivery. These mothers indicated that nursing support was very helpful in coping with the stress of labour and consisted of the nurses providing informational and emotional support. Gale et al. (2001) measured the provision of nursing support to women during childbirth, and the factors that influenced provision of this support. The authors defined supportive care as including: physical care for comfort purposes, instructional/informational support, emotional support, and advocacy actions. Direct care involving treatments and assessments, and indirect care involving charting and meetings, were not considered supportive actions. Similarly, Hong, Callister, and Schwartz (2003) discussed nursing support for breastfeeding mothers as consisting of emotional, informational, and tangible support. Unlike Gale however, assessments and direct involvement were considered supportive.

Two studies investigated support with family members of patients in critical care. Waters (1999) identified nursing support as professional support, in the development and application of the Professional Support Questionnaire for Critical Care Nurses Working With Family Members (PSQ). All items on the questionnaire from keeping family informed, reassuring them that the patient was getting the best care, and negotiating relaxed visiting rules, to orienting the family, allowing them to provide patient care, and providing for their physical and spiritual needs, were found by respondents to be supportive to greater or lesser degrees. Helping family members meet their perceived needs was considered professional nursing support. Kleiber et al. (1994) investigated the behaviours labelled by family members as supportive over the time span of a relative's (infant to adult) critical care hospitalization. The researchers defined support as "an action perceived by family members to relieve anxiety and facilitate coping" (p. 71). Overwhelmingly friends were considered the primary providers of support, with nurses considered the second most frequent source of support. Nine themes of general supportive nursing behaviours were identified: "a caring attitude" (including concern, helpfulness, friendliness, understanding, positive attitude, and reassurance), "truthful and understandable information", "presence", "communication", "assistance", "comfort measures", "empathy", "spirituality", and "distraction".

Thus the literature about support in nursing indicates the relative confusion that exists in how the term *support* and its derivatives are defined and explained. With one notable exception, there has been a significant shift since the 1970s in the identification of nursing support and supportive care as being comprised of components of social support, likely influenced by the ever-expanding investigation and dissemination of knowledge about social support from both social science and nursing disciplines which began in the 1980s. The significant exception is Kleiber et al.'s (1994) descriptive study of nursing support from the family's perspective. This literature review provokes the following questions: "Is supportive behaviour generic, no matter who the provider?" and "Is nursing support indeed a component of the umbrella concept of social support?" An overview of the literature about social support is warranted, in order to further situate the current knowledge relating to nursing support.

Social Support

The following is an overview of the most central, historical, and current knowledge about social support, including psychological and emotional support, and the various related terms of objective social support, professional support, surrogate support, and formal support.

Social support has been defined by Norbeck (1981) as mutual assistance that is not restricted by time and situation and that is exchanged among persons who have a social connection such as family, friends, neighbors, colleagues, and self-help groups. Gottlieb (1983) expanded on this definition: social support is “verbal and/or non-verbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence, and has beneficial emotional and behavioural effects on the recipient” (pp. 28-29). Shumaker and Brownell’s (1984) definition included reciprocity in terms of the exchange of resources as an integral component of social support. This exchange (i.e., reciprocity) was believed to effectively enhance the well-being of the recipients of social support. In the absence of reciprocity, both the provider and recipient are disadvantaged, and the imbalance in exchange threatens the relationship, and thus the provision of support. Langford, Bowsher, Maloney, and Lillis (1997) presented a concept analysis of social support based on their review of the literature. In this analysis, they identified emotional, instrumental, informational, and appraisal support as the defining attributes of social support. They also noted that reciprocity must be present for social support to continue. These defining attributes occur in the presence of antecedents (social network, social embeddedness, and social climate) and correlational research has indicated that social support is associated with positive health and well-being, possibly as a result of a perception of increased control.

If one adopts any of these definitions, then nurses are excluded from providing social support for several reasons: because mutual assistance and social connection are not foundational to the nurse/patient relationship (Lenrow & Burch, 1981; Norbeck); because nurses are not considered social intimates (Gottlieb, 1983); and because nurses do not enter into the provision of nursing care in expectation of reciprocity (Shumaker & Brownell; Langford et al., 1997). Additionally, Hupcey (1998a) completed an extensive review of the social support literature to analyze and clarify the concept. She proposed the following definition of social support: "a well-intentioned action that is given willingly to a person with whom there is a personal relationship and that produces an immediate or delayed positive response in the recipient" (p. 313). Depending on how a *personal relationship* is defined, this definition clearly removes the professional from the sphere of providers of social support. The exclusion of the nurse as a provider of social support, is further supported by Hupcey and Morse (1997), and Grossman (1995). Hupcey and Morse's (1997) review of the literature indicated that social support recipients consistently identified family members and close friends and not professionals, as the providers of social support. Based on reports from 39 critically injured patients and family members, Grossman identified social support providers as only the extended family and friends. The definition of social support that informed Grossman's study was that of Gottlieb, previously mentioned, in which nurses were not seen to be social intimates, and therefore not providers of social support.

Conceptions about social support differing significantly from those just presented have been proposed by a number of authors. Greene, Adelman, and Majerovitz's (1996) consideration of social support between physicians and older patients raises a number of points. These authors discussed both the asymmetry of power in the relationship and the social support that the patients provided the physicians, and in so doing, raised the possibility of reciprocity and the influence of power inequality on that relationship. Laireiter and Baumann's (1993) comprehensive review of social support studies, highlighted a number of points: (a) not all individuals find every supportive action helpful; (b) in times of crisis, individuals who have knowledge of the situation (such as professionals) become more significant providers of social support; (c) in everyday community life, professionals are considered less significant providers of social support than in clinical settings; (d) at times of crisis, the core support system is less effective; and (e) patients found nurses to be the most important supporters for meeting psychological and instrumental needs. Based on a subsequent review, Stewart et al. (1997) defined social support as "interactions with family members, friends, peers, and health professionals that communicate information, esteem, aid, or emotional help" (p. 85), a definition which excludes social intimacy, reciprocity, and exchange of resources as requirements, and which is in alignment with Laireiter and Baumann's review. Stewart et al.'s broad definition of social support can therefore include nursing support as one expression of social support. Although this definition may provide a basis for further exploring nursing support it may as well muddle the understanding of both nursing support and social support. Earlier, Rook and Dooley (1985) had cautioned, "social support achieved through [professional] interventions should not be assumed to be equivalent in its form or effects to social support normally available from one's family and friends" (p. 10). This raises the question of whether, in times of crisis such as in the case of the critical illness of a relative, the nature of the support family members receive changes from predominantly *social* to *nursing*.

Some authors refer to specific categories or forms of social support, such as *psychological* or *emotional* support. One of these, Cobb (1976), defined psychological support as a component of social support and as a process in which a person is assured that he or she is cared for, loved, valued, esteemed, worthy, and part of a common network of mutual obligation. Hanson (1994) and Hanson et al. (1995) identified the provision of psychological support as a significant activity performed by nurses with oncology patients, but this support was not defined. In Kristjanson's (1996) study, the provision of emotional support by nurses to family members of terminally ill patients was identified as important for over half of the family member participants. Again, psychological support was not defined.

Professional Support / Objective Support / Surrogate Support/ Formal Support

The distinction among the definitions of professional support and the related concepts of objective, surrogate, and formal support, are blurred. As well, the terms are frequently used interchangeably, and are loosely and variously defined in the literature.

House (1981) argued that each of the four categories in his definition of social support, i.e., emotional, appraisal, informational, and instrumental support, can be viewed in a matrix, vis-à-vis the source (informal or formal), the context (general versus problem-focussed), and the perception (objective versus subjective). Under the label of *formal* support, he discussed social support provided by professionals and self-help groups. Norbeck (1988) expanded on this definition, noting that *professional* support (sometimes referred to as direct, objective, formal, or surrogate support) exists within the context of the professional relationship involved in a health care situation, and ends when the professional service is no longer required. It is not reciprocal. This support is primarily solicited during a crisis when the usual providers of social support prove inadequate to sustain the family, either because of unavailability, lack of knowledge of the situation, or the family's inability or reluctance to discuss their concerns (Woolley, 1990). The professional support required is of high intensity, relatively short duration, and is primarily informational, instrumental, and emotional or psychological. On the other hand, Hinds and Moyer (1997) defined professional support as being primarily informational. McNiven, Hodnett, and O'Brian-Pallas (1992) identified four dimensions of professional support given to patients during the intrapartum period: emotional, informational, tangible, and advocacy. Physical comfort measures were considered indicative of the tangible dimension.

A more recent study reported on the development of the Nurse-Parent Support Tool, designed to measure parents' perceptions of nursing support provided to them during their child's hospitalization (Miles, Carlson, & Brunssen, 1999). This tool is based on a conceptual definition of nursing support (adapted from House and Khan's 1985 definition of social support) as professional support. The main components assessed were: (a) ongoing communication; (b) emotional support to deal with the situation; (c) esteem support for their parental role; and (d) caregiving support in terms of their perceptions of the quality of care their child was receiving. As previously mentioned, Waters (1999) identified nursing support as professional support (citing Norbeck, 1988) in the development and application of the PSQ. She did not define either nursing support or professional support. Kupferschmid et al. (1991) discussed critical care nurses' support for families and patients as *objective* social support, frequently necessary because of hospitalization. Objective social support is not defined but the authors state that it does include five dimensions of assistance: emotional, informational, instrumental, spiritual, and appraisal.

Stewart (1989; 1993) and Stewart et al. (1997) followed the lead of Norbeck (1988) in labeling the support provided by nurses during periods of crisis or transition to enhance the patient's informal social support, as *surrogate* social support. On the other hand, *formal* support was the label provided to the social support rendered to individuals who accessed professionals for their specialized knowledge from time to time (Stewart, 1993). Hupcey and Morse (1997) posed the question: "Can a professional relationship be considered social support?" They argued that due to the differing natures of the relationship between the provider and recipient of support, there are significant differences between social and professional support. Social support focuses on the assistance provided by individuals who are part of one's social network, which professionals generally are not.

As the preceding discussion indicates, *support* is a term used frequently in the nursing literature, as a verb and adverb in terms of the nurse demonstrating support, or supporting the patient; as an adjective combined with nouns such as in supportive care, supportive behaviours, and supportive actions; or as a noun, as with nursing support. Many authors have subsumed all categories of support under the primary label of *social support* regardless of the provider (Lairetier & Baumann, 1993; Stewart et al., 1997). However, many definitions provided for *social support* include dimensions that do not apply to the support that nurses provide (Gottlieb, 1983; Hupcey, 1998a; Hupcey & Morse, 1997; Langford et al., 1997; Lenrow & Burch, 1981; Norbeck, 1981; Shumaker & Brownell, 1984). More than 15 years ago, Gardner and Wheeler (1987) had discussed the vague and inconsistent definitions of social support, arguing that support provided by nurses should be studied separately from social support even though there are conceptual similarities. Kleiber et al.'s (1994) research identifying supportive nursing behaviours identified by critical care family members, represents one such study that adds to our understanding of nursing support from the recipient's perspective.

Family Members and the Critical Illness of an Adult Relative

Since the late 1970s, a growing body of literature has evolved about family members experiencing an adult relative's critical care hospitalization, as nurses have increasingly come to appreciate the interdependence of the family and patient, and that care of the patient includes care of family (Artinian, 1991; Doherty, 1985; Fleury & Moore, 1999; Hymovich, 1974; Kupferschmid et al., 1991). Research cited spans the spectrum from: (a) exploring the experiences of family members of the critically ill adult to; (b) identifying family member needs as perceived by both family members and health professionals; (c) ascertaining whether or not these needs were met and the family member was satisfied with the care received; and to (d) investigating nursing interventions with family members.

The Critical Care Experience of Family Members

Over the last three decades, a number of researchers have chosen to focus their research efforts on exploring family members' experiences with critical care, in an attempt to understand the experience in general, family members' stress appraisal and coping responses, and how family member roles are influenced. Many of the studies reviewed were longitudinal, extending into the post-critical care period, and most used qualitative approaches. Research focussing on specific aspects of the experience, such as end-of-life decision-making, organ donation, and death, are not included in this discussion.

As posited by Wright and Leahey (1987), a family member's beliefs about the critical illness or injury of a relative, influences how the illness impacts both the family member and the patient. Beliefs may be about the cause of the illness/injury, the treatment, and/or the outcomes. Wright and Leahey suggested that, "families are powerfully attached to their beliefs, and display more commitment to beliefs about life-threatening illness...because grave illness confronts beliefs about mortality"(p. 49). As a result, the learned and shared belief system can significantly influence the family member's choice of coping patterns and his or her physical and behavioural reactions (Wright & Bell, 1981). Reeder (1991) noted that family members of seriously injured adults described how they felt using words such as hurt, sad, afraid, worried, devastated, and shocked. She noted that nurses needed to be aware of the family member's perception of the event in order to plan appropriate interventions. Thematic content analysis of diaries kept by family members during their relative's critical care admission revealed the broad range of positive and negative emotions experienced by them. Anger, fear, worry, and exhaustion were dominant during the first 24 hours of admission. Feelings alternated between despair and joy depending on the patient condition, a veritable roller coaster of emotional turmoil. Similarly, Titler et al. (1991) indicated that in response to the critical care experience, family members' feelings were predominantly fear, vulnerability, and uncertainty.

Research about the family response to the critical cardiac illness situation has focussed on: (a) understanding the stress and anxiety of wives experiencing their spouses' cardiac illness (Caplin & Sexton, 1988; Dhooper, 1983; Harding & Morefield, 1976; Hentinen, 1983; Mayou, Foster, & Williamson, 1978; Skelton & Dominian, 1973); and (b) the comparisons made between patients and their spouses in terms of emotional distress and family functioning (Hilbert, 1994, 1996). Headaches, crying, and disturbances in sleep, appetite, and energy, were frequently reported symptoms. In two studies, Mayou et al. (England), and Dhooper (United States) reported that the logistics of visiting, increased responsibilities, and depleting finances were practical problems faced by wives. Seeing their spouse ill, dealing with their spouses' reaction to the diagnosis, trying not to upset their spouse, not being informed of changes in their spouse's condition (Caplin & Sexton), and dealing with the possibility of death (Caplin & Sexton; Harding & Morefield) were all sources of stress for spouses. Investigations of spousal response to their relative's critical care hospitalization for a myocardial infarction (MI) resulted in reports of feelings of distress, numbness, panic and unreality, followed by loss, depression, and at times guilt - all common during the acute stage (Dhooper; Hentinen; Mayou et al.; Skelton & Dominian). Cohen, Craft, et al. (1988) and Dhooper identified an all-pervasive feeling of fear, which subsequently led to the inability of family members to talk about the fear; instead they resorted to silence. Family members experienced intense emotions such as anger, shock, disbelief, fear, anger, and helplessness, all of which were not readily communicated.

Stress and anxiety experienced by family members of general systems intensive care unit (ICU) patients have been investigated (Cohen, Titler, et al., 1988; Halm et al., 1993; Jamerson et al., 1996; Koller, 1991; Potter, 1979; Rukholm, Bailey, & Coutu-Wakulczyk, 1991, 1992; Speedling, 1980; Titler et al., 1991). Results identified the uncertainty of the prognosis, waiting, the lack of privacy, not feeling useful in performing tasks for the patient, and factors threatening changes in family roles and responsibilities, as potential sources of stress. Sleeping and eating habits were altered, and somatic symptoms developed in some family members. Demographics, visitation policies and practices, and type of adult ICU did not influence the perception of stress. Halm et al. noted that family members reported higher levels of stress at Day 1 than at Day 28 and that sleeping, eating, and energy disturbances were common. Titler et al. (1991) in their phenomenological study of family members noted that the critical care hospitalization of their relative was perceived as an overriding threat, resulting in communication problems within the family, the need to protect children from painful information, disruption in home routines, changes in relationships, and role conflict.

Research suggests that in response to the stress, family members also mobilize internal resources to allay anxiety and to mitigate the impact of the critical care experience, as they strive to regain a measure of equilibrium. In an exploratory study by Geary (1979), intellectualization, repetition, acting strong, and remaining near the patient, were identified as the most common coping mechanisms used by family members of patients who had experienced a MI. Dhooper (1983) found that spouses reported smoking, overeating, passive acceptance, praying, talking to others about feelings, and seeking medical information and reassurance from the physician and others about the patient's prognosis, as helpful coping mechanisms. Increased use of alcohol and medications by family members has been reported as well (Halm et al., 1993). Koller (1991) found hoping, talking problems over, thinking positively, praying, and worrying, to be the most frequently reported coping mechanisms employed by respondents to deal with the stress. Of the eight possible coping styles, optimistic and confronting coping styles were most frequently used and reported to be the most effective. Qualitative data revealed that families viewed factors such as allowing frequent visits, providing information and emotional support, and demonstrating competence and a friendly manner, as helpful for coping. Although not reported as coping mechanisms, Jamerson et al. (1996) in their qualitative study previously cited, identified constellations of behavior exhibited by families attempting to meet their needs: "hovering", "information seeking", "tracking", and "garnering of resources".

Family members' personal characteristics appear to be important in influencing their responses to critical illness. Nyamathi, Jacoby, Constancia, and Ruvevich (1992) determined that there was a significant positive relationship between positive personality factors and problem-focussed coping, and between negative personality factors, emotion-focussed coping, and emotional and physical distress. Leske and Jiricka (1998) examined the influence of family members' stress and strengths on family member adaptation outcomes based on the Resiliency Model of Family Stress. Results indicated that family members' stress accounted for 40% of the variance in reports of family member well-being, and that family member strengths accounted for 45% of the variance in reports of satisfaction with family member adaptation. Problem-solving communication was found to be the most significant variable influencing positive family member outcomes. These results promote a greater awareness and understanding of the range of responses family members can have to the stress of the critical illness of an adult relative, and of the additional factors that can contribute both positively and negatively to these responses.

The overall experience of the critical care hospitalization has been investigated by a number of researchers. Through grounded theory analysis, Leavitt (1990) explored the family's experience of critical care hospitalization. The core category identified was "containment", and included constructed meanings for events as well as behavioral responses. "Containment" was defined as the “major and pervasive family coping pattern by which families regulated the impact of the crisis of diagnosis and surgery and worked to limit the distress of family disruption” (p. 487). The family narrowly defined the problem in terms of the surgical repair as a cure rather than as a palliative intervention, and the care providers who focussed on the patient care supported this definition. In a very similar grounded theory study with spouses of cardiovascular surgery patients, McRae and Chapman (1991) identified "holding death at bay" as the core concept, comprised of the three categories of "uncertainty", "helping commitment", and "reorganization". One subcategory dealt with the following coping strategies: "seeking information", "keeping busy", "focussing on the present", "keeping a positive outlook", and "crying for emotional relief". Plowfield (1999) examined 12 families' experiences with waiting during the initial period of their relative's admission to a neurological ICU. The themes of "uncertainty" and "searching for meaning" permeated their experience during this period. Uncertainty included "altered time", "loss of control", and "stress responses" as sub-themes. Sub-themes of "searching for meaning" were "learning the rules", "gaining control", "patients' worth", and "hope".

The aspect of families visiting based on wanting to be with the patient has been specifically addressed as well. Through microanalysis of participant observations and interviews, Speedling (1980) found that the separation of the patient from family members on admission caused a rent in “the family’s social fabric, and [resulted in] an assignment of individuals needing help to passive, dependent roles. The net effect was to create a barrier between patient and family, making visiting a source of threat rather than a source of comfort” (p. 13). This perception of visiting as a source of threat, resulted from the restrictive visiting practices family members had to either challenge, or appear to accept. Either response was stressful. Speedling further observed that family members experienced the ICU as a world unto itself, with little connection to the rest of the hospital. Clarke (1995) used grounded theory methods to investigate the process family members move through during visits to the ICU. Four stages were identified: "getting into the unit", "getting past fears and anxieties", "attempting communication with the patient", and "being there with the patient". The patient’s condition and the family’s reaction influenced the family's passage through these stages. Clarke noted that nurses could mitigate all family member responses to the situation and their passage through the stages. Clarke's grounded theory of the family's perspective about visiting represents a significant addition to the extant knowledge about the family member's experience with the critical illness of a relative. However, it does not address family members' perceptions about the process nurses engage in to mitigate the family response.

Needs of Family Members

Hampe (1975), Dracup and Breu (1978), and Molter (1979) were among the first nurse researchers to determine that families of seriously ill adults identified needs that nurses could address. These studies constituted a move away from the traditional focus on the needs of the patient, suggesting that the "family members [were] also patients" (Hampe, p. 119). The largest cluster of research about family members of the critically ill adult has been quantitative, investigating their perceived needs based on Molter's (1979) 45-item questionnaire, and Molter and Leske's (1983) 30-item questionnaire, the Critical Care Family Needs Inventory (CCFNI©). The CCFNI© has become the standard used, either in its original form, or adapted, modified, and administered to suit the particular research situation. Other studies used instruments developed by the researchers (Dockter et al., 1988; Dyer, 1991; Liddle, 1988; McGaughey & Harrison, 1994b). Despite unreported validity and reliability of these non-CCFNI© tools, the results from all studies corresponded with the categories suggested by Leske (1992b) who performed an analysis of the raw data gathered from 27 studies using the CCFNI©. Responses to each of the 45 needs statements were collapsed into five needs categories based on recurring or major themes, and are presented in order of reported importance: assurance (7 items), proximity (9 items), information (8 items), comfort (6 items), and support (15 items).

Psychometric properties of the CCFNI© were reported by Molter (1979), Molter and Leske (1983), Leske (1991), and Macey and Bouman (1991). Readability was at the 9th grade. Reliability (Cronbach's alpha of .85 -.98) and validity (expert panel) have been reported frequently by researchers using this tool or adaptations of it (Norris & Grove, 1986) or translations (Al-Hassan, & Hweidi (2004); Bijttebier et al., 2000; Coutu-Wakulczyk & Chartier, 1990; Fan, 1996; Lee, Chien, & Mackenzie, 2000; Lee & Lau, 2003; Morgon & Guirardello, 2004; Ponkala, Suominen, & Leino-Kilipi, 1996; Wong, 1995; Zazpe, Margall, Otano, Perochena, & Asiain, 1997). In Australia, Burr (1998) validated the CCFNI© through methodological triangulation, finding that the qualitative data provided contextual information for the CCFNI©, and therefore a deeper understanding of the family members' needs. She noted three needs identified in her qualitative data that were not represented in the CCFNI©: (a) families expressed a need to provide reassurance and support to the patient; (b) they needed to protect themselves; and (c) they needed to protect others.

The CCFNI© has been adapted and used by nurse researchers in countries such as Australia, Canada, Brazil, China, Finland, Jordan, Hong Kong, Norway, Thailand, Holland, Belgium, and in many states of the United States. Across studies, demographic data were not found to affect the ranking of the categories of identified needs, suggesting that the most important categories of needs (Leske, 1992b) remain relatively constant across populations, relationships to the patient, settings, language, country, diagnostic groupings, socioeconomic and education levels, and between genders (Price et al., 1991). Differences reported were in the ranking of importance of individual needs, rather than the ranking of importance of the categories of needs (Bernstein, 1990; Chartier & Coutu-Wakulczyk, 1989; Fan, 1996; Forrester et al., 1990; Freichels, 1991; Hunsucker et al., 1999; Jacono et al., 1990; Kreutzer, Serio, & Bergquist, 1994; Ponkala, Suominen, & Leino-Kilipi, 1996; Wong, 1995). However, in one Canadian study, the level of anxiety experienced by family members was found to influence ranking of family needs, and reports of anxiety were found to be influenced by sex, age, and education (Chartier & Coutu-Wakulczyk). Whether needs were perceived as met was influenced by the time family could spend with the patient (Murphy et al., 1992). The stage of the critical care experience did have an influence as well on need identification, with family reporting difficulty in concentrating during the initial 24 hour period and therefore being unable to clearly identify needs (Daley, 1984). Davis-Martin (1994) found no change in need identification over a protracted length of time (2 weeks), with family reporting functioning in a "continuous crisis mode". Most previous studies had sampled family members within four days of admission. These studies attest to the influence of selected contextual aspects on family member perceptions and ranking of needs, and raise the question of whether there are other contextual influences that have yet to be investigated.

The nurse's perception of family needs has been investigated using the CCFNI©, or an adaptation of this instrument. Comparison between nurse and family-identified needs demonstrated some similarity, with differences noted primarily in ranking of need importance between families and nurses (Dockter et al., 1988; Forrester et al., 1990; Kleinpell & Powers, 1992; Lynn-McHale & Bellinger, 1988; Mi-Kuen, French, & Kai-

Kwong, 1999; Norris & Grove, 1986; O'Malley et al., 1991). Forrester et al. included confederate pairs in their study. Similar rankings between confederate pairs were found for 15 of 30 needs demonstrated. However none of these 15 needs were those considered the most important by family members in this or other studies using the CCFNI©. O'Malley et al. (1991) investigated critical care nurses' perceptions of family needs, noting that baccalaureate nursing graduates identified family needs as less important than did associate degree nurses. A study conducted in Sweden comparing nurses' and physicians' self-reported perceptions of family needs using the CCFNI©, revealed marked differences between both the nurses' and physicians' responses as well as between male and female responses, independent of the profession (Takman & Severinsson, 2005). This large number of studies using the CCFNI© has validated the initial results, extended them, and tested the limits of generalizabilty (Haller & Reynolds, 1986). However, based primarily on this quantitatively-derived list of needs, to maintain that the existing knowledge comprehensively informs nurses about both families' experiences with critical care and how best to develop interventions for them, seems both forced and limiting. To do so constrains nurses from exploring beyond the boundaries of this list of needs.

Qualitative research investigating family member needs during the critical care hospitalization of an adult relative has extended the depth of the knowledge specific to family members' needs. Rasie (1980) interviewed and surveyed 30 patients and their relatives in an ICU in the United States. Content analysis revealed three recurring themes: (a) the need to relive the incident that led to the patient's hospitalization; (b) a fear of criticizing staff, needing instead to defend the quality of care; and c) the desire for medical information and the uncertainty about receiving it. The first two themes have not been identified in the CCFNI© research (Leske, 1992b). Using grounded theory methods, Coulter (1989) interviewed 11 relatives recruited from one general systems ICU in a teaching hospital in England. Analysis revealed six categories: "experiencing shock and gaining knowledge", "finding ways to cope", "needing information", "needing social support", "satisfying personal needs", and "retaining hope". Wilkinson (1995) used grounded theory methods to analyze interview data from six relatives of ICU patients in England. Six categories of needs were identified: "dealing with the shock and fear", "access and proximity", "positive environment", "social support", "information", and "hope". The categories identified in the last two studies overlap with the 5 categories of Leske's analysis of CCFNI$^{©}$ research (assurance, proximity, information, comfort, and support), with the addition of the needs for personal requirements and to have help to cope (Coulter), and for access to the patient, and a positive environment (Wilkinson). Reeder (1991) posed three open-ended questions to 112 family members in the United States, who were experiencing the critical injury of a relative. Two of the questions elicited information about family needs. Responses corresponded with families' needs for hope, information, proximity, and support, all identified in the CCFNI$^{©}$ research (Leske). The third question elicited the impact of the individual's belief about, and perception of, the injury experience, family problems, and the effect of the injury experience on other family members. Hospital-related comments were about waiting, visiting, the physical environment, and staff. McGaughey and Harrison (1994a) conducted thematic content analysis of semi-structured interviews with dyads of preoperative patients and relatives and determined that informational needs included the need to understand the operation, visiting, physical care, and schedules. As mentioned previously, Burr (1998) used content analysis of 26 interviews as one method in a triangulation study of family needs and experience. Participants were recruited from the general systems ICUs of four teaching hospitals in Australia. She identified the following themes: "maintaining the vigil", "the network rallies", "not knowing is the worst part", "the patient takes precedence", and "protecting". The last two themes were not incorporated within the CCFNI$^{©}$ and as such, in conjunction with aspects of Rasie's (1980), Coulter's (1989) and Wilkinson's (1995) findings, attest to limitations of this instrument to "fully capture" family needs. While identifying family members' needs has been an important undertaking, this research does not address how family members can best be supported during the critical care experience.

Meeting Family Members' Needs

Over the past few decades research has been conducted which addressed both specific and general nursing actions to meet the needs of family members involved in the critical illness of an adult relative. Interventions that involve meeting family needs through programs to provide information, promote proximity, support family presence during resuscitation, and refer family members to support groups, from the perspective of nurses or family members, are outlined.

Tangential to this research focus but meriting mention here, are the results of five specific studies. The first is an investigation of 226 ICU nurses' perceptions of their role with families in three United States hospitals (Hickey & Lewandowski, 1988). There was consensus about the non-participative role family members should play in patient care. Emotional support was provided by 75% of nurse respondents, even though many felt unprepared. The nurse's subjective feelings for the patient and family members, and the possibility of death, were the factors that most influenced their involvement with family members. This study was partially replicated by Fox and Jeffrey (1997) in Canada, with 47 family member participants from one general systems ICU. Their results supported the findings of Hickey and Lewandowski, and extended them by determining that nursing interventions "requiring more time, emotion, and skill in communication were expected but performed less often than those requiring a lesser investment of time, emotion and skill" (p. 21). Sirles and Selleck's (1989) results from an investigation of the impact of cardiac disease on families, suggested that nursing assessment of family function and emotional distress, was a therapeutic initial step in decreasing anxiety. Hilbert's (1994, 1996) results with non-probability samples of spouses of cardiac patients, using as instruments the Family APGAR (Smilkstein, 1985, as cited in Hilbert) and Affects Balance Scale (Derogatis, 1975, as cited in Hilbert) supported Sirles and Selleck's findings. The researchers suggested specific assessment activities such as completing the Family APGAR), and asking questions that encourage the couple to share their experiences and thoughts about the future with each other.

Providing Programs

A number of studies have been conducted to evaluate different programs of care for families of critically ill adult patients. A quasi-experimental study to evaluate a program to meet the needs of spouses of critically ill coronary patients demonstrated that needs were met more consistently for the experimental group who received care based on the identification of their own needs (Dracup & Breu, 1978). Through analysis of case studies, Atkinson, Stewart, and Gardner (1980) described a multidisciplinary team involving psychiatrists, nurses, physicians, social workers, and family members to assess the family members' coping mechanisms, psychological state, and support systems. Nurses were provided with an inservice, which included information about families in crisis, family systems, and the CCFNI©. Team debriefings followed the meetings. Timing, leadership, communication, and priorities were factors influencing successful meetings. Establishing empathetic rapport with the family was a necessary condition to ensure success. A Family Crisis Intervention Program (Hodovanic, Reardon, Reese, & Hedges, 1984) was shown to increase staff morale and family member satisfaction. This program incorporated family assessment, unit and hospital orientation, daily phone contact, a teaching pamphlet and volunteer activities, and included a follow-up of bereaved relatives. Another family intervention program found to be effective in addressing family needs and in reducing anxiety, fear, and hopelessness, involved using a teaching booklet, family assessment form, family conferences, telephone communication, regular educational classes in the waiting room, individual family follow-up, and post-transfer follow-up (Cray, 1989). Thompson (1989) conducted a randomized controlled trial in England, of nursing support with sixty couples (male MI patients and their partners), each couple randomly assigned to two groups, to compare levels of anxiety and depression. The intervention was a program of supportive-educative counseling provided by a coronary care unit (CCU) nurse. Mean scores for partner and patient anxiety were significantly decreased in the treatment group compared to the control group at Day 5, as compared to Day 1. Holub et al. (1975) reported on the results of Coronary Care Family Conferences initiated to provide a supportive milieu for emotional support, information sharing, reinforcement, anticipatory guidance, and for listening and supporting realistic goals for the patients' and families' futures. The conferences were accepted enthusiastically, with participants (n=48) reporting satisfaction at being able to express their concerns and fears. Evaluation forms completed by families and nursing staff provided evidence of the program's success. Lopez-Fagin (1995) developed a program for a surgical ICU by applying the results of CCFNI© research to improving the ICU environment. Guidelines were written for nurses caring for families based on addressing family needs for comfort, support, proximity, and assurance. Inservices about the CCFNI© were conducted. A component of the program included having volunteers present in the waiting room. Family members, nurses, and volunteers positively evaluated the program.

Providing Information

Spatt, Ganas, Hying, Kirsch, and Koch (1986), using a questionnaire based on the CCFNI©, reported that family members' need to talk with the physician and the nurse on a daily basis was unmet. Numerous studies support the value of meeting information needs of families to reduce anxiety, during the period of ICU hospitalization (Chavez & Faber, 1987; Henneman et al. 1992), and before and during surgery (Silva, 1979; Leske, 1992d, 1996). Leske, and Chavez and Faber, found that their intervention programs involving the provision of information, significantly reduced heart rate and blood pressure in the experimental group.

Westphal (1995) evaluated the use of storyboards to help critical care nurses meet family members' initial need for information, using an exploratory control group design. A series of largely pictorial "posters" with a brief narrative about each picture was developed about topics that could promote family member orientation, e.g., oxygen delivery, mechanical ventilation, heart monitoring, and patient emergencies. The storyboards were displayed in the CCU waiting room. Westphal found that both need satisfaction and information recall, were significantly higher in the experimental group. A quasi-experimental two-group, pretest-postest design was used to investigate the effectiveness of three components of a communication program: (a) discussion with a nurse within 24 hours of a relative's admission; (b) an informational pamphlet; and (c) a daily phone call from a nurse (Medland & Ferrans, 1998). The intervention reduced incoming family member calls but did not compromise satisfaction with care or information needs met.

Based on CCFNI© research, Gaw-Ens (1994) proposed a framework to guide nurses in their interventions with family members dealing with a relative's cardiac surgery. Fifteen specific informational support interventions were proposed for nurses to address in their care of these families. Bergbom, Svensson, Berggren, and Kamsula (1999) found that diaries kept by ICU nurses were helpful to Swedish family members (n=4) of deceased patients, and patients (n= 10) eventually discharged. Notes were made three times per day after each shift, and included information to the patient about visits, occurrences during the shift, patient progress, and weather information. No medical information was included. The diaries, which were offered to family members at the time of the patient's discharge or following the patient's death, served to fill in gaps resulting when the family member could not be present as well as when the family member's recollection of events was unclear. Improved understanding and acceptance of the situation resulted and family members reported that the diaries helped them return and adjust to everyday life.

There has been an interest in using technology to help meet family members' need for information. Johnson and Frank (1995) conducted a quasi-experimental, pretest/posttest control group design to evaluate the effectiveness of a twice-daily telephone call to a designated family member to provide patient updates. This intervention was found to be very effective in reducing family member anxiety. Menkhaus, Turner, Gueldner, and Michele (1996) demonstrated the value of nurses using beepers for communication with family members to decrease their anxiety during the critical care hospitalization of a relative. In a similar study, random surveys of family members given pagers, which enabled them to leave the ICU knowing they could be easily reached, revealed lower overall family member stress and higher levels of satisfaction (Olson, 1997).

Promoting Presence

Increasing numbers of investigations about the effects of visiting practices have demonstrated that family presence at the bedside is beneficial to both the patient and family member. Friesmuth (1986) conducted a quasi-experiment to evaluate the effects on family members of open versus closed visiting, and determined that with open visitation family had more of their needs consistently met than with closed visitation, most particularly the need for information and proximity. These results were supported by other researchers, whose quality improvement outcome evaluation studies indicated that open visiting was reported by family members as the most satisfactory for meeting proximity and information needs (Henneman et al., 1992; Giuliano, Giuliano, Bloniasz, Quirk, & Wood, 2000; Ramsey, Cathelyn, Gugliotta, & Glenn, 1999). However, a comprehensive analysis of 34 classic and current studies pertaining to critical care visiting demonstrated that while patients and family members reported benefits from open visitation, most nursing staff believed unlimited visiting was detrimental to the patient (Krapohl, 1995). Hopping, Sickbert, and Ruth (1992) surveyed 32 nurses about family members visiting. They found that nurses in teaching hospitals had higher education, the authority to control visiting policies, and a belief that visiting should be limited for the patient's sake. As a result, these nurses were more likely to establish and maintain closed visitation. It is disturbing to consider that more education did not equate with more informed practice.

Nicholson et al. (1993) investigated the effects of children visiting in adult ICUs using a quasi-experimental, post-treatment design in a pilot study. Their results indicated that facilitating child visitation might help children better cope with the critical illness of an adult relative. In a qualitative pilot study, Clarke (2000), investigating the question of children visiting an adult in ICU, recommended a collaborative approach to supporting families, as very often, adult family members chose to restrict children from visiting in order to protect them. A post-intervention survey conducted by Roland, Russell, Richards, and Sullivan (2001) following a change to open visitation in the critical care unit resulted in higher patient and family member satisfaction and a marked decrease in formal complaints, indicating improved perceptions of the quality of care. A quasi-experimental control group study of family participation in care revealed that open visitation was valuable for providing emotional support to both the patient and family members and for improving family member satisfaction and the relationship between the family members and the nurse (Martinez et al., 2003).

A number of investigations have been carried out looking at family member presence at the bedside in conjunction with resuscitative and invasive events. The first reported was of a program evaluation following a hospital's 9-year experience with family members being present during resuscitation. There were no instances of negative family experience reported (Hanson & Strawser, 1992). Eichhorn, Meyers, Mitchell, and Guzzetta (1998) wrote an impassioned article in support of what they termed the family presence movement, citing Hanson and Strawser, urging nurse researchers to help close the gap between emotionalism and fact. Robinson, Mackenzie-Ross, Campbell Hewson, Egleston, and Prevost (1998) conducted a pilot experimental study that demonstrated that family members present at resuscitative events were in no way adversely affected, and were satisfied with being present. Results were so overwhelmingly positive after 25 resuscitations that the trial was terminated to ensure that all family members could then have access to this intervention. In a more recent study by Meyers et al. (2000), family, nurse, and physician attitudes and experiences with family presence were surveyed. All family members thought it was their right to be present, and that being there was important and helpful. Providers overwhelmingly (>80%) supported family presence. It is interesting to note that all research on this topic has only been conducted in Emergency Departments. There are no reports of similar studies conducted in ICUs, although resuscitation and invasive events are frequent occurrences.

Referring to Support Groups

A number of researchers have investigated the value of nurses initiating support groups for family members of the critically ill. With one exception, they found that these groups were valuable for reducing family members' anxiety, providing emotional support, promoting hope, validating and normalizing the experience, sharing information, and diffusing negative emotions (Dracup & Breu, 1978; Halm, 1990; Halm & Alpen, 1994; Harding & Morefield, 1976; Mauss-Clum & Ryan, 1981; McHugh, Dimitroff, & Davis; 1979). The exception was the research by Sabo et al. (1989) whose comparative design used researcher-developed questionnaires with two groups. They found no correlation between attendance at one group session and decreases in anxiety, promotion of hope, or staff provision of social support. Nonetheless, attendance was perceived to be beneficial by family members in terms of expressing feelings and gaining information. The authors suggested that the patient's length of stay (1-3 days) precluded development of group cohesiveness that most probably influenced the results. Hildingh, Fridlund, and Segesten (1995) approached the study of using support groups for family members of a critically ill adult patient from a different perspective. Rather than exploring the impact support groups had on family members, as noted in the research cited above, they qualitatively investigated 12 CCU nurses' preparedness to initiate support groups for family members, which they labelled self-help groups. Interview data demonstrated that nurse's attitudes about their nursing role and their knowledge of social support, self-help groups, the patient, and their family, were important in determining whether they were prepared to use self-help groups as a support strategy for family members.

Family Perceptions of Needs Met: Satisfaction With Care

The following studies about needs met and satisfaction with care have been grouped together because the two are effectively equivalent. Both needs met and satisfaction, are outcome variables. It is assumed that if self-identified needs are met, those individuals feel satisfied with the care received. In general, the more recent studies use the terminology of 'satisfaction' informed by the quality assurance movement that began in the 1980s and gained momentum in the 1990s.

Several nursing studies investigated whether needs were perceived by the family to have been met (Dracup & Breu, 1978; Furukawa, 1996; McGaughey & Harrison, 1994b; Mendonca & Warren, 1998; Molter, 1979; Rodgers, 1983; Spatt et al., 1986; Stanton, 1984). All studies pointed to the nurse as being the most likely individual to meet the family's needs if they were met, and that patient care and information needs were the most likely to be met. Mendonca and Warren found that there was a negative correlation between the participant' s educational level and perceived support. Furukawa, in interviewing family members after the death of a relative, found that the majority of respondents reported that the death was handled in a dignified manner, and information was provided whenever it was needed, specific to the situation, and in an understandable manner. Murphy et al. (1992) noted that the more empathetic the nurse, the more likely it was that family member needs were accurately predicted and met, leading to satisfaction with care. They found that empathy was negatively correlated with years of nursing experience. This information coupled with that identifying the discrepancies in ranking, points to the value of nurses actively seeking to determine needs of families as perceived by the family, rather than acting on their own perceptions. Kosco and Warren (2000) investigated nurses' perceptions of family needs met, based on the CCFNI© and correlated this information with family members' perceptions of needs met. Only three of the top 10 needs identified by family were met. Nurses identified only three needs that were perceived as important and as being met. Interestingly the perception of support was selected as most important by both family members and nurses, followed by proximity, information, assurance and comfort. Experienced nurses rankings correlated more with family members' perceived needs than did less experienced nurses.

By the late 1990's, intensive care physicians had become interested in the investigation of family needs. In 1998, Johnson et al. conducted a comprehensive investigation of one Canadian ICU's ability (from both a medical and nursing perspective) to meet family needs using various demographic data and a modified Society of Critical Care Medicine Family Needs Assessment (1993). Needs met were assessed by measuring satisfaction with care. They found that continuity of care by both the nurse and the attending physician positively influenced family perceptions of satisfaction. Four domains of needs were identified: communication, attitude, comforting skill, and feeling isolated. In 2001, the results of a longitudinal, multi-site study conducted in the United States to further develop and validate the Critical Care Family Satisfaction Survey (CCFSS) were published in *Critical Care Medicine* (Wasser & Matchett, 2001a). The CCFSS initially informed by the CCFNI©, yielded five subscales: information, assurance, proximity, comfort, and support, the same as proposed by Leske (1986). This instrument is currently being used in a number of United States studies to further validate and explore family satisfaction with the nursing and medical care provided to family members in ICUs (Wasser & Matchett, 2001b). Of particular significance is the focus of virtually all of these studies on family member involvement in end-of-life decision-making. The satisfaction of these individuals in particular, is being assessed, the agenda to a degree being driven by economics. What does this say about the value of the satisfaction of all family members, no matter what the patient outcome?

Summary

Over the past three decades, descriptive knowledge about family members' experiences with critical care, their needs, their perceptions that needs have been met, and that they are satisfied with care has become increasingly available. Nursing interventions to meet their needs have been reported, some subsumed by the researchers under the undefined, or at best, ambiguously defined umbrella term of providing professional (social) support (Kleiber et al., 1994; Waters, 1999), or nursing support

(Bryanton et al., 1994; Thompson, 1989). Research has consistently demonstrated that the critical care situation is very stressful for family members as well as for the patient, that the family is important to patient recovery, and that addressing family member needs in the domains of information, comfort, support, proximity, and assurance, enhances individual and family coping, adaptation, and satisfaction. In reviewing the literature, it has become clear that the emphasis, and according to some authors, over-emphasis on CCFNI© needs in the body of critical care family research has constrained nurses' understanding of the full breadth and range of the family member's situation (Jamerson et al., 1996; Titler et al., 1991; Walters, 1995) and has not provided an organizing framework to guide practice. While Burr's (1998) research qualitatively revealed the family member's overall ICU experience, and Clarke's (1995) grounded theory revealed stages through which family members progress during visiting, how nurses support family members in their experience with critical care as they move through the stages of visiting, has not been addressed. Additionally, a nursing support framework developed from the perspective of nurses, was suggested as being useful in guiding the provision of care in oncology populations (Davies & Oberle, 1990). However, confusion and inconsistencies abound in the understanding of what constitutes nursing support, specifically for families of the critically ill adult. As support can only be considered supportive if deemed so by the recipient, the recipient's perspective must be sought (Lazarus & Folkman, 1984). It is timely therefore, to address the investigation of nursing support from the perspective of family members of the critically ill adult.

CHAPTER 3

METHOD

In this chapter, the grounded theory approach adopted for this study of family members' perceptions of support from critical care nurses is described. Key terms used in the study are defined. Although the nature of the grounded theory research process involves simultaneous data collection and data analysis, for ease of discussion, the activities engaged in are described sequentially. Elements of rigor addressed during the research process are presented. Ethical considerations attended to, conclude the chapter.

Grounded theory was first described by Glaser and Strauss (1967), and further interpreted by Strauss and Corbin (1998), among others. Strauss and Corbin's (1998) interpretation of grounded theory guided the approach used to address the research question and the resultant choice of research activities, procedures, and techniques. Strauss and Corbin consider grounded theory to be both a methodology and a method, methodology being defined as "a way of thinking about and studying social reality" (p. 3) and method defined as "a set of procedures and techniques for gathering and analyzing data" (p. 3). During analysis, data are subjected to a continual process of comparison, to first identify and then to develop categories. Data collection is guided by sampling on the basis of theoretically relevant concepts. Theoretical sensitivity, involving an awareness and responsiveness to the subtleties revealed in the data (Glaser, 1978) based initially on professional experience and considerable knowledge of the professional and disciplinary literature, influences the critical and creative interaction between the investigator and the data (Strauss & Corbin) and results in the analysis of data at higher and higher levels of abstraction. Theoretical sampling in conjunction with the corresponding constant comparative method of analysis, and theoretical sensitivity are three attributes that set this method apart from other qualitative approaches.

Definition of Terms

For this study, the family was defined as consisting of whomever the patient and/or family member identified, based on functional relationships with each other. This definition is not subject to investigator restriction of the family to a nuclear, biological, or legal entity. It is from those individuals identified as comprising the patient's family that participants were recruited and data were collected. The term "participant" is used to denote a family member who participated in the current research study. The patient is referred to as the "patient", "ill relative", and "critically ill adult" interchangeably. "Family member" and "relative" are the terms used to refer to the individual family member of a critically ill adult. When used, the umbrella phrase of "family" refers to patient and family members as a social unit. Additionally, the term "family member" is used when discussing the theory and refers to family members in general, not specifically to participants in this study. "Critical care" is the broad phrase used to refer to the provision of constant, intensive, and technology-supported nursing and medical care in an Intensive Care Unit (ICU) to adult patients who have an illness or condition involving imminent and/or potential danger of death. The terms "ICU nurse" and "nurse" are used interchangeably.

Data Collection

Data were collected from participants individually or in a family group, through face-to-face audiotaped interviews using open-ended questions. All but one interview was tape-recorded and transcribed. One interview conducted over the telephone was untaped, as the participant indicated a preference for the investigator to only take notes during the conversation. Other follow-up telephone interviews were recorded. Interviews were conducted in locations chosen to meet the requests of the participants. Observations made during the interviews were recorded in field notes.

Participant Recruitment

A colourful notice about the study (see Appendix A) was posted in each adult ICU waiting room, requesting that family members contact the investigator by telephone or email if they were interested in participating. Participants included those who were: (a) adult family members who visited an adult patient admitted to a critical care unit, (b) able to speak and understand English, and (c) cognitively able to reflect on and verbalize experiences and perceptions of nursing support. Sampling was engaged in until theoretical saturation was reached, that is, until no new themes were revealed (Dreher, 1994). Twenty family members from 14 families were involved, in one or two interviews.

Theoretical Sampling

As the investigator sought to explore family members' perceptions of nursing support, it was essential that the sample comprised family members recruited from participating critical care units. Ideally in grounded theory, after the first few interviews, data collection is guided by a strategy called theoretical sampling in which the investigator "goes to people, places, or events, that will maximize opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions" (Strauss & Corbin, 1998, p. 201). In this study, theoretical sampling was constrained by the nature of the recruitment process, wherein participants self-selected. As time passed and analysis progressed, with theoretical sampling in mind, study notices were posted again and staff revisited in those critical care units from which no participants had as yet been recruited. The unique perspectives of the additional five individuals recruited after this exercise, based on whom they were, where they were from, and the nature of the patient's circumstances, significantly enhanced the density of the categories and the breadth in variation of the emerging concepts and categories.

Interview Process

One or two interviews were conducted with each participant at times and in locations that they chose (e.g., one in the home, many in the investigator's private office, some in a quiet room in the hospital, one at a participant's place of work, and one in a restaurant). Three initial family interviews and one follow-up family interview were conducted face-to-face. Some follow-up interviews were conducted by telephone when the individual participants requested it for personal convenience and/or because they lived a considerable distance from the hospital. It was left to the family to choose whether a group or individual interview was preferred. This investigator decision was made with the full realization that interviews conducted with more than one family member at a time are difficult to transcribe and analyze. Since it was individual family member's perspectives that were being sought in this study, the "family data" were analyzed as individual family member data.

Prior to initiating each interview, participants signed an Informed Consent (see Appendix B, C). Demographic data from the family participant(s) were then obtained (see Appendix D) to elicit contextual information about the participant(s) and to serve as an “ice-breaker” at the beginning of the interview. After demographic data were collected, interviews began using an open-ended question. For example, typically the investigator asked the participant to “Tell me what it has been like for you since X was admitted to ICU”. Some chose to respond to this question initially by discussing the events that led up to the admission, before moving into discussing the critical care experience. Subsequent questions were asked with particular attention to ensuring that the participant's response was not being prematurely narrowed. That is, the participant was permitted to lead the direction of the interview initially, with probes or questions serving largely to redirect the conversation to the topic under investigation (see Appendix E).

The first few interviews about the behaviours of critical care nurses that supported (or did not support) family members in "getting through" the critical care experience were exploratory in nature. When non-supportive nursing behaviours were revealed, participants were asked to discuss what would have been supportive to them. Most experienced a range in nursing support behaviours during the course of the patient's critical illness, from being let in to the bedside, to being encouraged to become involved in decision-making and patient care.

During each interview, specific points raised by participants were explored further by asking the participant to "Tell me more about that". Following analysis of these initial interviews, additional interview questions were dictated by, and became directed toward, the emerging concepts and categories. Specific incidents that demonstrated the range and variation of the properties and dimensions of concepts identified in the data, and the relationships among these concepts, were explored by comparing the concepts to each other and to the literature in order to confirm, elaborate, validate, or limit their applicability. The concepts derived from these interviews were further developed, classified and reclassified, and interpreted at gradating levels of abstraction, until a constellation of interconnected categories and subcategories evolved. Activities to help "tease out" the core category and further refine the process included recruiting additional participants, focussing questions on validating the emerging categories to ensure saturation of all categories, and re-interviewing selected participants who had previously provided rich data. The second interview provided participants with the opportunity "to affirm, modify, clarify and elaborate on what was said in the first interview" (Chiovitti & Piran, 2003, p. 429), as well as to hear about the emerging theory and to confirm or modify evolving categories.

Twenty-five taped interviews and one untaped interview (handwritten notes made during a telephone interview) were conducted as expedient for the participant. All first interviews were conducted face-to-face. Six of the twelve follow-up interviews were conducted by phone. Face-to-face interviews occurred in a private room in the hospital, in a private office at the adjacent university, in the family home, or at the participant's place of employment. In four instances, other family members who were present at the time of the scheduled interview joined in a group interview (10 participants in all). Three conjoint interviews consisted of two individuals each; the fourth involved four individuals. Six of these family group participants were re-interviewed individually by telephone.

Field Notes

Field notes were taped following interviews, to record impressions, reactions, and observations that revealed contextual dimensions of the interview. These included descriptions of the setting, the participant's nonverbal behaviours, activity of other persons present during the interview, distractions, interruptions, and the investigator's response to the interview. Information recorded in these notes informed the discussion of the environmental context as well as subsequent data collection and analysis. For example, the level of distress or intensity portrayed by some participants and noted in the field notes influenced how the investigator interpreted the import of the specific event to those participants. This led to investigating with subsequent participants, their perception of the significance of the event if something similar had occurred to them as well. Another example involved including in the field notes, a drawing, that one of the participants had made during the interview to help explain a point.

Data Management and Analysis

The audiotaped interview and field note data were converted to text using the services of a professional transcriber. The investigator listened to the audiotapes to correct the transcription and to become re-immersed in the interview. Interview data were interpreted in relation to the context of the interview, which was recorded in the field notes. NUD*IST^{TM}(Qualitative Solutions and Research Pty. Ltd., 1997) was used to manage the transcribed interview and field note data and to track the emerging concepts and categories. Analysis proceeded compositively using constant comparison and memoing techniques in recursive interplay with coding procedures. Data analysis occurred simultaneously with data collection. The basic coding scheme used involved three overlapping processes: (a) open coding; (b) axial coding; and (c) selective coding.

Constant Comparison

Constant comparison techniques were engaged in during all coding activities, first, as case specific data were reviewed, resulting in the identification of concepts specific to that case. These concepts were further developed, by identifying their basic properties and dimensions. For example, one interview was coded overall as being about '*Uncertainty*', '*Being alone*', and '*Feeling Inconsequential*' based on the participant stating that there was no one to turn to and that there was uncertainty about knowing what to do. The feeling of being lost, alone, and undervalued in terms of the role that could be played with the patient were evident, as demonstrated by the following quote.

> *Nothing has helped me to get through; I'm just dealing with it. I just go home and I just lie on the couch and watch TV and cry.... I didn't have a clue what it would be like.... I'm the only one here. I'm his family, but then when I phone, sometimes they want to know who it is, and I tell them 'It's his wife', and they'll say, 'Well, what do you want?*

Codes reflecting these emotions were eventually grouped together into the category, '*Disconnected'*

This within-case analytic activity of comparing instances to instances, concepts to concepts, and categories to categories was completed for each interview. The emerging categories were further refined as the data were subjected to cross-case analysis, specifically analysis of the concepts common across cases and the characteristics and properties of the concepts across cases. Two types of cross-case comparisons were made, category-to-category and incident-to-incident. For example, the category of *'Welcoming '* was identified in the first three transcripts. The incidents revealing this category in the data, such as when the patient was first admitted, when the family member first visited, and later during subsequent visits, as well as consideration of other opportunities for *'Welcoming'* unrelated to the critical care situations, for example being welcomed by the captain and stewardesses at the beginning of a flight, informed the development of the properties and dimensions of '*Welcoming'*. There was consideration as well, of that which was not welcoming, and the opposite of ' *Welcoming'*, *'Saying goodbye'*. Properties of welcoming included being: cordial, approving, friendly, gracious, nice, neighbourly, inviting, open and receptive, and sociable. Dimensions of *'Welcoming'* involved the degree of welcoming, from ignoring or shunning, to being so overwhelmingly welcoming that one feels smothered, and the demonstration of *'Welcoming'*, from no display, to a nod or smile, through to "Hello", a hug, and kiss. With whom and where '*Welcoming*' occurs were considered, as certain behaviours are considered more appropriate given certain individuals, their relationship, the setting, the culture, their genders, and their ages. When were welcoming behaviours appropriate and important, and inappropriate and unimportant? Why and when does one respond to welcoming behaviours, and why does one exhibit welcoming behaviours? This example is one snapshot of how each concept was examined microscopically.

Theoretical constant comparisons were made by comparing opposites, to become sensitive to the range of properties that might be relevant to the data. For example '*Uncertainty*' was compared to *'certainty'*, and extremes, such as '*slightly'* or *'minimally uncertain'* was compared to '*completely lost'*. As well, incidents in the data were systematically compared to similar and dissimilar incidents identified in previous experience or in the literature.

Through constant comparison analysis, the emerging broader theme of family members *'work'* of *'getting through'* the experience, was constructed, based on interpreting family members' reports of the energy they were expending in trying to meet their perceived responsibilities. No one could do this work for them, but nurses could help them by supporting them in their efforts. Successive interviews were then directed to understanding how nurses helped family members in their work. This iterative exercise of constant comparison continued until no new properties were revealed. Saturation of the data was achieved and no more participants were recruited.

Open Coding

During open coding, relevant concepts and categories of concepts were identified in the raw data and their properties and dimensions developed. On first reading the interviews, the investigator identified the overall impression of "what was going on". This initially revealed the family member's overall experience. For example, one transcript was coded *'Let me in'*, based on participants' repeated descriptions of the difficulty encountered trying to visit. The investigator then went back to the interview data and began to code sentence by sentence. Concepts referred to in each sentence were written in pencil in the margin of the transcript. There could be more than one concept for each sentence. This open coding was completed for all transcripts, with refinement of the identified concepts resulting from the coding and recoding. For example, incidents such as the following were initially coded as *'Getting in'*, *'Questioning'*, and *'Getting Information'*.

> *Just being able to go in there and ask questions and have people answer for me in an honest way...*

The following incident was coded as *'wanting continuity'*.

> *It's just that I would like to have that continuity.*

'Getting in', *'Waiting'*, *'Frustrating'*, and *'Tiring'* were the codes assigned to:

> *Or I wait there, but I can't get in, so I come back four or five times every day, and that's frustrating to come all that way and wait for two to three hours to see him.*

All concepts identified in this last quote, were coded as the '*Work of waiting*'. Then *'Work of waiting'* was recoded as *'Gaining Access'*. *'Gaining Access'* was then compared to all the other categories mentioned above, revealing that they were all about *'Gaining Access'*: to information, the patient, knowledge of continuity of care, and honesty.

Codes within each transcript were first compared with other codes within the same document to determine whether one label was more inclusive or specific than the other. Then codes were compared between transcripts to arrive at labels more inclusive and representative of what was being said in all three transcripts. These broad labels were then used to start gathering data from subsequent interviewees. During this process, the analysis moved from concepts about the overall experience, such as about '*Getting in*', to a refinement of what was happening that influenced participants' perceptions that *'Getting in*' was important. Interviews built on each other, and the categories reflected this. Coding was now being entered into an electronic database using NUD*IST^{TM}. Once codes were entered into NUD*IST^{TM}, each code category was defined. This definition was based on an exploration of the various properties and dimensions of the concept, and changed in response to new information. As individual codes were developed, they were being assigned to clusters and categories. For example, the concept of '*Gaining Access*' was subsumed under '*Breaching barriers*'.

Axial Coding

During open coding, the investigator broke down the data into discrete parts, and labelled them, using either the participant's words or words she determined were most representative of the concept. During axial coding, concepts and categories of concepts were further refined, developed, and related to each other, as the investigator become more sensitive to the theoretical relevance of the concepts. Questions such as "what is going on here?" and "how do all these concepts and categories relate to each other?" were asked, in an attempt to ascertain the basic psychosocial process of perceived nursing support. The questions asked helped to link the data together and the numbers of categories were reduced, and new categories were generated. Determining where each of the subcategories fit was very challenging. For example, *'Informing us'*, a category that related to participants' need for honest, understandable, current information about the patient and environment through whatever means and in whatever form, related directly to how that information was made available. Participants had referred to the communication skills of the nurses, categorized variously under *'Showing empathy'*, or *'Caring demeanour'*. As a result, the category of *'Communicating with us'*, which subsumes the "what" as well as the "how" and includes as well *'Hearing us'*, and *'Anticipating questions'*, became the more appropriate label.

As the investigator became more and more immersed in the data collection and analysis activities, sensitivity to the theoretical relevance of emerging concepts grew. Theoretical sensitivity is defined as a personal quality of the investigator. Sensitivity "means having insight into, and being able to give meaning to, the events and happenings in data.... being able to see beneath the obvious to discover the new" in the data (Strauss & Corbin, 1998, p. 46) and is influenced by the investigator's knowledge of the clinical situation and topic (Dreher, 1994) based on clinical experience and a preliminary review of the literature (Strauss & Corbin, 1998). Theoretical sensitivity involves the investigator moving beyond initially held knowledge, biases, and assumptions regarding the concepts, so as to be "open" to knowledge revealed in the data. Data from initial interviews were recoded in light of the resulting insights, as the investigator became more sensitized to the evolving theory. For example, theoretical sensitivity and further data analysis indicated that *'Forming alliances with us'* did not adequately capture what later participants said. The associated data were re-analyzed and then recoded as *'Involving us'*.

Selective Coding

To identify the core or central category that links all the categories of the emerging theory together, coding became more selective. The core category is an abstraction that evolved over time from the continual analysis of the data until a constellation of interconnected categories and subcategories evolved, which ultimately revealed the central process that critical care nurses could engage in with family members to mitigate the impact of the critical care situation on them. "In an exaggerated sense, [the core category] consists of all the products of analysis condensed into a few words that seem to explain 'what the research is about'" (Corbin & Strauss, 1998, p. 146). All categories identified, including their properties, related to the core category, which, on further examination, proved to recur frequently, link the data together, and explain variation. The development of the core category through these selective coding activities was in response to the question "what is the nurse doing overall that supports the family in their work?" The family members' workloads exist and it is important that nurses not add to that workload. Indeed, if it could be lightened somewhat, is that not supportive? Is this then about lightening their workload? Further sampling of the data supported that when nurses were perceived by family members to be supporting them, their work was easier, and certainly no harder. '*Lightening the Load*' emerged as the core process of nursing support, capable of explaining the variation in the behaviour revealed in the data.

Additional Analytic Activities

In addition to the three levels of basic coding in grounded theory using constant comparison techniques, and with increasing theoretical sensitivity, the investigator engaged in two other types of analysis. The first was coding for process; the second was developing the conditional/consequential matrix (Strauss & Corbin, 1998).

Coding for Process

This level of analysis was engaged in concomitantly with axial coding. The actions and interactions associated with the categories were analyzed to note if there were changes over time, and if so how these changes were manifest. If there were no changes, the "why not?" was investigated. Diagrams were drawn depicting various interrelationships over time. For example, as a result of coding for process, the phases of *ENGAGING WITH US, SUSTAINING US,* and *DISENGAGING FROM US* came into clear prominence, under which could be subsumed all of the identified concepts and categories, presented in a loosely hierarchical (based on time) format. Each concept and category label was repeatedly subjected to this line of questioning to tease out the process, and the results were configured and reconfigured to reflect the evolving analysis.

Conditional/Consequential Matrix

Conditional/consequential graphic matrices were developed either as freehand sketches, or using index cards, "stickies" on a board or, in due course, computer graphics, to help portray the relationships among categories in terms of their conditions and consequences of nursing support at every level of analysis, from micro conditions to macro conditions, as well as across levels, based on the coding. These matrices evolved over time and served as aids in conceptualizing the emerging theory, and visually representing the interrelationship among the categories (Strauss & Corbin, 1998). A number of participants spoke directly of these conditions, which influenced to varying degrees the outcome of whether or not they felt supported by nurses. Micro conditions included the individual nurse's personality, experience, leadership, education, and personal characteristics, each family's dynamics and networks, the family member's knowledge, previous experience, and expectations, the patient's diagnosis, prognosis and stature in the community. Structural conditions included the unit supervisor's recognition of the importance of family, the nurse's workload, staffing patterns, patient assignments, physician's schedule, the waiting and quiet areas, and visiting rules. At a macro level, the hospital's provision of supports such as parking, accommodation, waiting and quiet areas, and adequate funding for staffing, were identified. The overall health delivery system in Canada, as encompassed within the Canada Health Act, was identified as a macro condition. One participant indicated that the law of averages influenced whether the nurse would be supportive or not. Each of these contextual conditions influenced to greater or lesser degrees both the family members' perceptions of nursing support, and their perception of the nurses' capacity to provide support to family members.

Memo Writing

A reflective log was kept to record “memos” - thoughts pertinent to the analysis as they occurred - to ensure that “intuitive leaps” and theoretical insights were not forgotten. These memos, in the form of diagrams and hand-written and typed notes, constituted a significant part of the decision trail, as they served as reminders of insights that occurred when not focussing on analysis. Memo writing activities were engaged in up until the final draft of the analysis was submitted. For example, a memo was written during an activity totally unrelated to the research process, teaching, to capture the ideas that some encounters between the family member and the nurse appeared to be only engagement and immediate disengagement, such as when a nurse covered for the assigned nurse for rest and meal breaks. Did the covering nurse still *'Lighten the Load'* of family members? On further consideration, sustaining did occur as family members were reassured that there was an alternate nurse available. Another memo was written while on a flight, in response to the "departing" comments and behaviours of the captain and stewardesses, to compare with the properties and dimensions of *'Saying goodbye'* being developed for the critical care situation. These memos were then referred to when the investigator was able to focus on the analysis once again.

Elements of Rigour

To address scientific rigour involving the overall trustworthiness of the findings, conscientious adherence to accuracy was undertaken. Additionally, openness, honesty, respectfulness, and constant attentiveness to detail, informed all actions, from how questions were asked and answered in interviews, to how findings were represented. Morse et al. noted that, "It is essential [to ensuring rigour] that the investigator remain open, use sensitivity, creativity, and insight, and be willing to relinquish any ideas that are poorly supported.... The lack of responsivesness is the greatest hidden threat to validity...." (2002, p. 11). Investigator responsiveness resulted in interviews conducted with family groupings as well as with individuals, held in a number of locations, all based on responsiveness to participant preference. As well, there was a willingness and even desire to resolutely seek evidence to abandon or adopt a categorization scheme. This has resulted in a scheme with stability.

Theoretical biases were made explicit *a priori* to address rigor (Streubert & Rinaldi-Carpenter, 1995). The investigator assumed responsibility for interpreting the data and in so doing was aware of her unique perspective, including prejudices, traditions, and pre-understandings which influenced the analytical process. A decision trail was documented to provide explicit evidence to demonstrate the link between the indicators in the data set and the analytic categories. The raw data and decision trail, together termed the audit trail, include: transcribed interviews and field notes; products of coding and analysis activities; products of reconstruction and synthesis activities including diagrams; and memos of rationale for decisions made.

Verification Strategies

Various verification mechanisms were used during the process of conducting the study, to incrementally contribute to rigour. Verification, the process of checking, confirming, making sure, and being certain, so as to ensure rigour, was addressed through the following constructive means: being responsive, being theoretically sensitive, and engaging in concurrent data collection and analysis (Strauss & Corbin, 1994), each of which has been discussed previously, as well as by ensuring methodological coherence and sampling appropriateness, and developing theory (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Methodological Coherence

There is congruence between the research question dealing with the process of nursing support, the choice of grounded theory conducted to understand a basic social process, and the components of grounded theory. The data gathered (e.g., interview data), and the methods used, to gather and analyze the data (e.g., constant comparison and analytic coding) match the data and the analytic procedures engaged in, previously presented.

Sample Appropriateness

Appropriateness refers to the practice of choosing participants purposefully, based on their experience, knowledge, ability to articulate their experiences, and on the emergent theory. The sample for the current study consisted of those family members who responded to the poster and word-of-mouth recruitment. In this study, participants were all dealing with the life threatening illness/condition of an adult family member admitted to critical care. Although family members' perceptions of nursing support were being investigated, incidences of non-support were included as well, as this information was useful for refuting or amending interpretations (Strauss & Corbin, 1998). Variations between interviews, in terms of whether it was a family group or individual interview, at which location the interview was conducted, and what questions evolved in response to family member feedback, increased the validity of the findings, since these differences become part of the data and were then identified, compared, and analyzed. Sampling continued until repetition from multiple sources occurred, indicating that categorical and theoretical saturation had been achieved.

Developing Theory

Lastly, a theory was developed as an outcome of the research process through both linear and non-linear thinking, a theory that is logical, comprehensive, parsimonious, and consistent (Glaser, 1978; Morse, 1997). The conditions that influenced whether family members of critically ill adult patients felt supported by nurses in getting through the experience were outlined. The explanatory power of the theory however, remains to be determined, referring to the "predictive ability [of the theory developed] to explain what might happen in a given situation" (Strauss & Corbin, 1998, p. 267). This is an evaluative criterion rather than a constructive strategy (Morse et al., 2002; Strauss & Corbin, 1998). However, at this point in time, the explanatory power of the theory is limited to the population of family members from where the participants were recruited. An additional evaluative criterion to note is reproducibility, which refers to whether other researchers using grounded theory to investigate nursing support, and "following the same general rules for data gathering and analysis, and assuming a similar set of conditions" will come up with a similar theoretical explanation (Strauss & Corbin, 1998, p. 267). Whether the theory is reproducible and/or whether additional research uncovers variations not included in this theory, remain to be determined.

Ethical Considerations

Ethical approval for conducting this research was obtained from the Health Research Ethics Board, University of Alberta. Institutional support was sought from the Patient Care Directors of the Intensive Care Units of the participating hospitals. Unit Supervisors and unit staff were notified of the study. There were no tangible benefits to the participants, although most stated that they benefited from the opportunity to talk about their experiences and ideas. They hoped to influence changes for other families in the future.

At the time of the initial face-to-face meeting the investigator provided an explanation of the study both verbally and in written form (see Appendix B). The investigator informed family members that participation in this study was entirely voluntary, could be withdrawn at any time, and that non-participation would not result in any recriminations or harm to themselves or their hospitalized relative. She reassured participants that their identity and the identity of the family would be kept confidential, and would be known only to the investigator. Actual names and initials would not be used in the transcripts or in the reporting of data. A number and letter were assigned to identify each family participant's data. Participants were advised that no risk was expected because of their participation. Any questions or points requiring clarification were discussed fully.

Summaries of the research results were offered to all participants. Each participant signed the Informed Consent (see Appendix C). At all times, each participant's level of comfort and anxiety was appraised. No identifying information was transcribed or included in the field notes. Transcripts and field notes were assigned an alphabetical code, and the informed consents and demographic information were kept separate from the transcripts in a locked cabinet.

CHAPTER 4

FINDINGS

In this chapter, the context of nursing support is introduced first, in terms of demographic information about family member participants and their respective patient relatives, the critical care environment, and the participant experience with critical care. Next, an overview of the core category of the process of nursing support, ***LIGHTENING OUR LOAD***, is provided based on the perspective of family members of a critically ill adult. The chapter concludes with a description of the process of family members' perceptions of nursing support, illustrated by quotations that informed the analysis.

The Context of the Critical Care Experience:
The Families

Flyers posted in all five waiting rooms serving seven adult Intensive Care Units (ICU) of two tertiary care centres, prompted 15 participants from 9 families to enroll in the current study. Five other participants learned of the study through an intermediary such as a social worker, family member, or nurse. One of these five became involved in a group interview when an original participant was re-interviewed. All voiced interest in participating in the study in order to potentially help others experiencing a similar situation.

> *And I feel good about talking to you about this if it's going to have some kind of impact on change in that whole protocol system.... And to me if there's something that comes out of this, then - you know what I mean? - Then it's worth it.*

The 20 family members involved in interviews corresponded to 14 adult patients admitted to one of four ICUs for a range of diagnoses such as: complications of cancer; postoperative sepsis; meningitis, stroke, and lupus; burn; respiratory failure; drug overdose; and head trauma (see Table 1). The ICUs included two General System ICUs, a Burn Unit, and a Neurosurgical ICU. Nine patients were still in ICU at the time of the initial interview; five patients had been transferred from ICU, two of these directly home. Three patients died in ICU during the period between the first and second interviews. Patient ICU length-of-stay ranged from 24 hours to 270 days. Patient ages ranged from

24 to 76 years. There were no family member participants whose relative was admitted to a Cardiothoracic Surgery ICU or to a Coronary Care Unit (CCU), although notices were posted in the respective waiting rooms. One of these waiting rooms, for CCU, was shared with a General Systems ICU from which 10 participants were recruited.

The family member participants, 7 males and 13 females, represented differences in their: relationships to patients, occupations, home locales, previous ICU experience, and marital status (see Table 2). Their ages ranged from 26 to 73 years, and interviews were conducted from 3 to 172 days following admission of their relative into an ICU. One participant was of aboriginal ancestry and three had emigrated to Canada from Europe. Seven participants had children at home for whom they were responsible.

Table 1

Patient Information

Patient	Age	Gender	Diagnosis
A	50	M	Complications of Cancer
B	76	M	Postoperative Sepsis
C	57	M	Complications of Cancer
D	70	M	Postoperative Sepsis
E	64	M	Postoperative Sepsis
F	57	F	Meningitis/ Stroke/Lupus
G	60	M	Respiratory Failure
H	24	F	Burn
I	68	M	Respiratory Failure
J	65	F	Respiratory Failure
K	29	F	Respiratory Failure
L	57	F	Overdose
M	26	M	Head Trauma
N	62	M	Head Trauma

Table 2

Participant Information

Age	Gender	Marital Status	Previous ICU Experience	From City	Occupation	Relationship to Patient	Admission to First Interview (Days)	Number of Interviews	
57	F	M	Yes	Yes	Professional	Wife	31	2	
37	F	M	No	No	Professional	Mother	89	2	
42	M	M	Yes	No	Tradesman	Son	133	1*	1
73	F	M	Yes	No	Homemaker	Wife	133		1
40	M	M	Yes	No	Tradesman	Son	133		1
36	F	M	Yes	No	Homemaker	Daughter-in-law	133		
34	M	S	No	Yes	Tradesman	Son	10	1	
36	F	M	No	Yes	Tradesman	Wife	7	1	
62	F	M	No	Yes	Professional	Wife	85	1	1*
67	F	S	Yes	No	Professional	Sister	270		
44	M	M	Yes	No	Professional	Husband	172	2	
52	M	M	No	No	Tradesman	Husband	8	1*	1
56	F	S	No	No	Professional	Sister-in-law	8		1
44	F	M	Yes	No	Homemaker	Daughter-in-law	27	2	
64	F	M	Yes	No	Professional	Wife	3	1*	1
44	F	M	Yes	No	Professional	Daughter	3		
42	M	S	Yes	Yes	Tradesman	Son	10	1	
26	M	M	No	Yes	Long Term Disability	Husband	172	2	
37	F	M	Yes	Yes	Professional	Daughter	11	2	
62	F	M	No	Yes	Professional	Wife	90	1	

* *Involved in conjoint interview*

The Context of the Critical Care Experience:
The Critical Care Environment

Participants repeatedly referred to the critical care environment. At one hospital the waiting room was shared by family members with relatives in the General Systems ICU (GSICU) and Burn ICU (BICU). The Neurosurgical ICU (NICU) had its own small waiting room, as did the Cardiothoracic Surgery ICU and the Coronary Care Unit (CCU). In the other hospital there was one waiting room shared by GSICU and CCU. All the waiting rooms were located outside the ICUs, which were accessible only by permission after first calling through to the unit by phone or intercom. Participants reported that they saw some BICU and CCU family members have immediate free access without calling in. Family members visiting the NICU and GSICUs often had to wait for prolonged periods until activities being engaged in with the patient were completed.

The waiting rooms were approximately 400 square feet in area, except for the NICU which was small, about 100 square feet in area with 6 straight back chairs. All others had chairs to accommodate approximately 12 to 20 visitors, some end tables, and a lamp or two. One waiting room had a TV. In each, posters and announcements were on bulletin boards; a clock was on one wall; magazines and pamphlets were on the tables. None had windows to the outside. Food and drink dispensing machines were not available. Each of the "large" waiting rooms had a payphone. At one hospital there was an open, widened hallway area beyond the doors into the ICU waiting area where family members could also sit. Each hospital had a chapel, in locations distant to the ICUs. Participants had to ask if there was a chapel and where it was located, as there was no signage about the chapels in the waiting rooms.

The ICUs from which participants were recruited were modern, predominantly single patient units, with some two, four, and six patient units, accessible through sliding glass doors. The most notable feature was the domination of the space by monitoring, resuscitative, and treatment technology. This “high tech” equipment was in evidence everywhere, even in the hallways. Participants spoke of this equipment as necessary and overwhelming, yet oddly reassuring. Many equated the number of machines in the room to the patient's level of acuity; the more machines, the more ill the patient.

Each patient on all units had a primary nurse assigned, generally for a 12-hour shift rotation. Participants described a range of staffing patterns from full-time nurses to those who worked part-time or casual hours at more than one hospital, the latter being frequently encountered. As well, participants described the experience level of nurses they met, from "inexperienced to expert". They spoke of nurses who were "young and appeared somewhat unsure or hesitant with family", of nurses of all ages who "exuded confidence, energy, and competence", as well as of nurses who "appeared very competent but who focussed only on the monitors" and who "ignored us". Participants indicated that nursing support was a function of the individual nurse, based on that nurse's personality and commitment, and was influenced by the "leadership" on the unit. Participants repeatedly commented that the nurse's "work was very demanding" that "there were not enough of them" and that "they were very busy". The nurse was pivotal to "everything"; the key individual with whom family members had "closest and most frequent" contact. A number of participants discussed the nature of critical care nursing and how that must affect the nurse, who was "always there".

> *I don't think you could last in the job if you got too personal. You have too many deaths that occur and stuff. ... So I can't imagine if you let yourself get totally personally involved with every situation up there, because you build relationships, and I think it would be really, really hard. I don't think you cannot build some sort of relationship as a human being; you do. But I think they try to keep their distance a little bit. I'm OK [with that].*

Many participants also mentioned that nurses had no control over the waiting room situation, or how nurses were assigned to patients. These were larger system decisions. Some noted that the Unit Supervisor, by his or her example, played an important role in the perceived value the unit as a whole placed on family members. Some participants discussed how physician staffing patterns negatively influenced the continuity of care the patient received.

All indicated that the "best" nurses should be assigned to critical care; "best" defined as those who were personable and who wanted to work with the family, as the needs of these patients and families were so complex. They expected "technical competence" to be a “given” for any nurse working in ICU. Participants freely shared their views about the education, hiring, orientation and staffing of ICU nurses, and offered suggestions about how to improve nursing in ICU.

> *The awesome and the great nurses will sort of set the stage for how that shift is going to work itself, because their personality and their leadership qualities will come out and reflect on the other nurses as well as the younger nurses that don't have the experience.*
>
> *I don't know if nurses know or understand what family members go through. I think if they understood that, they may take a little different viewpoint on all this. And how do you teach that?... Work with the great nurses. If you have an opportunity to work with a really high-class veteran nurse, I think that's where the learning comes from. And I think too, if there's problem nurses on the floor with a bad attitude and ignorant, that those nurses need to be reported, and they need to be moved to a different part of the hospital, because that part of the hospital, that ICU, is a very tough, very emotional place to work, and you need to get rid of the poor ones and keep bringing in the best people. If you drop off the bad ones and bring in a good one, she can get stronger and stronger, and they'll work together as a group and a unit, and they'll support each other.*

The activity levels in the ICUs during the daytime and evening were very high. Alarms rang at frequent intervals, and numerous conversations could be overheard from centrally located Nurses' Stations. A steady stream of individuals and small groups, identifiable as staff by their “uniforms”, or as family visitors by their "street clothes", passed into and out of the ICU doors, directly visible to those in all the waiting rooms.

The Context of the Critical Care Experience:
Family Members' *'Work'* of *'Getting Through'*

The admission of a relative to critical care constituted a crisis and placed an additional strain on families. Their previous way of being, at the very least was interrupted, and at the worst, was distorted beyond recognition. They had lost control over the day-to-day management of their lives and had been left feeling unbalanced and vulnerable.

> *So when you're one hundred percent completely and totally and utterly satisfied with your life at that point and it gets totally changed and turned around... you can accept it, but for me anyway I can't see it coming back.*
>
> *It's been a gut-wrenching experience, the worst time of my life. This year has been a tough year. I guess just from the stresses but this, it's the worst thing I ever went*

> *through. If she would just start getting better, it would really help, but I guess it's just been two weeks, and two weeks isn't very long in a lifetime, but it sure seems like a long time.*
>
> *You feel so out of control as it is, and there is no control over what's going on; your normal life isn't normal any more.*
>
> *But families...when someone's in ICU, the balance is lost automatically, because you have something going on that just isn't normal that you don't want.*

Nonetheless, participants described conspicuous resolve and resilience in order to '*get through*', with each family member bringing unique characteristics to the experience, including family structural and social network strengths. The following exemplars are illustrative of what contributed to their '*getting through'*.

> *You have to have some inner strength and a belief in yourself, and that's definitely been proven that me, because I get people saying to me, "I don't know how you survive. I don't know how you've managed to do all these things. I don't know how you've managed to go through all this.*
>
> *I think that I've got such a great network of people and support from people who helped me.... as friends, sometimes as professionals...that I wasn't isolated. I think that people who feel that they are isolated when they get in these situations must have a horrendous time, and I wasn't.*
>
> *And you also have to remember that I had three communities that my relative belonged to all behind me, so I, as an individual, was very fortunate. I also had a sister who was a nurse, who put eleven weeks of her life into my relative. Now, how many people are that fortunate? How many are flying solo? How many people have to phone the neighbor to get help? And I had people bringing casseroles and muffins and making sure I was eating.*

Notwithstanding each participant's resources, a relative's critical care hospitalization added to home and work commitments and forced them to shoulder increased and new responsibilities. Their extra *'work'* threw their lives off-balance and drained their resources.

> *That time could have been better spent doing - and then the hour we waited to find out what is going on, hour and a half. You know what? That was a cost, because that was wasted time.*
>
> *I can accept it [the change], but the zest, the punch, the joy that I had for my life is just sort of gone. It costs, physically; it costs emotionally, and financially.*

> *It's two months later almost, and it's been mentally and physically draining, without a doubt.... We've been going back and forth to the hospital from about nine in the morning to nine at night.... I was telling my mom about the hardships, financially.*

The patient and the hospital now became the family member's focus; other responsibilities were secondary. Their *'work'* was either visible, or invisible as demonstrated by the *'work'* of waiting and worrying, which cost them energy, expended in feeling angry, frustrated, and fearful.

> *Oh, it's much more intense than just being in the hospital and visiting for a day, and that person's home again. It takes up so much energy, so much energy to deal with that. And like I say, you deal with the fact that you might lose your relative; you deal with the fact that all of this other stuff's going on.*

Participants also expended energy in actively breaking down whatever barriers prevented them from getting what they needed.

> *Actually, in order to get the attention I did, I had to stand in the middle of the hallway. I stood with my arms crossed, and I just kept getting louder and louder until someone came and talked to me. That's what I had to do. And finally I got loud enough that people came out of all kinds of rooms and ushered me into a quiet room, and I just said, "If someone had just come and talked to me the first time I asked, this would never have happened".*

The "wall" between the waiting room and ICU came to represent all the barriers that participants had to breach to gain access to their ill relatives, to nurses, and to physicians. It became a barrier to access to information to allay fears about the patient and their care, and to trust in the professionals. Using energy to breach this "wall" served only to add to their *'workload'*.

> *Then when we got to that set of doors, the doors were open and I was walking through; a nurse says, "Where are you going? You can't go. Stop!" I said, "I'm going in." "No, you can't." And it was like, holy cow! Talk about feeling powerless. That just about killed me. It was all I could do; it was like, "Oh, who can I call? I'm so upset here. I'm dying".... You have no idea what that does to somebody when they're stopped right there and say, "No, you can't go past this point." So those doors are like the Great Wall of China, and once you're past those doors, you're a part of what's happening.*
>
> *It was just awful. You would go there, push it. No answer.... So you were behind this wall, no visible person to talk to. Before I left I was going to punch the damned thing out, I really was. That's how angry I was at that wall.*

Participants' most imperative *'work'* was to "be present" at the bedside, both to demonstrate their love and commitment to the patient and to remain vigilant, hovering to monitor the situation closely. They were concerned about the vulnerability of their relative, and saw themselves as essential to the patient's welfare.

> *Because I knew that he could hear me talking to him, and I needed to encourage him to fight. That was my first priority, him, because we are so close that I had to be there.*
>
> *I wanted to be there to hold his hand and help him through it. I needed to be there to see him.*

Additionally, being present enabled family members to observe the patient's circumstances, to be reassured about the quality of care that was being provided to the patient, and to advocate on the patient's behalf.

> *I think for me when I first came in, it seemed like it was fantastic [care] because it was so much more – [I had] no expectations, I guess it just seemed like so very, very much [attention].*
>
> *I would have still insisted that we be allowed to stay.... So that we knew that we were doing all that we could in case something happened for the worse; so someone could be there for her when she woke up; and, to be perfectly honest, to hold medical staff a little bit more accountable.*
>
> *I just feel I have to be there to protect her, whatever, whatever I can do.*
>
> *He cannot talk for himself; he can't even ring a buzzer when he's in distress. So therefore I have to be there to do that.*

Family members wanted to continue to "be there" with the patient during resuscitation attempts, procedures, and physician's rounds. They did not want to have to leave the patient, as they knew that staying helped them learn and understand better what was going on. In the case of a "code", if their ill relative died they would be reassured by having been there at the time of death, knowing that all that could have been done had been done. Their *'work'* involved trying to influence nurses to allow them to stay.

> *She said that "The doctors are doing a round; leave now." We wanted to stay.*
>
> *They could have said "When we're doing an exam, have one person in the room. Please stand back against the wall".... Because here's a man who may not make it, and they needed to be with him.*

Although participants willingly devolved primary responsibility for their ill relative to critical care professionals when the relative's condition deteriorated to a physically dependent state, they did not relinquish all responsibility. They were confident in the professionals, yet remained “experts” in terms of their knowledge of the patient, and witnesses to the experience and the care provided. As witnesses, they accompanied the relative in their journey with illness and relayed the story to others in the family. They were also the link to the patient's identity beyond illness, to the life they had lived prior to the critical illness. As a result, the participant's '*work*' involved providing information to the professionals about their relative.

> *And he's a very, very well educated man; which makes it all the worse... So she's gotten to know our life through me telling the stories about it.*
>
> *If there were twenty women in the room, ninety-nine percent of the time she was the prettiest one there. And that's not my point of view; that's everybody's point of view.*

Participants were ever hopeful, and *'worked'* to sustain this hope, whatever the changing situation.

> *That's why I'm hopeful, because our relative's doing all these things, doing different things. I said, "You don't give up hope.*

As one participant noted, hope provided him with the courage to do his '*work*'.

> *Hope gives me courage to do my job. My job right now is to help her. I know in my heart that somehow my presence is helping, that she would have no reason to struggle back without someone calling her name every day.*

The '*work*' of participants included reducing uncertainty by learning all they could. They wanted information: so they could be reassured about the patient's situation; to help them deal with the unfamiliar environment; to be as knowledgeable as possible in order to make the best possible decisions in relation to the patient and; to gain the nurses' and doctors' respect. They gathered information by observing at the bedside, and by communicating with professionals and visitors in the waiting room, and/or with individuals and professionals in the community.

> *There's a learning curve here, I think, [about] the system. I ask lots of questions about the ICU, and the treatments.*

> *One of our best friends is an ICU nurse out at Calgary, so what we do is, we talk to her regularly on the phone. She tells us what to ask, what to look for, and she explains everything to us so we have an understanding.*

The information gathered helped them become oriented to the equipment, the unit, and the hospital and promoted their understanding of the patient's current condition, prognosis, and care. They *'worked'* in order for this information to be relayed honestly, respectfully, willingly, and in a timely manner, with nothing withheld.

> *I had to conform to that person [different nurse] every time I came in here, sort of tap-dance around them until you can learn to read them, so you could get the information.*
>
> *I question things and I ask why, and I won't be treated as an idiot.*

Participants expended considerable time and energy worrying about what they didn't know, and waiting for access to information.

> *What's wrong? I'm really worried. We haven't heard anything. It's been two hours. It's been three hours. Where are you?" And they were very, very upset. And I know she said that that was just something that she couldn't sit through; it was just unbearable for her.*
>
> *When they don't tell you anything, then you have all kinds of horrific pictures in your head.... But when they just ignore you, like I was telling you about that first episode that I had, it was horrifying, because nobody wanted to tell me anything.*

Access to the patient and access to information were interconnected. The necessity to "wait" to gain access to the bedside and therefore to information, was dictated by the individual nurse and by unit policy. In both hospitals, each nurse had the authority to make decisions about family visiting based on patient acuity, treatments, change of shift, and the nurse's personal preferences about family presence. Some nurses never asked family members to leave; others kept the family waiting for long periods of time. Nurses also had the authority to speak with family about treatments and expectations. Some nurses never spoke with the family but worked around them. Patient length of stay was another influencing factor; the longer the stay, the freer the family member access became and the more there was opportunity for being informed. Regardless of the influencing factors, participants looked first to the nurse for access to information, most particularly because the nurse was "there".

> *[I wish nurses] had some more time off to talk about what's going on with B. But usually they say, "Just hang on a second. I'm busy right now." If a person's concerned, if a loved one is concerned, they should take some time off and explain some things. And they should have the same experience as a doctor, the same info as a doctor [instead of] saying, "You're going to have to ask the doctor that, because we don't know very much." Well, they should know lots. Because the loved one might have a question, and if the doctor has gone somewhere out of the hospital and the loved one comes to see their loved one, then they should know exactly what's going on. They should know the exact information so that while the doctor's out of the hospital, then they'll give the information to the loved one instead of waiting till the next day.*

Participants became more familiar with what to ask and look for, as well as with the routines, equipment, and terminology, as a function of proximity and time spent in the ICU.

> *I sort of learned and understand the routine and what happens in here, so it's easier for me to be able to deal with and understand what these people do so I can kind of accommodate around them. When you first come in off the street and you walk in here, you have no concept of what's going on, so it becomes a learning experience for you.*

Nonetheless, the unpredictable nature of critical care resulted in the continual need for family members to seek updated information about the patient and treatment options.

> *They managed to stop him from dying, and for a day or two there was kind of a respite period where balances were retrieved, and then it would gradually go down again for whatever reason into the next crisis. I just dealt with whatever happened. So there was really nothing that I could do other than be there and find out exactly. I always asked them exactly what they did afterwards and why they had done it that way; I always asked the questions.*

To better ensure their chances of getting access to the patient and to information, participants' '*work*' encompassed being courteous, accommodating, and diplomatic, in order to gain the professionals' respect and trust, and to avoid confrontation. The latter situation could result in the family member being "shut out" from the bedside and therefore from being informed. Their "good" behaviour on the other hand, might be "rewarded" with easier access to the patient and to information. Participants *'work'* involved a balancing act.

> *You don't want to be overbearing with them because you may piss them off where they avoid you or they don't want to talk to you, so you end up getting no*

> *information, so you find yourself in a balancing act where you're trying to get all the information and decide what's going on without offending anybody.*

Their *'work'* also consisted of providing some aspects of patient care, depending on the circumstances, and getting involved in decision-making.

> *They said I could brush her hair when I brought in the brush. And yesterday I noticed her skin was getting quite chapped, and I noticed that her cuticles were all really in, and so I asked the nurse, and it happened to be one of the casuals. He was really impressed with me, so I asked if it was okay if I put some lotion on her, and he said, "Oh, yes," and it would stimulate the circulation and that sort of thing.*

> *I had the idea in the back of my mind that this [end of life] was a decision that I was going to have to make.*

> *I went in to see the doctor to tell him that the family had decided, and I was in support of turning off the machinery. "You have been his strongest ally, and now you want to turn the machines off?"*

Ultimately, participants viewed themselves as indispensable to the patient care team and their involvement as a necessity. How effective they perceived their involvement, was based on their relatives' illness experience and the outcome. Some participants expressed regret about not having tried harder to be more involved and experienced anger and guilt as a result. This in turn influenced the time and effort required for them to move on following the patient's discharge or death.

> *I still think about it. I am still angry over it; I think I'll always be angry over it.*

> *I get so mad at myself, because I would say, "I should have said this, and I should have said that.*

Participants reflected on their experience with the critical illness of a relative, trying to *'work'* out the significance of the experience to them. These "searches for meaning" were individually experienced, and the meanings ascribed as diverse as the participants. Some spoke of rekindled faith, renewed relationships, new understandings, new purposes in life, and new realities yet to be discovered. These meanings were important to them in sorting out how and where this experience fit into their lives.

> *I'm carrying on for her. She's looked after me for twenty years; it's my time to look after her now, because she did everything for me. I was so spoiled.*

> *But there's been things happening that I can't explain, and there has to be a reason. There's so many people praying for her; there has to be somebody up there listening. Even my mother is! My dad was killed when I was ten years old, and she lost her faith. But recently she's started reading the Bible again. They say that always something good comes out of something bad, so who knows? But somebody's helping her.*

Lastly, participants' *'work'* involved activities to sustain themselves by conserving energy. How this self-care *'work'* was addressed varied, dependent on the trajectory of the patient's illness, the family configuration, finances, external responsibilities, availability of amenities, social support, and place of residence. For some this meant cutting down on the number or length of visits to the hospital, or choosing not to visit; for others it meant finding accommodation closer to the hospital; some sought out other professionals to promote hope and to deal with sleeplessness and stress; some developed new social support networks; others strengthened existing networks; some cried to relieve tension; others needed to be stoic.

> *I don't have the energy right now to be there every day, and I'm smart enough to know it... because I know I have to take care of myself and my kids. It's self-preservation. You have to do what you have to do, and this is how I have to do it. I still go every other day. My sister goes up when she can. I got a call from a nurse the other night. I'd been up during the day, and she said, "Your relative wants you to come up." She said, "she's lonely." And it breaks my heart. So I got my brother to go up. My dad's not handling it well, so he's not going up.*

Each participant's level of commitment to the patient was intense. Consequently, the *'workload'* participants shouldered and the '*energy*' they expended in meeting their perceived responsibilities in order to *'get through'* the experience, led to the interpretation of this *'work'* being akin to '*carrying a heavy load*'.

> *Oh, it's way more than work. I've said that to a lot of people. This is the hardest job I've ever done in my life; it's just the hardest job I've ever done in my life.... Being involved in this now is like going to a job that you just hate. You can't stand it. But you're so far in debt you just have no choice, type of thing. You just have no choice, and you just hate every second and every minute and every day, but you still have to do it...." So when you have that type of responsibility, or that commitment, you've committed to doing that, you've got to be there for the person you love most in the world.*

It therefore follows that from the participants' perspective, nursing support was at the very least about "not adding to our *'work'*", and ideally, about ***LIGHTENING OUR LOAD.***

> *I think where you come in on [in this study], is the important side of the family members – and what it takes for them to get through this with the least amount of grief and heartache.*

The Process of Nursing Support:
LIGHTENING OUR LOAD

Overview

The process of nursing support from the family member's perspective was revealed within the context of health and family systems, the critical care environment, and the *'work'* of family members of a critically ill adult. Analysis of the data gathered from the perspective of individuals who were recipients of nursing support ultimately resulted in the development of the core category of this process, ***LIGHTENING OUR LOAD.*** Nurses impact the family member's *'workload'* along a continuum from positively, through neutrally, to negatively. Positive involvement is supportive and the converse, unsupportive. When nurses engage in activities perceived by family members as supportive, the nurses are ***LIGHTENING OUR LOAD*** (see Figure 1).

When supported, a family member's *'energy'* is conserved, rather than directed solely at activities to remove barriers. On the other hand, unsupportive nursing creates or maintains barriers that prevent family members from fulfilling their perceived responsibilities to the patient, the family, and themselves, increasing their *'workload'*. *'Energy'* is not conserved, and nurses do not *'lighten our load'* but indeed add to the family member's *'workload'*.

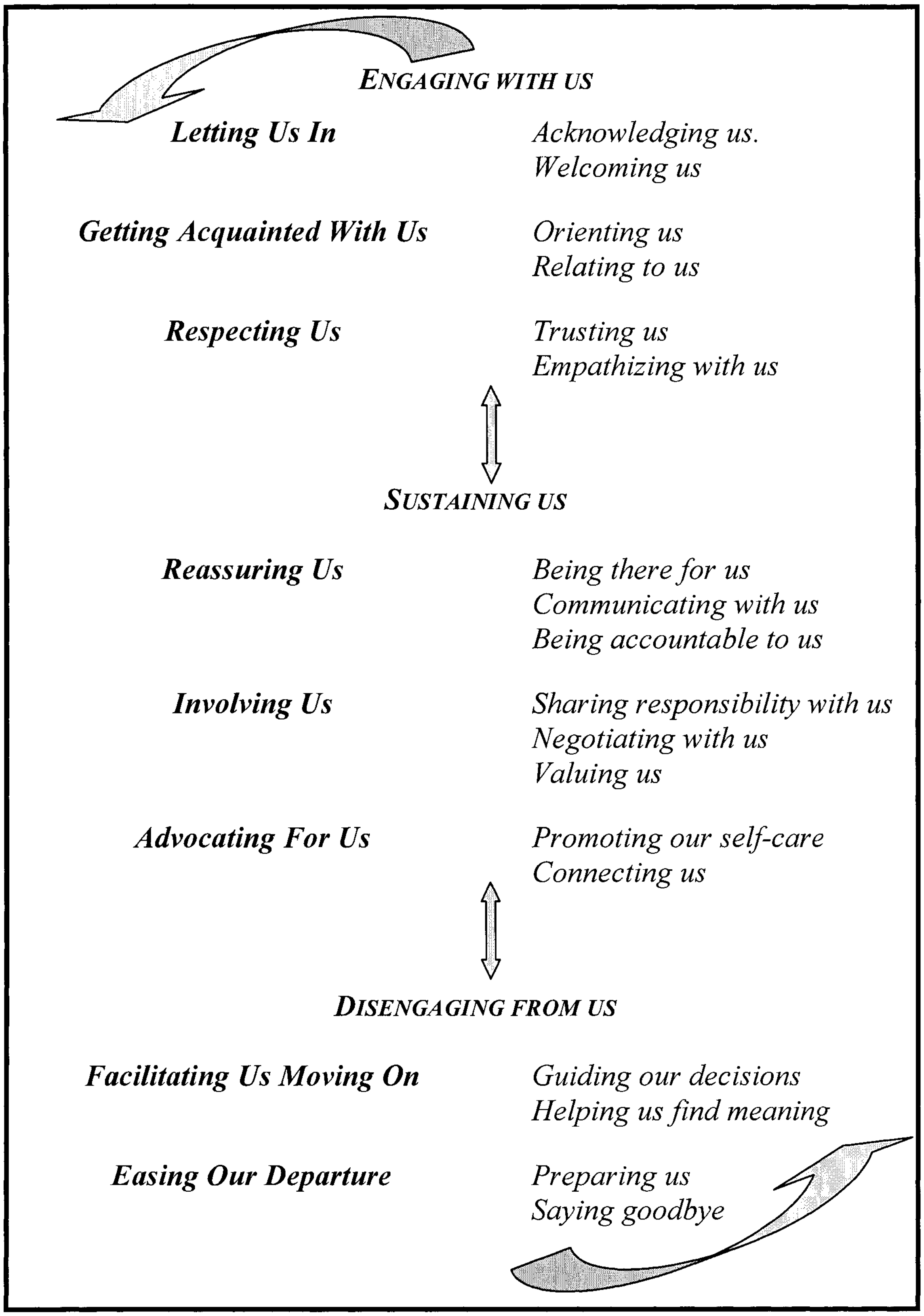

Figure 1. The process of ***LIGHTENING OUR LOAD***.

The process of nursing support, ***LIGHTENING OUR LOAD*** consists of three interconnected, cyclical, and recursive phases: ***ENGAGING WITH US***, ***SUSTAINING US***, and ***DISENGAGING FROM US***. Though the process is presented linearly as discrete phases and categories, there is an interdependent aspect that a one-dimensional representation cannot adequately capture. This process of critical care nurses ***LIGHTENING OUR LOAD***, begins with the admission of the patient to the critical care unit and is based on family member participants' perceptions of critical care nurses helping them in their *'work'* to *'get through'* the experience. The end of the process is much less defined, but in general terms, draws to a close following the death or discharge of the patient. The process of nursing support therefore, is situation specific.

ENGAGING WITH US is the initial step taken by nurses to support family members, during which a relationship with the family is begun. Nurses do this first by ***Letting Us In*** to the unit as soon as possible. This involves ***Acknowledging us***, in terms of the family member's relationship to the patient, his or her overriding need to be at the bedside, and the patient's need for family members to be there, and by ***Welcoming us***. When the nurse begins ***Getting Acquainted With Us*** by ***Orienting us*** and ***Relating to us***, the developing relationship with family members is strengthened. Names are shared; relationships and visiting privileges are clarified; expectations, roles, and responsibilities are discussed; and orientation information is provided as the situation and patient acuity allow. If the nurse and family member have met before, they become re-acquainted. As they become acquainted or re-acquainted, ***Respecting Us*** begins or is extended, as family members perceive nurses to be ***Trusting us***, by looking upon family members as competent and asking family members questions about the patient. Engagement with family members is further strengthened when nurses are ***Empathizing with us,*** by demonstrating an awareness and appreciation of what is important to family members such as when keeping waiting times to a minimum, and when providing family members with frequent updates about the patient.

Next, family members perceive being supported when nurses are involved in ***SUSTAINING US***, which further strengthens the developing relationship between them. Nurses sustains family members by ***Reassuring Us***, first by ***Being there***, present at the bedside, then by ***Communicating with us*** through listening, sharing information, helping family members understand, and chatting with family members, and lastly by ***Being accountable to us,*** in terms of providing competent, consistent, and responsive care. Family members are being sustained when nurses offers them opportunities for ***Involving Us*** in patient care, through ***Sharing responsibility with us***, ***Negotiating with us,*** and ***Valuing us***. Further, nurses are ***Advocating For Us*** in terms of our personal needs, by ***Promoting self-care,*** in which basic amenities for food, rest, and comfort are made available, and by ***Connecting us*** with other professionals and services, such as by organizing interdisciplinary meetings, referrals to other professionals, and case conferences with physicians. In so doing family members are further supported in their *'work'* to *'get through'* the critical care illness of their relatives.

When the nurse responds to the range of situations signifying "departing", such as when leaving for breaks or at the end of shift, family members are supported by nurses ***DISENGAGING FROM US***. This also includes nurses responding to family members' departures at the end of visits, when the patient is transferred from the unit, as well as when the patient dies. For each of these departures, supportive nurses react to the changing nature of the situation, ***Facilitating Us Moving On*** by ***Guiding our decisions*** and ***Helping us find meaning***. In supporting us by ***Easing Our Departure,*** nurses are ***Preparing us*** for the transition and then bearing witness to the intimacy inherent in the experience by ***Saying goodbye***. ***Saying goodbye*** could include nurses attending the funeral, visiting the family on another unit, and sending a card on an anniversary date.

From the family member's perspective, each of these phases of the process of nursing support occurs over minutes, hours, or days, based in large measure on family members and nurses being present together at the bedside, and the length of time they are together. The phases of the process of nursing support, ***LIGHTENING OUR LOAD,*** recur to greater or lesser degrees, with every family member and nurse encounter. The extent of the connection may be minimal, as is the case when the nurse comes into the room to help or cover for the assigned nurse. In this instance ***ENGAGING WITH US,*** result simply from being greeted, ***SUSTAINING US***, from the nurse's presence, and ***DISENGAGING FROM US***, when the nurse waves goodbye. On the other hand, the strength of the engagement may be such that family members are not only included as members of the patient care team and involved in decision-making, but following discharge to another unit, the patient and family may be visited by critical care nurses. Alternately, following the patient's death the nurse might attend the funeral, or send a sympathy card.

Thus, whether or not the family member and nurse have met before, how each encounter unfolded, the time spent with each encounter, and the length of the patient's admission, influence the speed, depth, and breadth that each phase is experienced. The individual nurse, patient, and family member circumstances, as well as those of the family unit, the specific ICU and hospital milieu, and the nurse's workload, schedule, and level of comfort working with the patient while family members are present, also influence how the process of nursing support is enacted over time. This context represents dynamic forces, which collectively shape and reshape the process of nursing support. ***LIGHTENING OUR LOAD*** alleviates some of the family's *'workload'*, and in so doing, bolsters the family's innate resources to '*get through*' the critical illness of one of their members.

LIGHTENING OUR LOAD:

ENGAGING WITH US

Family members are overwhelmed at the time of admission by burdensome emotions such as uncertainty, fear, disorientation, and frustration due to protracted waiting. Family members want to be "allowed in" to the bedside and when there, for nurses to demonstrate “people skills and compassion” and “nursing from the heart, not just the head”. When the nurse accepts the importance of working with the family, and is helpful, friendly, and responsive to them, family members feel supported.

> *Being supportive is knowing that there's a lot of turmoil. There's a lot of stuff going on besides the person that's in the bed; and the nurses having the smarts to know that you are not only dealing with a sick person, you're dealing with his family and everything else that goes with it. Taking a genuine interest in you as a family. That's the kind of support [we need].*

Conversely, when the nurse keeps family members waiting, and after finally letting them in, does not greet, smile, or otherwise respond, family members perceive a barrier between the nurse, and the family. As a result family members become even more anxious, not knowing where to turn for help, and sensitive to both positive and negative cues. Some family members may choose to confront the nurse. Such anxiety drains family members of energy needed to meet their needs and responsibilities, and make it harder for them to *'get through'*.

> *Oh, my heart was just pounding. I was having an anxiety attack. Do they realize how stressed you are? All it would take would be for someone to come out and say, "He is fine, but we have a crisis with someone else." We as the loved ones, or whatever you want to call us, the thorn in their side, that's what we really are. They don't want us around. We're not treated as having any feelings or emotions.*
>
> *It was actually to the point where I said to the head nurse, " This nurse cannot be supportive of us, so maybe you need to find another nurse for my relative."*

Nurses begin to lighten the family member's *'workload'* by ***ENGAGING WITH US***. When the nurse lets family members in (or speaks to them on the phone) and greets the family with a smile, and responds both verbally and non-verbally to them with compassion and respect, the weight of the family member's load is lightened.

> *The good nurses...they'll speak to you. They will actually treat you right, with compassion.... It is so helpful.*
>
> *That one nurse is in my corner. The nurse is your first line of defense. She's the one that sees you; she's the one that sees the patient.*

Overall, the nurse is seen to be someone who can help family members to accomplish what is important to them. Thus, for the family, ***ENGAGING WITH US*** involves the nurse ***Letting Us In***, ***Getting Acquainted With Us*** and ***Respecting Us*** (see Figure 2).

Phase 1: ENGAGING WITH US

Letting Us In	*Acknowledging us* *Welcoming us*
Getting Acquainted With Us	*Orienting us* *Relating to us*
Respecting Us	*Trusting us* *Empathizing with us*

Figure 2. The categories and sub-categories of ***Phase 1: ENGAGING WITH US***.

ENGAGING WITH US: Letting Us In

In order to meet their need to "be there" for the patient, family members want access to the critical care unit. When they are provided with ready access, they feel supported.

> *If there was a protocol or a system where they can offer you... "Would you like to come in and stay with your family in here? That would be so helpful.*
>
> *It would have helped to have had better access to my [relative].*

Generally family members feel that it was their right to be at the bedside.

> *You're invading their space [the bedside]. This isn't their space; this is our space.*
>
> *As a family member you know you damned well have the right to be there. You're her relative, and you should be able to be there when she asks you. Because it's contradictory when they say, "The patient is in charge. Whatever the patient wants is what the patient gets." And then the patient says, "I want my relative here"; they say, "No, he can't be in here." Sorry, then it's not what the patient wants.*

Some however see it as a privilege that can be earned by "good behaviour".

> *And they need to understand, people need to understand that it's a privilege to be allowed in here. It's a privilege to be privy to that information and being treated like an equal as a doctor or a nurse; it's not a right. And if people understand that or are clear on that up front, they may save a lot of problems in here down the road, because people get frustrated and they get pissed off when they're left out, they're not communicated with, they're not told what's going on, or they're treated or they're talked down to, right?... I don't believe they have a tendency to come here and cause a problem. What they do is, they get frustrated and they're hurt because a family member is where he is. And some people don't respond properly. Some people aren't mature; they take wrong decisions.*

Either way, family members are frequently "shut out" of the ICU and "shut out" from access to "engaging" with the nurse. One participant, who was "allowed in" to the unit and the patient's bedside, but "shut out" from access to the nurse by the nurse's aloof demeanour, stated, "the chair and I were the same thing". In these situations, family members are relegated to frustrating and fear-inducing waiting on the one hand, to feeling useless and in the way on the other. Family members in this situation expend energy in internalizing their feelings or in working actively to remove the barriers to access.

> *But once you're not in those doors, you phone and the nurse says, "Give us fifteen minutes." You phone in fifteen minutes, say, "Give us another ten minutes." You're lost; you're just lost.*

Family members question why some nurses kept families at arm's length.

> *Why do nurses fear families being at bedsides?*

Family members know that when the nurse lets them in to the unit, they have a chance to be "let in" to be with their ill relative and to what is happening with the patient, of prime importance to fulfilling their perceived responsibilities. ***Letting Us In*** by ***Acknowledging us*** and ***Welcoming us*** in a timely manner, results in family members being supported.

> *You can come in and see him now." They were never excluding the family, ever. We were always totally included, and that was really good.*

Conversely, when family members are not allowed easy access, their *'workload'* is increased.

> *So you're going through this mental battle, the waiting, waiting, waiting.... You've been told twenty minutes; now it's going to be another twenty minutes, thinking, My God, what's going on? They said twenty and it's been an hour now. There's got to be a problem. They don't think of what they're doing psychologically to the person outside. We have enough to deal with, and they're adding to it without even realizing it.*

Letting Us In: Acknowledging us. To be *Letting Us In'* the nurse must first *Acknowledging us* as "family", important to the patient's well-being and recovery, as well as acknowledge our "need to be there" for the patient and the family.

> *But families need to be there, for themselves and for the patients. My wife has said several times, several times to me - and it's hard to talk that way, but several times to me that she would not have made it if I wasn't there. And maybe that's not true; maybe she would have. But maybe she'd be a lot more bitter.*
>
> *One unit up there is very good; they want family support [for the patient].*
>
> *And also for them to realize that, yes, they're dealing with an extremely dangerous situation here, but the family does have a viable part to play. They are important, because that person in the bed responds to the fact that there are people from their own family, who are close to them, who are nearby and are willing to give them support.*

Family members do not accept the notion that the critical nature of the patient's condition precludes them from being allowed at the bedside, although some may accept being asked to leave at specified times. The supportive nurse acknowledges by his or her behaviour, the primacy of the patient and family member's need to be together.

> *It would be nice if you could be allowed in, to be part of the process when shift changes occur. ...We were always encouraged to be part of every process, except for ones that required that it had to be a sterile atmosphere. Obviously, we weren't allowed in if they were doing any invasive process on his body. But otherwise we were always allowed into the rooms, whatever was going on, which was very important.*

Letting Us In: Welcoming us. Nurses are *Welcoming us* when those hospitality actions involved in welcoming are performed: reducing waiting times; greeting the family warmly; inviting them inside; sharing introductions; and attending to basic comfort needs. If the situation is such that a longer waiting period is necessary, family members want to be provided with the reasons why, and with frequent updates, both of which help relieve their uncertainty. The manner of the nurse in *Letting Us In* or asking us to wait is supportive if characterized by warmth, openness, respect, and compassion.

> *When I would come in they would give me a hug. I think hugs really help.*
>
> *Nobody says you have to smile or have to be friendly, but it sure helps.*
>
> *What I experienced at the local hospital was close to hospitality.*

The range in individual nurses' responses to the presence of family is disconcerting to family members, as they are never sure what to expect, and need to be prepared for a different response with every shift.

> *He makes us feel welcome the second you walk in. Then you get a different nurse; all of a sudden you feel out of place, right? You can sense that they don't want you there.*

ENGAGING WITH US: Getting Acquainted With Us

In ***Getting Acquainted With Us***, learning who constitutes the family, and facts pertinent to helping the family members adjust to the critical care situation, are collected through completion of a family assessment. *Getting Acquainted With Us* by ***Orienting us*** and ***Relating to us*** is not only supportive because family members are validated, but also because family members' uncertainty and disorientation are alleviated as well. As the nurse and family member are *Getting Acquainted With Us*, the relationship between them is strengthened beyond the cursory "Hello, I'm L.V., your nurse".

Getting Acquainted With Us: Orienting us. Receiving information about the critical care environment lowers the barrier of lack of knowledge. *Orienting us* provides an introduction to the patient situation, initial information about the equipment, routines, and visiting, as well as facility information about parking, access, food, and lodging, all as required and at a pace dictated by family. As family member stress may influence retention of information, nurses review orientation information.

> *Sit down with the family, sit down with the members and say, "Hey, look, this is our routine. This is what we do. This is the reason why we do what we do. How much do you want to know? And then basically, this is what we expect out of you guys," so as we go through all the different nurses, we basically have a common ground of where we can stand. ...Yes, just a silly little thing. When you come from out of town, you don't know this hospital. Learning the shortcuts would be really nice. Took us what, four or five days to figure out?*
>
> *I says to the nurse, "Can you tell me exactly what a social worker does in here?" She says, "If you need to get things arranged for your family or hotel rooms or parking passes." I says, "Parking passes? What do you mean, parking passes?" She says, "You can get a parking pass for the car park; you don't have to pay." I says, "Why didn't they tell me that?" I had been paying for private parking over in the other car park. Now, if I hadn't said to that nurse that day, I would never have found out that.*

When *Orienting us* does not occur, family members are left struggling with the unknown, shouldering the responsibility for learning the routines and the system. They do not feel supported.

> *When I went in the first time...I didn't know if it was good to touch her or not, and here we are all gloved and that sort of thing, and I did want to reach out and touch her, and I didn't.... It would be nice, I guess, to have that offered; to be told that it was OK.*
>
> *Some things that you have to find out yourself: Where do I get parking? And you're panicky; you're trying to get up to ICU, and you're trying to get things in a machine, and then you have to worry about running back out again. Somebody could have said, "If you're going to be in here for awhile, we can give you a parking pass so that you don't have to worry about things like that." There could have been a lot more information to families.*

Getting Acquainted With Us: Relating to us. In *Relating to us*, nurses demonstrate an interest in the patient's family so as to understand who constitutes the family, and to begin exploring family members' perceived needs and their understanding of the situation. The completion of the initial family assessment is pivotal to the nurse learning about the family using a systematic format. This activity, requiring the nurse to focus on the family rather than the patient, provides opportunities for nurses to begin to "know" and understand the family and their individual situation. The information is included in the patient's chart, available to other nurses later assigned to the patient. Updates to the family assessment are ongoing. Change-of-shift reports include the most relevant details of the assessment. Furthermore, in *Relating to us* nurses and family members share snippets of information about each other as a function of proximity, time, discovering shared life experiences, and individual personality. Both the formal and informal aspects of *Relating to us* serve to transform the relationship from one of strangers to one of acquaintances, based on the developing familiarity between the nurse and the family.

> *When they remember your name, when they remember something about you, when you take on more than just being a family member and become a real person to the nurses, what a difference that makes and how supported it makes you feel.*

Relating to us includes getting to know who can have access, based on the family's wishes. This prevents the situation of access being provided to individuals outside of the family's “allowed” circle.

> *There were two people who had tried to get into his room that we didn't know. I had said that nobody was to get in there except myself, and my GP.*

Additionally, *Relating to us* involves the nurse learning more about the patient and their life before hospitalization, by listening to the family member's comments. As well, requesting a photograph of the patient and other members of the family for displaying at the bedside, validates the patient and the family who are *'working'* to ensure the best care for the patient. Photographs help nurse and other professional “see” the patient as a “person” with a life before critical illness, and help induce compassion and respect for both the patient and family.

> *He's such a character. If you knew him before - loved life. He worked fast, he thought fast, he read fast; he was a speed-reader.*
>
> *And some of the nurses, like I said, looking at the picture and saying, "Oh, is that your relative? And who's this?"*
> *She said, "I promised him that I wouldn't leave until he was better. But she's had to go back to work this week. Now there's pictures all over of her [to remind everyone she's still there]. They have this very special bond.*

ENGAGING WITH US: ***Respecting Us***

Once family members' goals of gaining access to the patient are met and they are somewhat comfortable with the environment, they begin to expect more in terms of how the patient and family are being treated.

> *I think that if the patient is being treated with the respect and compassion that they deserve, the family's going to see it, and the family's going to be happy with that. I was treated with respect, dignity, privacy. ... they do it politely.*

Respectful, dignified, and compassionate interaction between the nurse, patient, and family by ***Respecting Us*** is conditional on the nurse both ***Trusting us*** and ***Empathizing with us***. Conversely, a lack of regard for the patient and family members, as evidenced by protracted waiting, being asked to leave the bedside, and being ignored or patronized, and the need to gain the respect of every new nurse assigned, adds to family members' frustration and anxiety, and hence to their overall '*workloads*'.

> *After I talked to the head nurse and I talked to her supervisor, I got a little bit more, I guess, respect or a lot more freedom, I guess to be with my mom. But then when the shift changed, I had to go through it all again, so the frustration resurfaced.*
>
> *I just don't get much response from them at all. I don't know if it's the fact that I'm not his relative or even married to him. I'm younger; everybody calls me his daughter, and I'm not his daughter and that's mean. I'm tired of that.*

As time passes and experience with the critical care situation develops, family members expect nurses to respect that the family's knowledge has expanded, and to relay this information to other staff. Respecting family members as contributors to the team effort is perceived to be a "right".

> *After being there two to three weeks, you are not naïve about what's going on, you have a right to ask questions and get answers, and you have a right to be treated*

> *like somebody who is part of their team instead of being this person that comes in at odd times to visit.... They treat you like what I call the blank page. ... initially you are because you don't know really what's going on. You catch on fairly quickly what's going on here. And I think at that point, maybe after a day or two, they should rethink who you are and find out a little bit more about you. If you're there for any length of time, then they need to do that. People like myself, have as much knowledge very often as these people who are doing the treating. They just have the extra skills that I don't have, but I have the knowledge. And to treat me like a blank page is a little ignorant, and I did find it very distressing. Some...began to treat me with respect.*

When the nurse is perceived to be *Respecting Us* by *Trusting us* and *Empathizing with us*, family members feel supported in their *'work'* on behalf of the patient, and feel further validated by the nurse's concern about the well-being of the patient and the family members.

Respecting Us: Trusting us. Supportive nurses trust family members for who they are, for what they can do, as well as for what they know and have learned. As a result family members feel that they are then being regarded as intelligent and competent individuals with unique knowledge to share about the patient. This trust develops over time as a result of *Getting Acquainted With Us.*

> *There's a trust thing that goes on here. So when you're seeing the nurses all of the time, you start to feel more comfortable with them and them with you."*

When nurses trust the family member with the critical care situation, the family member is called in frequently or allowed to stay at the bedside more.

> *I get paged when they're done her procedures. Yes, they page me so that I know when to come over. They tell me "Everything is so much calmer when you're here." The environment just calms down. And I think that's what they have to realize, that everything can be calmer and stuff, and it's easier for the nurses,*

On the other hand, when the nurse is not *Trusting us*, family members feel patronized.

> *But I think they need to respect that I know my relative better than they do.... But what they did at one point is, what had happened is, they wanted to do an ECG on my mom, and they told me that having extra people in the room could affect the reading of the ECG. I looked at the woman and I said, "You've got to be kidding me. ... I said, "You've got to give me more credit than that".*

If the family member is considered "a troublemaker", doors close. Nurses *Trusting us* as demonstrated by allowing easier access to the patient, the nurse, and to information, can prevent such a situation from occurring.

> *I was talking with the nurse about some bad family people, and I think, nurses may save a lot of problems in here down the road, because people get frustrated and they get upset when they're left out, they're not communicated with, they're not told what's going on, or they're treated poorly or they're talked down to, right? The nurse figured, about twenty-percent of the family members he gets are troublesome. People, I don't believe they have a tendency to come here and cause a problem.... [It happens because] they're shut out and not trusted.*

Respecting Us: Empathizing with us. Family members are respected by nurses *Empathizing with us* when they: give of themselves; are understanding, kind, and compassionate; and demonstrate a deepening engagement with, and consideration of, each family's uniqueness.

> *I was sitting crying one day, and two of the nurses that came in spoke to me, and they started crying too. I've never seen a nurse cry; I always thought nurses had to be really hard. I knew that there was compassion there.*

> *It shows that they're interested and they almost want to be sharing in your feelings. If a nurse didn't have those qualities, then it's kind of like a cold feeling, and it's like he could be just any patient lying there. But it's just that you want to feel that they think he's special.... It's just showing [themselves] to be concerned.*

The empathetic nurse realizes what is required in any given situation.

> *They have empathy and sympathy for my position, and they convey it. She was really helpful in getting us a car pass and just being empathetic.*

> *They sympathized with me, and they wished that they could do something for me; was there anything they could do for me? Because being alone in this country now, I've got so many responsibilities, you wouldn't believe.*

Furthermore, nurses demonstrate being "in touch" with the family, by personalizing care for both the patient and family members, from nurses painting the patient's fingernails or curling a patient's hair, to bringing videos for the family members to watch.

> *Do you know that he [the nurse] arranged for the lady harpist that was playing at Christmas time and in the lobby to come and play outside my relative's door, because he knew that he loved classical music? I had told him this. I just, I was so overwhelmed I couldn't believe that somebody would do that.*

By ***ENGAGING WITH US***, access in terms of the patient and the nurse is open, which promotes nurses and family members getting to know each other, and family members feeling respected by nurses for the role they can play. ***Letting Us In, Getting Acquainted With Us***, and ***Respecting Us*** are supportive to family members *'working'* to meet their perceived responsibilities in order to regain a degree of control.

> *I think one of the things that really got me to begin with was the fact that you had to call in before we went down. But once we had set up a relationship with the nurse, we didn't have to any more; we could just go back and forth.*

By contrast, when the nurse is not ***ENGAGING WITH US***, family members are unable to meet their perceived responsibilities. This situation therefore involves more *'work'* and *'energy'* expenditure.

> *In that room [waiting room] there were probably six families, and they were all saying the same thing. They were all just so upset by the fact that they felt they had no say or control in what was going on. Had a nurse offered it [access] to them as an option, I think they would have been less sad, less troubled, because they would have had more access; they would have had more control; they would have felt that they had more input.*

LIGHTENING OUR LOAD:

SUSTAINING US

SUSTAINING US involves nurses supporting family members in "going the distance" in terms of accomplishing their goals and fulfilling their perceived needs and responsibilities in response to the critical illness of their relative. Family members are reassured when the nurse is at the bedside, providing information about the patient's situation and communicating warmly with them. When family members experience nurses providing competent care that is consistent among nurses, and when nurses respond to family member feedback, family members are reassured and supported in their *'work'* of monitoring the patient situation. Family members see themselves as integral to the patient's recovery, involved to varying degrees, in providing care to the patient and in decision making. Finding a range of amenities readily available promotes family members' self-care, required over the long term to sustain them in "carrying on". Interceding on their behalf with physicians and making referrals to other professionals, individuals, and services, are additional nursing actions considered supportive to family members, particularly in terms of sustaining them over time. Therefore, when the nurses are *SUSTAINING US,* family members are not only in a better position to concentrate on the *'work'* of "being there", "gathering information", "advocating", "and "caring" for the patient, but can concentrate as well as on the *'work'* of "self-care" related to individual, family, employment, and social obligations. Thus, ***SUSTAINING US*** involves nurses ***Reassuring Us***, ***Involving Us***, and ***Advocating For Us*** in supporting family members work to *'get through'* the critical illness of their relatives (see Figure 3).

***Phase 2:* SUSTAINING US**

Reassuring us	*Being there for us.* *Communicating with us.* *Being accountable to us*
Involving Us	*Sharing responsibility with us.* *Negotiating with us.* *Valuing us.*
Advocating for us	*Promoting our self-care.* *Connecting us.* *Relating to us.*

Figure 3. The Categories and sub-categories of ***Phase 2:* SUSTAINING US.**

SUSTAINING US: ***Reassuring Us***

Reassuring us occurs then, when nurses are: visibly present at the bedside providing competent, compassionate, patient care that is consistent among them; using effective communication; volunteering information; and ensuring that both patients and family members understand care decisions and feel safe in sharing their concerns. They may even share informal conversations with family members, as well as humour and touch. Therefore, *Reassuring Us* results from nurses ***Being there for us***, ***Communicating with us***, and ***Being accountable to us***. These measures taken together, serve to decrease family members' uncertainty about what is going on, to promote their trust in the care and the care providers, and to strengthen their hope. Family members need to keep hope alive, and to this end, look for reassurance in terms of the nurse's presence, the information sharing, knowledge about the patient's situation, and competence in providing care.

> *And they would tell us little things on a day-to-day basis what was happening the night before, and we would be always pleased just to hear. "His ICPs weren't quite as high last night." Just any little thing would be a plus.*

Hope is essential, but is also easily undermined.

> *I don't care. I think no matter what situation you're in you have to have a little hope. You have to have some hope. I don't care how desperate the situation is, even if you focus off the problem and focus onto something else for hope. If there was no hope for him, could they not have focussed on me and wondered about where I was?*
>
> *You people don't believe this [that she'll recover]. And you don't want me to have hope. You seem resolved to take from me, the one thing I need to carry on.*

Reassuring Us: Being there for us. Family members are reassured by the nurse's presence at the bedside. They see this as evidence that the nurse is available to both the patient and the family.

> *[Nurses were] absolutely, very, very supportive. They're always there. They come right up to you when you come in. "I'm right over here.*

Since excellent patient care is of paramount importance to family members, the nurse's presence at the bedside provides an indication that their relative is being well cared for.

> *The one thing I really like is the fact that whenever they're dealing with P., even though he doesn't respond to them properly and they don't know whether he can see them properly, they always call him by his name, and they tell him exactly everything that's going on and why they're doing what they're doing, and they do it all the time. And I think to me that's giving him total support; that's giving him the benefit of, "I'm not sure whether you really understand what's going on here, but I'm going to try and allay your fears." And that's what I mean about [me] having total support.... They treat my relative properly; it's very important [to me] that they do that.*

Being there provides nurses with the opportunity to share information, to anticipate and respond to questions, and to respond compassionately to cues regarding the family's emotional response to the situation, be it hopelessness, fear, and frustration, or joy, and relief.

> *I haven't had any problems. They're [nurses] right there; they're honest. They tell us what's going on; all you've got to do is ask. If you've got some questions, I'll answer your questions."*
>
> *Someone just to hand you a Kleenex or just hold your hand or just be there.*
>
> *They were all very supportive. They knew we were from far away, and I think that kind of added to the sensitivity. They were constantly just putting their hand on my shoulder or just talking about things in general, asking questions about back home, and just their overall concern.*

Compassion takes on many forms, not the least of which is the manner in which the nurse addresses and attends to the patient. When family members see the nurse working to make the patient comfortable, speaking to a patient who is comatose, and "doing little extras", they are reassured that the best care is being provided to the patient, care the family would have provided if they could have.

> *When they're doing things for F. that are a little extra, one of the on-callers has pulled the music table over to her. Now, how do you think that's supportive to me? Well, that's supportive to me because I see them doing little extra things for her that might make it a little bit better.*
>
> *I like to feel like, yes, they are trying to make him comfortable, as comfortable as they can. Even if they can't make him comfortable, but you feel like they are. And it makes you feel good, because you feel kind of helpless. You've got all these tubes there; you can't very well go turning him over and doing all these things that you feel he needs. So I think... you'd call that compassion for the person who's ill.*

Being left alone with the patient for long periods of time, only serves to increase the family member's anxiety, and hence, their *'workload'*. They want reassurance that the patient is not being forgotten or overlooked and that the family member is not responsible for handling events such as alarms ringing. A nurse being present most of the time is supportive, as the family member then does not have to be as vigilant as when there is no nurse present. If there is no constant supportive nursing presence, many family members feel they must work at being vigilant, by remaining with their relative.

> *When a nurse wasn't at his bedside, it was scary. It was like, "Are they going to be here if anything drastically happens?"*

> *She's just totally vulnerable, and that hurts me. And anybody who's totally vulnerable like that I think looks for as many things as they can find to feel secure, to feel like the people around them are going to keep them safe and secure. If they've got somebody in the room that's treating them bad or being miserable to them, that just takes away their secure feeling. So I have to stay.*

Reassuring Us: Communicating with us. Family members are reassured when nurses use open, respectful communication with family members about the patient's situation and family concerns, on a "professional but human" level as well as on a social level. *Communicating with us* supports family members in their *'work'* of strengthening hope, reducing uncertainty, making decisions, and advocating for the patient. Knowledge is power. The nurse *Communicating with us* results in family members being empowered to manage their *'work'*. Conversely, when nurses communicate poorly, family members are left feeling frustrated, alienated, and/or patronized. They are disempowered and therefore need to expend energy internally, feeling frustrated, or externally, in fighting the system. Their *'workload'* is not lightened.

> *What they do, they come in the room, check it out, sit down, read the paper or whatever, look at the monitors, sit down, whatever. I was here last time for three hours, and not once did she speak to me.*

Supportive communication through informing us, helping us understand, hearing us, and chatting with us, is vital to enhancing the relationship between the family member and the nurse. Additionally, the nurse's approach or style of communication influences the nature of the relationship with the family, including tone of voice, facial expression, body language, and touch. Sharing humour and touching as appropriate, strengthen the connection between family members and nurses, and serve to decrease the family member's isolation.

> *When I would come in they would give me a hug. I think hugs really help.*

> *Communication is the key. The more you communicate, the better the world gets along. The less you communicate, the more problems you have.... And if people understand that or are clear on that up front, they may save a lot of problems in here down the road, because people get frustrated and they get pissed off when they're left out, they're not communicated with, they're not told what's going on, or they're treated or they're talked down to, right?*

Initially, family members are most interested in getting information about the patient situation. Nurses, in informing family members, support them in their 'work' to gather information.

> *They don't just wander over to their desk or anything; they come up and they say "If you have any questions, I can answer them for you" sort of thing, and they almost immediately tell you, "No worse, no better" sort of thing, which is good, because it's nice to know that right away, because a lot of people will stand there and just stare. They're afraid to ask questions. ….*

To be supportive entails more than just the nurse providing information. It involves nurses relaying information in a friendly manner that is both respectful of the recipient's level of interest and that is non-patronizing. Family members want nurses who are "up front", and honest, to help allay anxieties. Family members are reassured when they know what is going on, and know that they are "in the loop".

> *They're friendly. They were doing everything they were supposed to do.... and everybody's been up front, which is probably what's been the easiest, instead of you dragging it out piece by piece to get through, so it makes you anxious. I haven't been anxious; nobody's given me a reason to be anxious. I think that's it. I always knew exactly what's going on.*

An unrealistically positive approach "painting a rosy picture" does not help, nor does information provided in such a way as to be disrespectful of the family member's need for hope. In the exemplar that follows two different individuals explained the same situation to the participant; the second individual promoted hope.

> *"We don't want things to happen quickly, because just as quickly he'd come down." He says, "Just slow and steady," and that's what he is doing, slow and steady.... [Rather than]"Your relative's age is against him, and quite frankly, in my experience, in all the fifteen years I've been doing this, I have never seen anybody recover after this, blah, blah, blah, blah, blah." Some people gave me no hope. There was no hope in those words.*

When nurses communicate honestly to family members, they feel respected and valued and in a better position to make informed decisions.

> *Just being able to go in there and ask questions and have people answer them for me in an honest way.... They give me respectful answers and treat me like I am an intelligent person and I can understand what's going on. That's very important to me.*

Effective communication between family members and nurses involves active listening for both verbal and non-verbal cues, in order to "hear" the family member. When nurses demonstrate their interest in family members by listening carefully and actually hearing in order to understand what is important to them, family members are reassured.

> *I just smiled to myself, because it made me realize they'd actually heard what I said in the end.*
>
> *So those are the things that matter to me, that people actually listen to what I say.*
>
> *They listened to me when I was talking and telling them about my problems and things like that.*
>
> *It's got to be intimate to the individual based on their relation with that individual.... Then in that aspect, the nurse needs a course on active listening.... You've got to read the individual,*

As well, when nurses are *Communicating with us*, it is necessary that they check the family member's understanding. When nurses clarify and promote the family member's understanding, the family member becomes more confident in their knowledge of the equipment, the care, the nurse, and the terminology.

> *Say, "Hey, I'm going to check his blood pressure right now. Do you want me to explain to you what blood pressure's all about?" That'd be wonderful. But don't tell me big stories. I don't want big words.*
>
> *But the more she understands, I think, the easier it is for her.*

When the nurse explains "why", family members are reassured that they know what is going on and can have more certainty about their knowledge when they convey the information to others.

> *They were very caring, they were very kind, they were very patient, and communication was excellent with them. They'd go to L. and say, "This is what I'm doing. This is the reason why" and stuff like that so that you understood what was going on and could tell the others.*

Conversely, when explanations are not readily available from the nurse, family members have to look elsewhere, adding to their '*workload*'.

> *We went to the outside to get that information, because they didn't seem to open up and explain to us what was going on. If someone doesn't tell you what questions to ask, how do you know, without training? So you kind of walk in here,*

> *you look at the living dead, and you have no clue of what's going on and whether things are going in the right direction or the wrong direction, because the important thing for people is to come in and be able to understand what direction those people are going. If he's on the upswing or the downswing or if he's in neutral still, right? Because that's what you have to go home and think about and go to sleep with.*

Nurses and family members spend a fair amount of time in each other's presence. When nurses move beyond communicating patient-related information to sharing on a more social level by "chatting", family members are gratified.

> *I don't mind that [having a social conversation] at all, because at least I see them as human beings that way, and that's important to me.*
>
> *Some of them tell me, especially some of the people who have been doing this for a while, they tell me what they've done in the past, who they have worked with, what their interests have been in terms of their medical development as it were, and things that they've done. They also tell me about their own personal experiences with various things too, to explain stuff sometimes. And some of them are quite willing to talk about their family situation and theirs compared to mine.*

Communicating with us by "chatting socially" is valuable to family members, as this type of conversation involves them in an informal social interaction with individuals to whom they do not have to explain the situation. Staying at the hospital for days on end socially isolates family members, both because of the nature of the situation and because of the demanding nature of the effort required to explain the situation to friends. It takes little effort on both sides for social chit chat to occur between nurses and family members, and results in family members feeling respected, more "a part of", and less lonely. They may even benefit from the release that a bit of humour can bring.

> *And I feel the same for myself that they don't know me that well, but they treat me with respect, and they include me, and I can have a conversation, because it's a very lonely kind of a situation to be in for yourself*
>
> *They [nurses] bring a sense of humor out there, and that's very important to have that sense of humor too.*

Reassuring Us: Being accountable to us. Family members look to nurses for reassurance that excellent care is being provided, and that there is continuity in the care provided. This reassurance affords family members confidence that all that can be done is being done, confidence that they know what to expect from shift-to-shift and day-to-day, as well as confidence that family members can leave the bedside without having to worry about the quality of care. Nurses who are *Being accountable to us* take responsibility for their actions to provide competent care. They acknowledge and address errors to ensure that patient care is not further compromised, and they respond to family member feedback. Therefore, in *Being accountable to us*, nurses demonstrate to family members that they are individually competent and that there is continuity in the provision of patient care across nurses, and that they are responsive to feedback from the family.

Indicators that their relative is being well cared for begin with the patient's admission to the critical care unit, which corroborates the family member's understanding of the severity of the patient's condition. Family members expect that the critical care unit is the place where the most intense care is provided, and where patients receive one-on-one attention from expert professionals.

> *I think for me when I first came in, it seemed like it was fantastic [care] because it was so much more – [I had] no expectations, I guess it just seemed like so very, very much [attention].*

They are reassured by seeing the individualized care being provided to their ill relative.

> *They're continually talking to him like he's a person rather than just somebody they have to look after because they're getting paid to do it.*

Family members are further reassured when they observe that the nurse is competent in providing this individualized patient care. To them, nursing competence should be the "norm" in critical care.

> *I think competence is really, really important.*
>
> *But to me that's nice to see that someone is looking after my relative that cares that he's getting care, good care.*
>
> *But then once I saw the care my mother was getting, then I felt more comfortable. Ultimately, though, the care for my mother was very good, and that's all we cared about.*

Consequently when the nurse demonstrates competence, family members do not feel that they have to remain constantly at the patient's bedside to protect and care for the patient. Conversely, when nurses are seen to be less than competent, related to the nurse's experience, knowledge, workload, and commitment to the patient, family members feel that they cannot leave the bedside, and if they do, they worry until they return.

> *I felt like part of her safety was in my hands because of the things I caught: leaking IVs and lines being pulled and stuff that they should have noticed that they just didn't.*
>
> *The things that have happened, and nobody around; a bleeder in her chest that nobody noticed. I had to find it.... Well, geez, I wonder what they do all night while I'm asleep. So you worry about that stuff.*
>
> *They kept saying, "You have to go home and get your rest?" and I said, "I can't go home, because I have to watch that he's getting the care."*

When competent patient care is consistent among nurses, evidenced by continuity in care provision, family members are reassured as they have a sense of what to expect over time. However, participants complained of a lack of continuity, related to patient care being inconsistent across time and among nurses, rooted in individual nurse attitude, overwork, understaffing, and the short-term nature of most critical care admissions.

> *I think that the continuity problem was definitely a major concern, and thinking about it, it still is. And I don't think that in many cases the nurses had the opportunity to deal with continuity issues. They never did have the time. If anybody new came on, they never did have the time to read back through all those notes and be really up-to-date with everything.*
>
> *So nurses could be used in a better way as far as continuity goes.... I think that the case-management situation should be handled in a different kind of way if it is looking like it's a longer-term situation. See, they're only geared up for the short term, because they basically believe that the person comes in, they either get the crisis dealt with immediately and then get moved off to somewhere else, or the person dies.*
>
> *So you have the nurses changing every shift; you have the doctors changing every week, if not more frequently than that, and there seems to be cracks that occur then in terms of information being shared back and forth.*
>
> *I felt there was lack of communication. And then again the frustration when their shift changed, and I had to go through the whole process again.*
>
> *This lack of consistency has nothing to do with cutbacks; it definitely has to do with people not appearing to care.*

Consistency requires that patient records are updated as changes occur, and that summaries are made available. These actions are supportive to family members by providing them with reassurance about the reliability of patient care over time.

In responding to family members, the nurse is "open" to comments from them, and reacts to their questions and both positive and negative feedback and suggestions, in a professional and responsible manner. Consequently family members feel "safe" and supported in their *'work'* to gather information and to advocate for the patient. In *Being accountable*, responsive nurses realize that family member questioning helps family members clarify their knowledge, and that the feedback family members provide nurses is meant to be helpful in the overall care of their relative.

> *What you need to ask yourself is, what is acceptable to the family? Because that person in that room is more important to us than that person is to you." And I kept saying the same thing over again: "We want what's best for my relative. I don't want to jeopardize her care, but if the nurse is having a problem with us being there, then find us another nurse.*

> *She really was snooty with me that day, and I said to her, I says, "If you're going to have an attitude like this, I think you'd better leave here," I says, "because I don't need anybody in here like that. I've got enough stress on me," I says, "without having to deal with somebody like you." So she apologized for it after that. So she says, "I just thought", and these are her actual words, "Why would anybody want to know about that?"*

Despite wanting accountability from nurses, family members are apprehensive about reporting errors or being seen to complain. They are anxious on the one hand, that overworked nurses are not penalized for being human, but concerned that their relative's care may be negatively affected by nursing actions. They either choose to complain or to remain silent. They walk a tightrope between the two options, their loyalties being divided; their *'workload'* is increased.

> *Everybody's human, and that's the thing I realize and that everybody realizes. Everybody can make a mistake, and I'm okay with that. But there has just been too many for me to not be here and not feel protective and not try to stay involved. But I still won't complain because I don't need him getting mistreated.*

SUSTAINING US: ***Involving Us***

Family members want and need to be involved in making decisions and in providing care to the patient. They prefer to do so through negotiating their level of involvement with the nurse, so that it is mutually beneficial to both the family and the nurse. They want to *'work'* with the nurse. They do not want their involvement to in any way detract from the care the patient receives, or to be burdensome to the nurse. Indeed they see their involvement as enhancing the nurse's role, and potentially helping the nurse with their work.

> *All the studies that I've read about and all the articles I've read and information I've picked up tells me that if you want a family member to get better, one of the things you do is, you include the family as part of the caring team.*
>
> *I think that they need to include the family in the intensive care more than they are, and I find that's where a lot of my frustration comes from, is because we do include the family in the palliative; the family is included totally. They're very aware of the client's condition. They're welcomed in; they're asked to participate in the care, even if it's a backrub or a foot rub or anything like that. They're never made to feel in the way. And I find that a lot in the ICU, that we're made to feel in the way.*

When the nurse involves family members, they no longer watch from the sidelines, or wait in the waiting room when care is being administered. They are "part of what is going on".

> *They actually encourage family members to be present. They explained how the monitors worked; they explained what they look for in improvement or things that don't go well, so that if we see any kind of changes and a nurse isn't right there, we can ask someone to come in and check. They allowed us to help bathe, to help feed if that was happening. So we were participating in the care of our relative.... Then because they knew that we were accommodating to when they needed to do examinations, that we weren't being intrusive in any way, that we didn't get in their way, that we were being more than willing to work with them and help them, they were far more understanding in allowing us more freedoms and answering our questions without thinking that they were being watched.*

By *Involving Us,* both nurses and family members achieve a level of familiarity and trust, beyond the relatively passive activity of each of them "being there". As such, *Involving Us* by ***Sharing responsibility with us***, ***Negotiating with us*** and ***Valuing us*** is validating and stress reducing for family members, and helps in ***SUSTAINING US*** for the duration of the critical care experience.

Involving Us: Sharing responsibility with us. Nurses involving family members in helping the patient beyond "being present" and "providing feedback" about care, by *Sharing responsibility with us*, further sustains family members. The activities associated with family member involvement are both validating and stress-reducing for them, and as a result, supportive to them in their *'work'* to *'get through'*. As well, *Sharing responsibility with us* serves as an orientation to personal care that may need to be provided by family members following the patient's discharge or transfer from the critical care unit.

> *Yes, that's what they did: "We're looking after him. We're going to make him as good as possible, but in the end we're going to have to hand him back to you, so therefore, you'd better be here and see what's going on so that when you have to take him home, you won't feel uncomfortable about doing that, and you will have the knowledge you need, and you won't be as fearful of whether you can care for him or not." That was where they were coming from, so that was what they did. They included us as much as we wanted to be included.*

Sharing responsibility with us also involves including family members in decision-making about the patient, which helps family members in their *'work'* of advocating for the patient and the rest of the family. Again, this is validating to family members, and demonstrates an acknowledgement of the central role they have to play.

> *And I think family needs to have some input on maybe the decision-making process, or certainly discuss it and get the doctor [to understand], their feelings and what they think should happen and what we should do together as a group.*

On the other hand, *Sharing responsibility with us* requires the nurse to "strike a balance". Limits on the extent to which the family members are involved need to be considered, most particularly in the case of a long-term admission, so that the family members do not feel "trapped" at the bedside, overly depended upon and left alone to provide care, and therefore feeling unable to leave. This situation only adds to family members' *'work'* and the stress they feel.

> *It's not that I wouldn't have been there, because that was my need. But I wouldn't have felt trapped. I wouldn't have felt like her safety was in my hands.*
>
> *I'm there, so they're concentrating on getting the other two done that don't have anybody there. But they still have to realize that he's there. That just locks you in more. Just think what's going to happen if he doesn't get care from you?*

Involving Us: Negotiating with us. Family members are willing to negotiate with nurses, to ensure that agreements made about family involvement in patient care and decision-making are respectful of the nurse as well as the patient. *Negotiating with us* involves discussion about the nature, scope, and specifics of the family member's involvement, including the critical care unit rules. Family members believe that they can be helpful to the nurse.

> *[Nurses should] have that common respect for the purpose for each other being in the room and utilizing me to the best of their ability, that if they need to go for their lunch breaks or coffee breaks and they're sharing one nurse between two rooms, to feel comfortable that that one nurse may be busy with somebody else, and I can be in there monitoring my relative, my relative's progress. And if something happens, I can call for help when she can't.*
>
> *I think nurses need to ...at least offer that[negotiation] to the family.... The nurse said, "When we're doing an exam, have one person in the room. Please stand back against the wall when we're doing our exam, and just give me some quiet time while I'm doing it. I'll be more than happy to answer questions later. If you're not feeling comfortable, by all means leave, but don't have somebody else come back." We knew what to do.*
>
> *You know how visitors, regular visitors are supposed to leave. But since I was the relative, they let me stay longer.*

Family members are very aware that not all nurses are comfortable with them being involved. Focussing on the "shared goal" of the patient helps during negotiating.

> *But they also did say that there are nurses who do not feel comfortable with this.... I think if the nurses understand that the family members and the nurses have the same goal, to see the person who's in ICU get well and understand that I have a lot of respect for the nurses, something can be worked out.*

Negotiating should include a mechanism whereby what has been agreed upon with one nurse is communicated to all nurses, so that the negotiation does not have to be repeated. "Having to do it all over again" is stressful and adds to the family member's *'work'.*

> *She never explained to the nurse coming on what had been decided. So then I had to go through it again with the next nurse. Fortunately, by the third shift the second nurse had explained to the nurse coming on the situation, so everything was fine by then, so we didn't have to go through the whole process.*

Involving Us: Valuing us. Nurses including family members in providing patient care and in making decisions demonstrate that the nurse is *Valuing us* by tacitly acknowledging that family members are important to the patient beyond being visitors at the bedside. The knowledge that family members have about the patient is considered by nurses to be of benefit to them in providing the patient care that family members expect and the patient deserves. Family members feel useful when actively participating.

> *The tube gets plugged regularly, and I've probably unplugged that tube fifty times, and all the nurses know I do it. In fact, a couple of them say they wish they could take me to other rooms because I get it cleared so fast.*

When the family member's knowledge or involvement is not seen to be valued, they are concerned that patient care may be compromised.

> *We could have told them that every time you move him and ignore his knees, you're hurting him; you're causing him severe pain. You may even be doing him damage.*

Encouraging and praising family involvement further strengthens the family member's resolve to *'work'* to support the patient. Playing an active role provides them with a sense of worth and purpose. They are part of the team, supported in their *'work'* to *'get through'* by the stress-reducing benefits of activity and recognition of their efforts.

> *And what was really nice is that—and I think I mentioned this. One of the supervisors, she actually came in and said to me, "I'm glad you did that, and I think more people should do that."*

SUSTAINING US: ***Advocating For Us***

In ***Advocating For Us*** family members are sustained by nurses who assess the family member's desire for advice about looking after self-care needs and who provide tangible aid by ensuring the availability of amenities. As well, in *Advocating For Us,* nurses make referrals, organize meetings with physicians, and represent family members' viewpoints as indicated by the individual family situation. As a result, *Advocating For Us* consists of ***Promoting our self-care*** and ***Connecting us.*** Together these actions are supportive to family members in their *'work to get through'* the experience.

Advocating For Us: Promoting our self-care. *Promoting our self-care* is of secondary importance to family members who consider the patient to be the nurse's primary responsibility. Family members are not open to the nurses supporting them meeting their self-care needs unless the patient is receiving appropriate care.

> *The patient is the one that is the most important. I wouldn't want a nurse that was just excellent for me and served me coffee and everything else, but ignored my husband lying there with bedsores.*

Promoting our self-care is achieved then, as a result of two levels of nurse involvement: at the unit level, where nurses collectively influence which amenities are made available to family members; and at the individual nurse level, where nurses respond one-on-one to the needs of family members at the bedside.

Family members are supported when nurses ensure that the waiting room includes the availability of: food, beverages, and personal care items; change dispensing machines; and storage space for personal belongings. Additionally, parking, quiet spaces, and accommodation information is made available. At the bedside, the provision of chairs and blankets supports family members' comfort. Family members are very grateful and relieved when they do not have to expend energy organizing all of their own self-care. These amenities and services are basic necessities to sustain family members for the duration of the critical illness of their relative.

> *You want a good cup of coffee you go downstairs to the cafeteria, to the main cafeteria. Sometimes the pain's so bad with some of these people that they don't want to go down there.*
>
> *In the Emergency there's these nutrition centers set up where you can go and grab a cup of coffee or a glass of ice water. Not a whole restaurant, but something....*

Conversely, when these amenities are not provided, families experience a range of negative emotions such as anxiety, anger, and frustration.

> *I had nowhere to park. My relative's in ICU; I'm told that he's more than likely going to die, and I can't park anywhere, and that just burned me. I got angry. I was flustered, my mother was flustered, and everybody. It was just nuts.... Extra time had elapsed, and I was pretty shaken and agitated and angry, basically. That's just extra, added stress...especially if they're already upset.*
>
> *You've got coats and boots and everything. You can't just leave them. I think lockers are something that they really need desperately in there. [Some] people that have come probably either off the bus or the plane or whatever, and they've even got suitcases as they've come directly there because, after all, this person is very ill, right?*

As well, space needs to be made available to family members for grieving, and for quiet time to rest or relax, separate from the main waiting room. Small children, the sound of the TV, and family members who are visibly grieving, are intrusive.

> *[They] just sat there and cried, and I thought, "Don't they have a quiet room for this family to go and to sit quietly and with each other and just collect themselves before they all get up and go to their cars, sort of thing.*

Offering alternatives to the main waiting room is supportive to family members.

> *It's very difficult to go out in that corridor and sit in that room when there's twenty people there, and people are looking at you; it's not a comfortable place to be. And what's probably given us the saving grace is this room here, because we come in here all the time now. We get to sit, and I've laid down on the chairs and rested. You can't do that out there.*

The nurse at the bedside is *Promoting our self-care* by offering family members chairs, blankets and pillows, and other amenities.

> *One of them went to the drugstore, brought us toothbrushes, brought us breath mints, brought us Kleenex, and brought us things that we weren't thinking of needing. Just the little things, because you're there so much, and you're not aware that you're not eating properly, or you're not aware that you're not taking care of yourself.*

Understandably, family members seldom want to be very far from the bedside. When family members decide to remain constantly at the bedside or when they decide to reduce visiting time, nurses demonstrate respect for their decisions. Remaining constantly at the bedside is wearing on family members, but they may be unwilling to leave.

> *I was coming in early in the morning, and I was staying till late at night; I wasn't eating properly; I was standing all day. I'd find that if I hadn't been sitting by the end of the day, then my legs were sore, and my feet were sore.*

Nurses support family members in their self-care *'work'* by suggesting that they take "time out", particularly if the family member is reassured by word and deed that the patient will be well cared for in their absence, and that if there are any changes the nurse will page or call them.

> *They went to her [patient], and said I couldn't do it any more because I was wearing thin; they could see it. And oh, I couldn't handle anything any more. I was just breaking down at any point, every point.*

Advocating For Us: Connecting us. Nurses represent the family's interests by *Connecting us* through establishing and/or promoting formal and informal opportunities for family members to interact with others. Informally, family members are supported in connecting to other family members, if the waiting room is provisioned in such a way that interaction easily results, such as over coffee.

> *I see these people day after day after day, the same people. If I was sitting there with a cup of coffee in a room where they were making a cup of coffee, that would probably give you more opportunity to be able to support and help these people by talking.*

Formally, the nurses are *Connecting us* when referrals are made to professionals, support groups, or to discharged patients and family members who share similar experiences.

> *But he [a discharged patient] came in, and he touched on everything that she was worried about.... So when he left she felt a lot better; she felt like there was light.... So yes, after he left she said she was glad that he came in. And so was I....The nurses got in touch with him about coming in.*

Family members are also supported when nurses refer them to social workers and pastoral care workers, and when they organize family conferences.

> *The nurse said "If you have to park your car, you can see the social worker, and he will give you a pass if you're going to be in here any length of time".*
>
> *So maybe having a conference with the family, especially if it's long term, once a week or once every two weeks, to sit down with the charge nurse and sit down with the doctor and say, "This is what's happened in this last two weeks."*

Care needs to be taken however, to understand which referrals family members want, if any. Failing to understand family wishes is perceived as unsupportive, even though the intent might have been to be supportive.

> *But I think what should happen is, the nurses should sit down with us and say, "Hey, look, here's our services. Would you be interested? Here's some information; here's a sheet. Okay, basically take it home, read it, and digest it," because here a lot of people, their mind is not focussed on what's going on, right? So you give us a sheet and go home and think about it. Then we read it, we understand it, and maybe three days from now we'll say, "Hey, look, we need to speak to a social worker".*
>
> *Come and speak to us if you want a social worker to approach us. Don't have them walk up, put us on the spot, because I have a real problem with that.*

Further to *Connecting us,* family members expect nurses to represent their viewpoints and interests, and ensure that they are considered, when family members are unable to be present during discussions with other family members or professionals, or if unable to speak for himself or herself.

> *I had to phone and I asked yesterday if the nurse could ask the doctor. What about these drains? Why are they still draining so much? Because chances of getting hold of him are pretty slim. And I can't be waiting around a phone all day waiting for him to call, or make sure I'm up at the hospital for those eight hours and maybe get to see him.*

SUSTAINING US is considered supportive by family members beyond the initial *ENGAGING WITH US*, to further meet the responsibilities of their *'work'* in order to *'get through'* the critical care illness of their relative. When nurses are ***Reassuring Us*** they are present at the bedside, using effective communication and providing competent, consistent, and responsive patient care. Additionally, ***Involving Us*** by appreciating our involvement in patient care and decision making, and ***Advocating For Us*** by promoting family members addressing their self-care needs and making referrals to other individuals and groups, further supports family members in "carrying on", sustaining their *'energy'* for the duration of the critical illness of their relative.

LIGHTENING OUR LOAD:

DISENGAGING FROM US

DISENGAGING FROM US is not merely the "ending" of the process of ***LIGHTENING OUR LOAD***. Rather, it signifies as well, movement towards the denouement of the process, a moving forward and beyond and in the archetypical situation, where "everything is made clear and no questions or surprises remain" (Encarta® World English Dictionary, 2005). As such, three of the four sub-categories within this phase are future oriented, pertaining to supporting the family on the verge of *'getting through'* a particular "ending" in the critical care experience, or on the verge of *'getting through'* to a new reality beyond critical care. This future orientation is tempered by the immediacy of all the departures that occur in the present, due to the interconnected, cyclical, and recursive nature of the process of nursing support. As a result *DISENGAGING FROM US* involves ***Facilitating us moving on*** beyond the immediate critical care experience, and ***Easing our departure*** for the present as well as the future (see Figure 4).

Family members look to the nurse for support as they struggle with the *'work'* of decision-making and trying to understand the critical care experience. The nurse is seen as someone intimately involved in their experience, with whom family members can safely discuss options and ideas, as they search for help in making decisions on behalf of themselves and the patient, and as they search for the meaning of their critical care experience. Additionally, family members are supported when the nurse responds proactively to the range of circumstances signifying "departing" from nurses leaving for breaks or at end of shift, to the patient transferring from the unit, or as well, to the family members departing after visiting or after the death of the patient. These transitions, which necessarily alter the family's connection with the nurse, are inevitable, due to both the nature of staffing and visiting, and to the reality of the patient's imminent death or discharge. For each departure, the nurse *Saying goodbye* completes his or her involvement in the process of ***LIGHTENING OUR LOAD*** for family members. Whether the nurse and family member become engaged again depends on the staffing patterns, the trajectory of the patient's illness, and the depth of the engagement between them.

Phase 3: Disengaging From Us

Facilitating Us Moving On	*Guiding our decisions* *Helping us find meaning*
Easing Our Departure	*Preparing us* *Saying goodbye*

Figure 4. The categories and sub-categories of ***Phase 3: DISENGAGING FROM US***.

*DISENGAGING FROM US: **Facilitating Us Moving On***

The nurse, as an individual with whom family members have developed a relationship based on trust, respect, proximity, and shared experience, supports family members in their *'work'* to garner hope and understanding in order to make informed decisions and to make sense of their experience. Therefore, nurses are ***Facilitating Us Moving On*** by ***Guiding our decisions***, and ***Helping us find meaning*** through activities such as listening to family members and offering them facts and advice. These activities serve as well, to support family members moving towards, and adjusting to, a reconfigured reality.

Facilitating Us Moving On: Guiding our decisions. In *Guiding our decisions*, family members seek help as they struggle to make decisions, from challenging treatment and end-of-life decisions, such as the decision to donate organs or to discontinue treatment, to the decision about how often and how long to visit. Nurses do not guide in terms of directing decisions, but rather by being available as a support for family members in making decisions. The nurse is open to discussing options, demonstrated by "being there" and listening attentively to family member's views and questions, providing honest information, clarifying details, and scheduling meetings with physicians; all supportive to family members.

> *Yes, he might be [needing to] make decisions about whether or not to do surgery or what's going to happen. The nurse is your first line of defense. She's the one that sees you; she's the one that sees the patient. She's who you talk to. The doctor comes in once a day or twice a day or whatever if there's a crisis, but he's not the one that I look to for the information [to make a decision].*

Each of the decisions made by family members involves a movement away from a previous way of being, an "ending" of one reality and the emergence of a new reality, as family members move closer to the threshold of *'getting through'* the experience. Family member decision-making *'work'* concerns decisions about visiting, employment, and other family members. When nurses are involved in supporting the family member's efforts to make decisions, nurses are involved in promoting hope as well. One participant mentioned that talking with [a nurse] had gotten her to reflect on her decision to try to normalize things with her family. She had found this to be very valuable and very worthwhile for her, and she appreciated the time spent listening to her. When nurses take the time to explore family members' options and to listen to and support their decisions, family members' *'workloads'* are lightened. Family members may feel alone and vulnerable when nurses are not approachable for discussing options and decisions.

> *Sometimes I don't know how much I should be here. When I leave and I go home, I feel guilty because I'm not here.... But just being around here too much sometimes is upsetting, and I want to be here as much as I can. I don't know what's right.*

Some participants regretted not being more involved with decision making, wishing they had asked more questions and provided their opinions more. They indicated that the nurse could have proactively explored their understanding of the situation, and provided additional information to inform their decisions and referred their concerns to the physician.

> *I asked his nurse, and she said that she would let the doctor know that I wanted to talk to him about my decision.*
>
> *If we'd known, if the nurse had told us, then what we could have done is, we could have forced the issue; maybe we could have made the decision and said, "Look, we're going to take our chances.... They [family] need to know what the options are, what the odds are. The nurses can help us.*

Facilitating Us Moving On: Helping us find meaning. In *Helping us find meaning*, the nurse supports family members seeking an understanding of "why" and "what". *Helping us find meaning* involves the nurse providing encouragement to family members through listening, providing honest information, and discussing family member's ideas. Finding meaning is a hope engendering exercise for family members and it is supportive when nurses validate family members' thinking by just listening. *Helping us find meaning* includes nurses helping family members understand their reaction to, and understanding of, their experience.

> *And my experiences are something I've been told by one nurse, if put down properly, would help a lot of people in a lot of different areas understand what's going on... people who have been hurt major who go through life-changing things, physical or mental; because there's a lot to understand.*
>
> *And then somebody would explain to you what was going on and why that made you feel a certain way. Then it would help you with knowing why you were upset about something then, because somebody would explain to you in a little more detail.*

The meaning "found" by family members takes on many forms, and can influence the family member positively, such as in the case of renewing or discovering a spiritual faith, or deciding to get involved with other families dealing with critical care.

> *I've been thinking of all the time sitting in the waiting room. When I go back home, that I might just sometimes go to the hospitals back there and just be around families and talk with them, because I think it's so important.*

For some family members, their experience leads to renewed or reconfigured family ties, a greater value being placed on living each day fully, or to the decision to donate organs and plan for future critical illness. Nurses, aware of the potential that exists for positive change for family members in response to the critical care experience, consequently support the family member's unique journey and understanding of their critical care experience, beginning with listening to what family members have to say about the meaning they are discovering in the experience.

When nurses do not assess the family member's understanding of their experience, and the meaning they give to that experience, they miss an opportunity to intercede to influence a change in the perceived meaning of the experience from one that is predominantly negative, as indicated in the excerpt below,

> *I would never leave one of my loved ones in the hospital without me being there or without someone being there to watch over things and make sure that things are being done, because it was horrific. So to be honest with you, that's exactly what I'd be telling anybody that I knew. I'd be saying, "Hey, maybe you'd better just be there." It assures you, but also at the same time then you can step on things if you don't feel that things are quite the way they should be.*

to one that is positive.

> *I think it's [nursing care] really what I expected and hoped for.*
>
> *ICU was probably more than I expected as far as a concern for me and for my relative.*

DISENGAGING FROM US: Easing Our Departure

Whenever the nurse, patient and/or family member leaves for any reason and for any length of time, family members appreciate being prepared for the departure, and for the departure to be acknowledged. Family members are supported therefore when nurses are ***Easing Our Departure*** by ***Preparing us*** and ***Saying goodbye***. During any given day family members and nurses experience a number of departures: nurses leaving; family members leaving; and possibly, the patient leaving or dying.

> *When they need to go off on their breaks, which they obviously need, or when they have to leave the floor for whatever reason. There are all kinds of reasons why a nurse has to go off to do something or other and come back and then leave it to another nurse.*

Departures range from the relatively straightforward, such as at the end-of-shift to the stress-inducing transitions of death or transfer. Further, although transfer out of the critical care unit is a positive experience for family members on the one hand, signifying as it does that their relative's health is improving, more often than not family members find this situation very stressful. If the nurse acknowledges the family's anxiety about an impending transfer and intervenes with some advance planning to prepare them for the changes, family members' *'workloads'* are lightened.

Easing Our Departure: Preparing us. For every nurse departure that is of a short-term nature, it is very helpful to family members to be advised of this a few minutes in advance. *Preparing us* allows family members to get ready for when the nurse will be absent, to ask "last minute" questions, and to be reassured about who would be providing coverage during the nurse's absence. End-of-shift is similar, although in this instance, *Preparing us* also includes an introduction of the "new" nurse and discussion about the day's events.

> *At shift change, I saw my relative for a while; I went out and I talked to her [the new nurse] and I said, "So how did they say today went?" Then she started to tell me stuff, because I wanted to know.*

In *Preparing us,* nurses acknowledge and discuss the anxiety family members may feel about removing monitors and pumps, and about discharge from the critical care unit to other units, where the patient-nurse ratio is much higher.

> *When they started to gradually take some of the equipment from him, and some of them were at the last week, it was just the heart monitor, and sometimes it would go way off.*

Prior discussions about the reality of the nurse-patient ratios on units that patients are to be transferred to, and about how to understand and manage that reality, are supportive to family members. As well, orientations to the new unit may be instrumental in preventing or mitigating negative reactions, as the family member has some time to assimilate some of the differences. When family member's concerns are not discussed and they are not provided with an orientation, they may be shocked and upset by what they experience.

> *It's so hard when you leave a caring place like the ICU [for] a place that, "We'll get to him when we have time." People in ICU aren't used to that. You're cared for, you're talked to; people care about your family member, and when you leave ICU, boom! That's it. There's no more caring, there's no more talking.*
>
> *But no, that was a total shock to me.... And I didn't realize there were going to be so many much older people. I figured it was just going to be a mix.*

In the situation where patient recovery will be prolonged or where the patient condition is now chronic, team conferences to discuss probable and possible futures are supportive to family members. If not provided, family members are frustrated, further adding to their *'workload'*.

> *[Information] in terms of, "K. is going to be disabled," or "You can expect this, or you can expect that." And "You can qualify for this, or you can go here for this, or you can go there for that." I've had to find out all these things myself.*

At the time of transfer from the critical care unit, the primary responsibility for providing nursing support devolves to the nurses on the new unit. When nurses on the new unit do not embrace this responsibility, family members are once again involved in the *'work'* of breaking down barriers to engage with nurses and to find reassurance that the patient is getting the best possible care.

> *We couldn't even get people to read his chart for the first week. So that's why he had a full tray of food on his table two days after he leaves ICU, with a trach and a tube down his nose, and they've got a full tray, and not one nurse thinks that that might not be right. Nobody has read his chart, nobody has a clue, and this is what you deal with when you leave ICU. Twenty-four hours a day they know exactly what's happening with that person. When you leave, nobody knows, and most everybody doesn't care.*

Easing Our Departure: Saying goodbye. When family members leave the critical care unit, because of transfer or death, some nurses say "goodbye", in word and action, and if they see the patient and/or family later, acknowledge them. *Saying goodbye* is supportive to family members as this action provides evidence that the nurse respects and recognizes the family's critical care journey.

> *Whenever they'd see us sitting around in the atrium, they'd wave to L. or us, and it was a tremendous response. Just smiling and just saying, "Hey! Way to go, L.!" It was very encouraging.*

Therefore, in *Saying goodbye*, the nurse acknowledges the family and is courteous. He/she recognizes the familiarity that has developed from being present together in such intimate and grave circumstances and bears witness to this engagement and departure with a word, a look, a handshake, a hug, or tears.

> *But even when they leave for the evening, when they finish their shift, even when they leave and look at you with a smile, they acknowledge you. That's a big help. That's support.*

Saying goodbye may be attenuated, such as when a nurse attends a funeral, marks an anniversary date by sending a card, or simply chats with family members when they see each other outside of the critical care unit. This protracted "Goodbye" respects and celebrates the shared experience and the depth of the engagement that often occurs at this particularly vulnerable period in a family's life.

> *A couple of the nurses gave her their phone numbers, and we'll call them for coffee sometime and stuff.*

Conversely, family members are disappointed and angry, and therefore unsupported by nurses when family members perceive that the decision to transfer the patient is responded to as if the patient has already left, resulting in a virtually non-existent "goodbye". This is seen as emotional distancing of the nurse from the patient and family member.

> *As soon as the nurse knew that he was going, she shut right down It was awful. It was just another case of put a tag on his toe.*
>
> *There was no care, no consideration, no attention paid to him because all this paperwork had to be done, and he had to be shipped out. So that sort of disillusioned us about caring nurses in even intensive care.*
>
> *But we both reacted strongly to the day he was discharged from the unit, when he became nothing; he was just a body to be transferred.*

As well, if a meaningful *Saying goodbye* does not occur, family members feel ignored, and unimportant, despite all the time that they have spent with the nurse at the bedside. When the engagement between nurses and family members is nominal, *DISENGAGING*

FROM US is an empty feeling. There is nobody *Saying goodbye*. The family members walk away, burdened by this apparent disregard for their family and the time spent together with the nurses in such intimate circumstances.

> *We were in the room basically, and we watched her die and kind of stood around speechless for two or three minutes, and one relative said, "Look, it's over; let's go." No one spoke to us. From there we just walked out of the hospital.*
>
> *As a matter of fact, when she left she didn't even say, "I hope everything goes well for your relative," whatever. Not very courteous.*

On the other hand, family members are very grateful for the nurse's calm efficiency when death is imminent, and *Saying goodbye* is inevitable. One participant in particular spoke of one nurse's actions on the day of her relative's death. There was no big production; she just pulled the blinds in her own quiet way. She gave the family privacy, which they needed. She was there if they needed her, but she did not intrude upon their grieving. This participant found this nurse to be an absolutely excellent nurse. It was as if the nurse knew exactly what was needed and what to do for that family, and she competently, quietly, and efficiently did it, in a way that demonstrated support for the family. In ***Easing Our Departure,*** nurses are supporting us by ***Preparing us*** and ***Saying Goodbye,*** completing the final phase of ***LIGHTENING OUR LOAD.***

Critical care nurses are advantageously situated for ***LIGHTENING OUR LOAD*** by supporting family members in *'getting through'* the critical illness of an adult relative. This process of nursing support for family members is initiated when the patient is admitted to a critical care unit. ***ENGAGING WITH US*** begins the relationship between the nurse and family. *Letting Us In*, by supporting the family's access to the patient and the nurse, is the linchpin of this phase and indeed of the entire process, as first and foremost, family *'work'* is centered on the patient. Access to the patient begins the support for family members in their focal *'work'* of "being there", "garnering hope", "advocating" and "understanding", both for the patient and for themselves so as to be reassured that all that needs to be done for the patient is being done. Through *Letting Us In*, nurses become acquainted with, and demonstrate respect for, the family. ***SUSTAINING US*** builds on the relationship begun with the family, and serves to support family members in their ongoing *'work'* for the "long haul" of the patient's critical care admission. Nurses provide reassurance by their presence, their communication, and their accountability in terms of patient care. They involve family members in patient care and advocate for them, and in so doing are further ***LIGHTENING OUR LOAD***. In ***DISENGAGING FROM US*** family members are supported in their *'work'* of making decisions and moving on from this experience, leaving previous realities behind. Nurses prepare for and acknowledge the inevitable nurse and family member departures that occur on a daily basis, including patient discharge from ICU (or death). Family members variously experience the timing of "definitive" disengagement, as nursing support draws to an end. How successful nurses have been in supporting family members in ***LIGHTENING OUR LOAD*** influences in large measure, the satisfaction family members feel overall with their experience of the critical illness of their adult relative, and the role they played.

CHAPTER 5

DISCUSSION

In this chapter, a discussion of what nurses were supporting family members through, namely the critical care experience, is presented first. Next, the emerging theory of ***LIGHTENING OUR LOAD*** is compared to the literature about family needs and the theoretical perspectives of caring, comfort, supportive care, social support, and professional support, in order to demonstrate how this grounded theory of nursing support, corresponds with, and differs from, extant knowledge. Finally, limitations of the study and implications of the findings are addressed.

The purpose of this study was to delineate the process of nursing support from the perspective of family members of critically ill adults. Participants' dominant activity was to *'work'* to *'get through'* their relative's critical care hospitalization. The process of nursing support for family members of the critically ill adult, is comprised of three interconnected, cyclical, and recursive phases: ***ENGAGING WITH US****;* ***SUSTAINING US****;* and ***DISENGAGING FROM US****.* ***LIGHTENING OUR LOAD*** emerged as the core category accounting for variations in the process of nursing support for family members. Each phase occurring over minutes, hours, or days, is influenced by the presence of nurses and family members, and reoccurs with every family member and nurse encounter. The individual patient, family member, family unit, nurse, and nursing unit contextualize the expression of nursing support. One notable finding, previously unreported in the literature, is that *LIGHTENING OUR LOAD* is initiated by the family if not by the nurse, at the time of the patient's admission to the Intensive Care Unit (ICU). Family members work to gain support from nurses, if this support is not immediately forthcoming. When a nurse supports a family member, his or her load is lightened, and the energy conserved is available to be redirected to other activities that sustain the patient, the individual family member, and the family as a whole.

Family Member's Critical Care Experience:
The *'Work'* of *'Getting Through'*

The critical illness of an adult relative constitutes a crisis for the entire family. Family members in the current study experienced a loss of control over the day-to-day management of their lives and a sense of being off-balance and vulnerable throughout the stressful crisis of the critical illness. Researchers have repeatedly reported the "overwhelming" and "unpredictable" nature of the crisis of a relative's critical illness (Bedsworth & Molen, 1982; Buttery et al., 1999; Carr & Clarke, 1997; Carr & Fogarty, 1999; Cohen, Craft, et al., 1988; Coulter, 1989; Gardner & Stewart, 1978; Hilbert, 1994; Kleiber et al., 1994; Leske, 1992c, 2002, 2003; O'Malley et al., 1991; Price et al., 1991; Titler et al., 1991). Johnson, Craft, et al. (1995) described the emotional roller coaster experienced by family members of adult ICU patients. The crisis of a life-threatening illness resulted in high levels of stress for family members of the ill relative, described by Morse and Johnson (1991) during the "Stage of Disruption" of their patient/family Illness-Constellation Model. Similarly, Auerbach et al. (2005) reported that family member stress during a relative's ICU admission was measured to be as high as it was for patients admitted for Posttraumatic Stress Disorder, while anxiety and depression were prevalent in a large sample of family members of ICU patients (Azoulay et al., 2005). Family members in Leske's (2000, 2003) studies described the coping involved in managing the crisis of their relatives' ICU admissions, regardless of whether the admission diagnosis was gunshot wound, motor vehicle accident, or coronary artery bypass graft (CABG) surgery: their coping scores were higher than the national (United States) norm. Their hardiness scores, lower than the national norm, indicated that they could be classified as "vulnerable families".

Notwithstanding the critical care experience being perceived as a crisis, participants demonstrated conspicuous endurance and resolve. In response to the stress, family members actively engaged in *'work'* in order to *'get through'* the experience, doing whatever had to be done due to their commitment to their relative. Morse and Carter's (1995) definitions and discussion of enduring and suffering in reference to the patient, relates in part, to the '*work*' of families in the current study. These researchers stated:

"Enduring is defined as the capacity to last, to get through, to survive an experience or an intolerable situation. Situations that must be endured are situations the individual is forced to undergo; the individual has no alternative but to endure" (Morse & Carter, p. 39). They posited that the outcome of enduring is suffering and that suffering is defined as the emotional response to the situation in terms of mourning the loss of the future. Mourning responses include grief, anxiety, anguish, guilt, anger, depression, and loss of control, until coping and reformulating occurs (Morse & Carter, 1996). The participants in the current study vacillated between enduring and suffering, but instead of enduring only for themselves, family members endured primarily for the patient, and family members' suffering was for the patient as well as for themselves. Similarly, Hupcey (1999) found that family members expended energy enduring the critical care experience, and suffered privately. However, the fact that the participants of the current study sought out nursing support and in particular, access to, and involvement with care, is evidence that they had moved from primarily enduring and suffering (Morse & Carter, 1996), to coping by finding release through the activity of their work. The primacy of the patient in the family member's work took precedence, which was also previously reported by Burr (1998).

Family members in the current study wanted to be taken seriously, and they worked to gain the respect and trust of professionals. Thus, their work encompassed becoming as knowledgeable as possible, being courteous, accommodating, and diplomatic with each nurse encountered, in order to gain respect and trust. These actions helped prevent confrontation with nurses and the possible experience of being "shut out" from the patient, the nurse, and information. Family members' work to gain trust has not been overtly documented in previous studies. However, researchers have reported that family members conformed to rules in an attempt to gain staff's acceptance (Millar, 1989), did not feel trusted by nurses and physicians (Plowfield, 1999), felt that they had to be respectful, accommodating, patient, and cooperative (Bogoch, Sockalingham, Bollegala, Baker, & Bhalerao, 2005), and devised strategies for "being a good visitor", while at the same time getting more attention from busy or inattentive nurses (Hupcey, 1998b, 1999).

Working to sustain hope whatever the changing situation, was of prime importance to family members in the current study. They worked to meet their needs, and this helped them to maintain hope. Burr (1998) discussed the family's need for hope as fundamental to "maintaining the vigil". Additionally, hope sustaining activities for family members, were identified by Clarke (1995) as: "getting into the unit", "getting past fears and anxieties", "attempting communication with the patient", and "being there with the patient. In fact, the optimism scores of family members with a relative in ICU in one study were comparable to those of a normative sample of adult non-patients and less than those of a normative sample of psychiatric outpatients, despite the gravity of the patient situation (Auerbach et al., 2005).

Participants in the current study yielded primary responsibility for their ill relative to professionals. However, this action was qualified. They maintained control in terms of monitoring the situation for the patient, based on deep commitment to their relative over the long term. Family members demonstrated that they were trying to understand what had occurred and why, to help their relative get through the experience. Similar findings were reported previously: the family vigilance category of "commitment to care" (Carr & Clarke, 1997; Carr & Fogarty, 1999); the core category of "holding death at bay" (McRae & Chapman, 1991); and the stage of "maintaining control" (Morse & Johnson, 1991). As well, family members in the current study assumed additional responsibilities over and above their usual commitments to the patient and family. Waiting long periods, breaking down barriers to reduce uncertainty, providing information, hovering so as to be there for the patient, bearing witness, and providing aspects of physical care to the patient, all added to their workloads. These finding are comparable to: (a) the categories of "maintaining the vigil", "not knowing was the worst part", and "protecting" (Burr, 1998); (b) the themes of "waiting", "being present", "communication and information giving" (Fulbrook et al., 1999a); (c) the family coping behaviour of "remaining near the patient" (Geary, 1979); (d) the category of "changes in responsibilities" (Hupcey & Penrod, 2002); (e) the stages of "hovering" and "tracking" (Jamerson et al., 1996); (f) changes in family roles and responsibilities (Johnson, Craft, et al., 1995); (g) the roles of "kin as witness", "kin as providers of direct care", and "kin as first responders" (Levine &

Zuckerman, 2000); (h) the concept of vigilance (Mahoney, 2003); and (i) the category of “managing role transitions” (Morse & Johnson, 1991).

The work of family members in the current study was frequently invisible, as demonstrated by the work of waiting, worrying, and enduring and suffering. They expended energy internally, dealing with uncertainty and feeling impatient, angry, frustrated, and fearful, as noted previously by Morse and Carter (1996) in their discussion of enduring and suffering. Visible energy was used by family members to in break down external barriers represented by the "wall" between the waiting room and their relative. These barriers prevented access to the patient, to professionals, as well as access to information to allay uncertainty. Stannard (interviewed by Paladichuk, 1998) had previously noted that the first step in family involvement is "ensuring access”. As well, the significance to families of "being present" at the bedside has been identified by Clarke (1995), Geary (1979), Speeding (1980), Walters (1995), and Hupcey (1999). With the barriers lowered, participants in the current study became involved in the patient's situation and learned as much as possible by observation and questioning. Eventually, many became familiar with routines, equipment, and terminology, and found their niche. Their work also involved self-care activities to help regain and conserve energy to sustain the ordeal. Others have reported similar findings: (a) Burr (1998) addressed family members learning within the theme of "not knowing was the worst part"; (b) Carr and Clarke (1997) and Carr and Fogarty (1999) discussed family members observing, learning, and getting involved under the category of "commitment to care", and looking after their self-care needs under the category of "resilience"; (c) Halm et al. (1993) explored family members' self-care behaviours of sleeping, eating, and physical activity; (d) Hupcey (1999) explored family members "finding a niche" and "remaining on guard" in terms of family members trying to help nurses, and feeling comfortable about their role; (e) Jamerson et al. (1996) discussed family members' "information seeking", "tracking" and "garnering resources" behaviours to address, learning, involvement, and self-care needs; and (f) Plowfield (1999) addressed families getting involved in the patient situation under the sub-theme of "gaining control".

Family members in the current study identified getting involved in decision-making and patient care work. Similar involvement had been previously reported, specifically in terms of proxy decision-making (Ellers, 1993; Hardwig, 1995; Jacob, 1998; Jacoby, Breitkopf, & Pease, 2005; and Mirr, 1991). Molter (1979) and Leske (1986, 1992b), and many others investigating family needs using the CCFNI© or versions of it (e.g., Auerbach et al., 2005; Hunsucker et al., 1999; Price et al., 1991; Levine & Zuckerman, 2000), consistently found that family members wanted and needed to be involved in the provision of patient care. Interestingly, none of the CCFNI© research identified family members getting involved in decision-making. There are no items referring to this in the questionnaire. Recently, physician adaptations of the CCFNI© (Azoulay et al., 2002; Heyland et al., 2002; Johnson et al., 1998) have addressed this limitation. Their results support the findings of the current study. As well, the importance of family involvement in decision-making has been included in discussions and research supporting the importance of ICU nurses developing nurse-client partnerships (Bisaillon et al., 1997; Gallant, Beaulieu, & Carnevale, 2002; Hammond, 1995); promoting family-centred care (Henneman & Cardin, 2002; Hutchfield, 1999); and collaborative care (Tracy, Ceronsky, & Charles, 2001). To Gallant et al., the "process of partnership embodies power sharing and negotiation" and results in "client empowerment, which is understood to be the improved ability of the client to act on his or her own behalf" (p. 149). Further, Kellett and Mannion (1999) reported that family members' work to provide care in the home added meaning and significance to family members' lives. This finding resonates with the current study wherein family members who became involved in patient care felt significant to the welfare of the patient, and exuded a confidence about their abilities and their role.

The concept of family work has received limited attention in the literature, and that attention has focussed primarily on non-ICU situations (Brown and Stetz, 1999). However Plowfield did maintain that "waiting is the work of families" (1999, p. 231), a task demanded of them by health professionals. Recently, Bischofberger and Spirig (2004) wrote of the "work" of family caregivers of relatives with HIV in terms of kinds of work, conditions of work, and consequences of work. The most comprehensive and descriptive discussion of family work was by Strauss et al. (1984). The "work of kin" of the chronically ill, is relatively "unrecognized work in hospitals, except of course, the 'psychological work' and 'work on pediatric wards' " (Strauss et al., p. 143). They specified that the hospital work of kin involves: (a) comfort and safety work; (b) sentimental work of providing emotional support; (c) legal-administrative work of advocating on behalf of, and representing the patient, when the patient is unable to act for his or herself; and (d) decision-making work. All these work activities are addressed in the current study. Buttery, Eades, Frisch, et al. (1999) interviewed family members dealing with a difficult hospitalization of a relative and also identified "working through" as a core category.

Other studies noted the term "caregiver burden" as the label for a phenomenon similar to the family member work of the current study. Most of this research involved family members providing care in the community for a relative who was dying or not expected to improve (Bischofberger & Spirig, 2004; Hoffmann & Mitchell, 1998; Montgomery, Gonyea, & Hooyman, 1985), or for whom improvement was protracted (Covinsky et al., 1994; Davies, 2000; Foster & Chaboyer, 2003). There is a perception that work defined as "the physical or mental effort or activity directed toward the production or accomplishment of something" (Neufeldt & Guralnik, 1991, p. 1538), implies a proactive role. This was certainly the case for participants in the current study. On the other hand, "burden" implies a more reactive response that occurs because of feeling overwhelmed by the work required to get through (Hoffmann & Mitchell, 1998). Labour usually refers to "hard, physical work, and can involve emotional work as well" (Neufeldt & Guralnik, p. 753). There are similarities between the work identified by participants in the current study and the "labour" and "burden" reported by family caregivers in other studies. These similarities involve the commitment of the family members towards the patient, the changes and expansions in family members' roles and responsibilities, the disruption of their schedules and routines, the tasks to be performed on behalf of the ill relative in addition to "usual" tasks, the financial costs, and the physical costs to family members of stress, lack of sleep, and inadequate nutrition (Covinsky et al., 1994; Foster & Chaboyer, 2003; Swoboda & Lipsett, 2002). The interpretation of *work* versus *burden* may be shaped by the differences between the two populations of patients: hospitalized patients and patients living in the community. Hope, experienced by participants in the current study may have been more predominant, influenced by the nature of acute versus chronic illness in terms of the patient's diagnosis, the relatively short duration of critical illness, active treatment, and nursing support. Over time, work may be perceived as a burden when there is no end in sight, and when the workload increases due to the deterioration or chronicity of the patient's condition, inducing feelings of hopelessness. Whether a person perceives that adequate nursing support and dynamic treatment are being provided may also influence their interpretation of their work as a burden.

In this study, family members revealed that their work to get through the critical care experience involved much more than the physical, emotional, and behavioural responses to crisis and stress. The work they engaged in was motivated as well by their intense response to duty, love, and commitment, based on their relationship with the patient - a social response, as noted by Morse and Johnson (1991). Together, all aspects of their work constituted their workload. The energy required to tackle this all-consuming workload challenges nurses to '*not add to the load*', but rather to lighten the load for family members. Langford (interviewed by Fulbrook et al., 1999c) stated that, "the quality of support given [to families in ICU] can drastically affect the families' ability to cope with the crisis as it develops" (p. 229). As Chandler wrote, "We may not always be able to prevent stressors/distress but we can alter the intensity and duration of the stress" (1993, p. 88).

LIGHTENING OUR LOAD and Family Needs

Overall, participants' perceptions in the current study are compatible with results from studies investigating critical care family needs using instruments such as the CCFNI© (Molter & Leske, 1983) or any of the many instruments derived from this inventory. The significant needs perceived by family members reported in study after study and considered to be universally experienced, have been categorized three ways: (a) by factor analysis under the labels of assurance, proximity, information, support, and comfort needs (Bijttebier et al., 2000; Leske, 1986, 2002; Mendonca & Warren, 1998; O'Malley et al., 1991); (b) using the labels of reassurance, information, and convenience needs (Hickey, 1990); or (c) using the familiar labels of emotional, cognitive, social, and practical needs (Verhaeghe et al., 2005). Whichever way family needs are categorized, all are captured within *LIGHTENING OUR LOAD*:

1. Assurance, reassurance, and emotional needs are addressed within the phases of *ENGAGING WITH US*, *SUSTAINING US*, and *DISENGAGING FROM US*.
2. Proximity needs, defined as needing access to the patient and physician (Bijttebier et al.) are addressed within *Letting Us In*, *Reassuring Us*, *Involving Us*, and *Connecting us*.
3. Information or cognitive needs are addressed within *Letting Us In*, *Orienting us*, *Communicating with us,* and *Facilitating Us Moving On.*
4. Social needs, defined as needs that concern relationships (Verhaeghe et al.) are addressed within *ENGAGING WITH US*, *SUSTAINING US*, *Being there for us*, *Communicating with us,* and *Connecting us.*
5. Comfort or convenience needs are addressed within *Orienting us*, and *Promoting our self-care*.
6. Support needs, defined by Bijttebier et al. as needs for resources, support structures, and services to access emotional support or help with financial, health, or family problems, are addressed within *Orienting us*, *Communicating with us,* and *Advocating For Us*.

When asked, "What interventions are beneficial for family members?" Leske (2002), one of two developers of the CCFNI© and one of the most well-known and respected nurse-researchers in the field of critical care family needs, responded with the following statement which resonates with the description provided in the current study for the process of nursing support.

> *Interventions begin on initial contact with family members, continue throughout the critical care period, and extend beyond discharge from the hospital. Professionals and families begin by establishing a relationship that is mutually respectful, trusting, empathetic, and collaborative. The efficacy of further interventions depends on the rapport established between care providers and family members (p. 63-64).*

Over the past 10 years, a number of clinical trials initiated by medical critical care personnel have investigated whether family members' needs have been met from a quality improvement perspective. Five of particular note, included more than the physicians' role in their findings (Auerbach et al., 2005; Azoulay et al., 2001, 2002; Heyland et al., 2002; Johnson et al., 1998). The phase of *ENGAGING WITH US,* and the specific sub-categories of *Welcoming us*, *Orienting us*, *Trusting us*, and *Being accountable to us* correspond with results from these studies. These categories are implied as well by Azoulay (2001) who noted that the "relationship between families and ICU caregivers evolves from trust and the mutual goal of wanting what is best for the patient" (p. 2001), and that written and verbal orientation information improved family comprehension. Family members may have perceived this orientation information as a message of welcoming and openness (Azoulay et al., 2002).

ENGAGING WITH US and the categories of *Reassuring Us* and *Involving Us*, correspond with results of a number of these medical studies (Auerbach et al., 2005; Connors et al., 1995; Johnson et al., 1998; Heyland et al., 2001, 2002; Puri, 2003). Specifically, Johnson et al. (1998) used a version of the CCFNI© adopted by the Society of Critical Care Medicine (Harvey, 1993), and found that interpersonal qualities such as courtesy, personal contact, demeanour, manner of communication, and continuity of care were very important to family members in their study. Furthermore, Heyland et al.'s (2001, 2002) large (600 families) multicentre, Canadian trial indicated that the determinants to overall family satisfaction had most to do with the quality of the communication, the completeness of the information, the treatment of patients and family, and the amount of care provided to the patient. Respect and compassion were two variables significantly correlated with satisfaction. As well, Puri (2003) noted the significant differences between the results of the SUPPORT trial (Connors et al., 1995) conducted in the United States, and the Canadian trial. Interestingly, Azoulay et al. (2002) attributed these differences to the manner in which information was relayed. Most recently, Auerbach et al. (2005) noted that ICU nurses rather than physicians, were the primary source of information and support for families, who wanted to feel accepted, close to, and emotionally supported by health care professionals. Family members also wanted to participate and share control in decision-making.

The comparisons made between the results of the current study and critical care family needs research provides evidence that despite the recurrent emphasis on "needs" research, a complete "picture" of the family's needs has been missed (Dyer, 1997).

Johnson et al. (1998) suggested that, "global measurements of family needs are clearly dependent on interpersonal relationships which may have important structural constraints" (p. 5). The process of nursing support, *LIGHTENING OUR LOAD*, includes numerous actions dependent on relationship, for which there is no correspondence in the CCFNI©, an instrument for which the authors do not claim a theory base (Neabel, Fothergill-Bourbonnais, & Dunning, 2000). *Trusting us*, *Communicating with us,* and *Being responsive* have not been captured by these CCFNI© based instruments. As well, the entire phase of *DISENGAGING FROM US* has not been captured, perhaps because these instruments were generally administered early in the admission and/or none of the items were specifically relatable to "disengaging", no matter what the time period of the hospitalization. Harvey (2004) questioned this fact, referring specifically to Heyland et al.'s (2002) study in which the quality improvement timeline ended when the patient was discharged or died.

> *When the patient dies we have the privilege of grieving with the family....[who then] becomes our primary focus. [The timeline] should not end when the patient survives and is discharged from ICU. Is it natural to just let go of something we have invested so much physical, mental and emotional energy?* (p. 1977)

The limitations of the CCFNI© aside, researchers have begun to demonstrate interest in the latter stages of critical care hospitalization. The phase of *DISENGAGING FROM US,* specifically the category of *Easing Our Departure*, is consistent with the results stemming from post-ICU follow-up research (Sawdon, Woods, & Proctor, 1995), and research investigating transfer anxiety (Bokinskie, 1992; Chaboyer, James, & Kendall, 2005; Coyle, 2001; Haines, Crocker, & Leducq, 2001; Jenkins & Rogers, 1995; Leith 1998, 1999; Leske, 1999; McKinney & Melby, 2002; Mitchell, Courtney, & Coyer, 2003; Mitchell & Courtney, 2004; Paul, Hendry, & Cabrelli, 2004; Streater et al., 2001; Swoboda & Lipsett, 2002; Weller & Miller, 1977). Termed initially both "transfer anxiety" and "relocation stress", the latter was adopted by NANDA International and defined as "a state in which an individual experiences physiological and/or psychological disturbances as a result of transfer from one environment to another" (Carpenito, 2000, p. 715). Swoboda and Lipsett concluded: "systems that provide support to both patients and families should be emphasized both in the hospital and after discharge" (Conclusion section, ¶ 1). These systems included various measures to prepare the patient and family for discharge and follow-up after discharge. Additionally, *Helping us find meaning* is supported by Davies and Oberle (1990) and Oberle and Davies (1992), who identified "finding meaning" as a dimension of their Supportive Care Model; Enyert and Burman (1999) who discussed caregivers finding meaning by "being with" and "doing for" their loved one; and Wright and Leahey (1987) who discuss the implications of the family's conclusions about the meaning of the patient's diagnosis.

Facets of *Saying goodbye* are supported by numerous studies (Angelucci, 1994; Hall & Hall, 1994; Kirchoff, Song, & Kehl, 2004; Tunnicliffe & Briggs, 1997; Wilson, Norbury, & Richardson; 2000; Williams, Harris, Randall, Nichols, & Brown, 2003). These authors discussed in-hospital bereavement services and after-care services to help meet the needs of relatives, and included such measures as a bereavement room, condolence notes, phone calls, anniversary of death cards, and invitations to attend a support group. None of this research specifically addresses nurses *DISENGAGING FROM US* and *Guiding our decisions* as necessary or supportive to family members throughout their course of their relatives' critical care admission.

LIGHTENING OUR LOAD **and Conceptualizations of Caring**

Much of the extant literature reviewed pertains to conceptualizations of caring in nursing in general, and ICU nursing in particular, referred to variously in the literature as caring behaviours, caring models, caring frameworks, or theories of nursing care. For the purpose of this discussion all are referred to by the term "conceptualizations". There are many similarities between the results of the current study and this literature. Clearly, it is not the intent or the focus of this discussion to enter into the debate about the concept of caring in nursing, either as an ethic, a characteristic, or as the essence of nursing. Rather, in relation to family members of a critically ill adult, the overlaps between the process of nursing support as revealed in this study are compared to and contrasted with selected aspects of these conceptualizations of caring. Questions are posed concerning the implications of the relatedness of the two concepts.

Based on the results of the current study, one could claim that nurses demonstrate "caring" for family members by supporting them in their efforts to get through the situation. This claim is borne out by Gardner and Wheeler (1981a) who noted that the purpose of support, as a dominant caring concept, may very well be to help a person cope with an unfamiliar or difficult situation. As well, in terms of the findings of the current study, the salient aspect of Rawnsley's (1990) claim that caring is the domain of nursing, is her contention that caring in nursing is about a caring connection defined as "instrumental friendship derived from a framework of human bonding to help resolve tension between practice and theory" (p. 43). Instrumental friendship, a means to achieve a particular end, corresponds to the intent of nursing support in *LIGHTENING OUR LOAD*. Human bonding in the caring connection correlates with the phase of *ENGAGING WITH US*. The discussion Rawnsley engages in, at a philosophical and theoretical level, is based on the premise that for nursing to claim "caring" as its domain, nursing must articulate "the ways in which caring and nursing are uniquely integral" (p. 41). In the current study, participants identified what helped them get through the situation, and they labeled this help *support* rather than *care*.

One could argue that the "culture" of critical illness impacts the way caring is perceived and enacted, and indeed influences who is involved and how (Leininger, 1991). Leininger identified support as one of the caring constructs. Without a doubt, the process of nursing support "fits" well with Leininger's theory, as it does with Watson's (1988) and Rubin's (1968), though specific to the family in the ICU, rather than the patient. For Watson the root of caring lies in the interpersonal relationship that requires personal commitment in the form of individual attention, concern, and attachment (Gaut, 1983). Previously, Rubin had proposed: "ego maintenance and support during the stressful dependency situation is a primary goal of nursing" (p. 210). Together, the writings of these theorists provide additional support for considering that critical care nurses care for family members by supporting them in their work.

Care, labeled as such, was not investigated in the current study. What helped families however, was investigated, and family members identified this unanimously as support, rather than care. Gardner and Wheeler (1981a) had previously suggested that support was a more specific nursing behaviour than caring, and indeed possibly a subset of caring. Furthermore, based on a meta-synthesis of five perinatal phenomenological studies, Swanson (1991) defined caring as “a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility”. The five caring categories she inductively identified are, "knowing", "being with", "doing for", "enabling", and "maintaining belief". Each of these categories and many of their sub-dimensions, though specific to the perinatal patient situation rather than the family situation in critical care, resonate with the grounded theory of *LIGHTENING OUR LOAD.*

Implicit in *LIGHTENING OUR LOAD* is the understanding of accompanying the family on their journey and helping them along the way. Pearson, Borbasi, and Walsh (1997) suggested that the therapeutic content of nursing lies in the relationship between the nurse and the nursed. The core of the nurse's caring relationship was the sharing of the illness journey as a skilled companion, the term companion being understood as one who shares a journey for a fixed period. *Letting Us In*, *Getting Acquainted With Us*, *Respecting Us*, *Reassuring Us*, and *Involving Us* are integral to the idea of partnership as outlined by McMahon and Pearson (1991), and endorsed by Mills (interviewed by Fulbrook et al., 1999b). These scholars see nursing as a therapy in itself, the nurse-client relationship distinguished by partnership, intimacy and reciprocity. Mills argues that the value of therapeutic presence, defined as making a positive difference, is at the heart of nursing practice where professional detachment is abandoned in favour of professional closeness with clients, adding additional support to the grounded theory of *LIGHTENING OUR LOAD.* Creasy further stated that nurses need to be personally involved beyond physical nursing presence, and must be committed to both the patient and the family members (interviewed by Fulbrook et al., 1999c).

Each component of Caine's (1989) framework for ICU nurses working with families, and his subsequent "Humanistic Care Model" (1991) is subsumed within *LIGHTENING OUR LOAD.* He discussed interventions that stress the preventive and supportive care of families, from eye contact and touch, to encouraging participation in care, and organizing family conferences. Caine's model incorporated four overlapping components of care, concerned with preserving, protecting, and enhancing human dignity: "empathy", "communication", "advocacy", and "reciprocity". The area of overlap of all four components is associated with the patient-family system, and all are rooted in the establishment of a rapport with the family. Caring was noted to involve nurturing as a supportive endeavour to help family members. At times, Caine refers to support and caring interchangeably.

The first three themes of nurse caring behaviours identified by Warren (1994) as "informing", "enhancing", and "touching" based on investigation of the family member's perspective, are included within *LIGHTENING OUR LOAD*. The fourth theme, "spiriting", consisting of the nurse intuiting, having the power to heal, and being guided by a higher power, was not revealed by participants in the current study. In all probability, this disparity is a function of the cultural differences between the two samples. Additionally, *Reassuring Us*, and *Involving Us* are supported by the results of Artinian (1991). She found that family members felt supported by nurses when they were reassuring and providing good explanations, and when the care provided to the patient was competent and personalized.

The categories of *Respecting Us* and *Involving Us,* in particular *Negotiating with us,* are similar to the results of Aranda and Street (1999). In their study about the nurse-patient interaction, they posited that care could be negotiated in such a manner that the personhood of both the nurse and family member was respected. *Respecting Us* and *Reassuring Us* are supported in part by Benner (2004) who noted that the nurse-patient (including family) relationship creates a "disclosive" space. Solace, trust, and reassurance can then occur, conditions supporting the possibility for patients (and their families) to disclose their concerns, fears, and discomfort. Bokinskie (1992) spoke of neurosurgical ICU nurses "bonding with families" as a result of working closely with them. Walters (1994) wrote of the bond that develops with families as a function of the nurse and family being at the bedside. This bond was comforting to family and friends and resulted in part from the nurse being able to "put one's self in their place" (p. 614).

Hupcey's (1998b) research used categories previously reported by Morse (1991) when investigating the patient-nurse relationship. "Demonstrating commitment" was a nurse strategy that included individualizing care, providing explanations, spending time with family, encouraging their participation, respecting family rituals, anticipating their needs and showing empathy. "Persevering" involved nurses developing the relationship further by spending time and exchanging personal information. The last category, "Being involved" was associated with nurses advocating, bending or breaking rules, sharing information, and willingly providing explanations. Hupcey's wide-ranging findings support the first two phases of *LIGHTENING OUR LOAD*, and indeed many of the categories and sub-categories: *Letting Us In*; *Getting Acquainted With Us* by R*elating to us*; *Respecting Us*, by *Empathizing with us*; *Reassuring Us* by *Being there for us*; *Communicating with us* by hearing us and helping us understand; and *Advocating For Us.*

Caring behaviours of the nurse from the nurse's perspective, identified by Barr and Helen (1998), Bush and Barr (1997), and Beeby (2000) are incorporated within *ENGAGING WITH US* and *SUSTAINING US*, specifically the categories of *Letting Us In*, *Respecting Us*, *Reassuring Us,* and *Involving Us*. Barr and Helen (1998) interviewed ICU nurses to better understand their experience of caring. Bending the rules to allow longer visiting, letting family members touch the patient and provide some aspects of care, and helping family members feel special, were caring behaviours reported. Bush and Barr maintained that it was necessary for ICU nurses to care for the family's emotional and physical needs. Furthermore, in response to the question "What is caring for ICU nurses?" Beeby (2000) identified three themes. The theme of "being involved" included "being there", "being close", "feeling for", "respecting the person", and "involving the family". "Involving the family" was considered as important as, and interconnected with, caring for the patient, and included acknowledging the family's need to be there and letting a relative stay with the patient. "Respecting the person" was a second sub-theme for valuing the needs and dignity of the patient and the trust placed in the nurse by the patient and family. Another sub-theme, "feeling for" involved the nurse having hope and empathy for the patient and family. The second theme, "sustaining" referred to "being supportive", "having experience", and "feelings about work". "Sustaining, within caring, means the nurse provides support for the patient " (p. 156). "Being supportive", meant caring for the patient, colleagues, and family, the latter by providing information, explanations, and reassurance. The overlaps between the results of the current study and Barr and Helen's, Bush and Barr's, and Beeby's results, are mentioned because these researchers used nurse informants. That these nurse informants reported caring behaviours for family members that corresponded to what family member participants revealed as supportive behaviours from nurses, adds strength to the validity of the current study.

In 1998, the Synergy Model was proposed by the American Association of Critical-Care Nurses (AACN) Certification Corporation to describe nursing practice based on the unique needs and characteristics of patients and their families (Curley, 1998). Comparison of this model with the grounded theory of *LIGHTENING OUR LOAD* indicates significant overlap. Interestingly, the "historical" conceptualization of nursing mentioned by Curley in fact relates to quite recent history, Rubin's (1968) nursing model. The Synergy Model shares the simplicity of Rubin's Nursing Care Model, which emphasizes the primacy of the patient. Curley noted a constellation of nursing activities comprising the caring practices in response to the patients' situation. These nursing activities were explained by Stannard (1999) using the metaphor of dance partners, with the nurse as one of the partners and the family member as the other. Each nurse and family member comes to the situation with unique strengths and characteristics. Together they learn to respond to each other in the "dance". For some the dance may be smooth, and for others, less so. The Synergy Model has been untested to date. Nonetheless, it is being used by the AACCN for certification of acute and critical care nurses in the United States (Curley).

What does this overlap between the results of the current study and the literature cited about conceptualizations of caring in nursing in general, and caring in critical care nursing in particular, say about the relationships among caring, support, and nursing? First, other than in the case of the Synergy Model, these conceptualizations of "care" do not take into account that family members present with inherent strengths and abilities to get through the situation, which can be enhanced by the nurse. Second, this investigator posits that critical care nurses demonstrate caring to the family members of an adult patient in a particular way through the process of nursing support, *LIGHTENING OUR LOAD* for family members working to get through the experience. There appears to be a circular continuum to the concept of caring in nursing, with nurturing being necessary at least at the beginning and end of life, and as indicated by the complexity of the patient's psychological and intellectual deficits. Nursing support is somewhere along that circular continuum, variously experienced and defined depending on the specific situation, and based in large measure on the fact that the individuals being supported are requiring help to manage a particular situation, as opposed to needing to be "cared for". "Caring" is not a specific enough concept to explain nursing practice with this cohort, as caring implies the nurse being in the primary role of caregiver. "Support" as identified by participants in this study, which includes the critical dimension of the nurse being in a secondary or subordinate role, is a more appropriate concept. With the provision of nursing support, the individual in control shifts from the nurse (in caring) to the family member (in support). The family member directs the support that is needed so that the family member can ultimately care for himself or herself.

LIGHTENING OUR LOAD and the Concept of Comfort

In the grounded theory of *LIGHTENING OUR LOAD*, providing comfort is associated with *Advocating For Us*, specifically in terms of *Promoting our self-care*. However, all actions that positively influence an individual's state of unease, such as *Letting Us In* and *Reassuring Us,* can influence a family member's level of comfort. Morse and colleagues addressed the phenomenon of comfort in an extensive program of research (Morse, 1992; Morse, Bottorff, & Hutchinson, 1994; Morse, Havens, & Wilson, 1997). Although focussed on patient comfort, they did note that comforting family members was an indirect way to provide comfort to patients and implied that family members were recipients of comforting from nurses. Comfort was defined "as a state of well-being that may occur during any stage of the illness-health continuum" (Morse, p, 93). Comforting is a patient-driven activity, provided by the nurse in response to the patient's needs (Morse et al., 1997). Similarly, participants in the current study revealed that the process of providing nursing support was a family driven activity, where nurses provide support in response to the family member's needs. Family members work to get nurses to support them to get through the experience, if this support is not immediately forthcoming.

Interestingly, in all papers reviewed in which Morse was an author, the "support" of others is noted to be required in order for comfort to be achieved (Morse, 1992; Morse, Bottorff, et al., 1994; Morse, Havens, et al., 1997). Indeed, Morse (1992) specifically noted that "bringing in and supporting the family" was one type of comfort for the patient used in the emergency room, and that the nurse's role was "to support the enduring behaviours" of family members (Morse et al., 1997, p. 6). Previously, Gardner had defined support broadly as comprising those activities aimed at providing comfort and the promotion of health (1979). Nurses in Gardner and Wheeler's (1981a) study claimed that providing physical comfort was supportive, a finding later corroborated by patients (Gardner & Wheeler, 1981b, 1987). Walters (1994) identified the comforting provided by critical care nurses as involving appreciating the patient as a member of a family. The nurses in her study developed a bond with family members and comforted them by, "talking honestly", "listening to their concerns and promoting understanding", "empathizing", "appreciating that care doesn't stop with the patient", and "being with the patient and being with the family". Nursing support appears to be the broader concept as the components of comforting proposed by these other researchers, are included in the phase of *ENGAGING WITH US,* and the categories of *Reassuring Us* and *Advocating For Us*. Comfort appears to be one outcome of the process of nursing support, LIGHTENING *OUR LOAD.*

LIGHTENING OUR LOAD and Supportive Care

Results of research identifying supportive care, supportive behaviours, and supportive activities nurses employed on behalf of parents of hospitalized children, oncology patients, families of terminally ill patients, acute and critical care patients, and families of critically ill patients, are discussed in relation to the grounded theory of nursing support, as there is considerable overlap, despite the inconsistent use of the terms.

When supportive nursing interventions identified for parents of hospitalized children, and parents of infants who died in hospital, were compared to the current proposed theory, similarities were evident. Behaviours associated with *Letting Us In*, *Getting Acquainted With Us*, *Easing Our Departure*, and *Helping us find meaning,* were identified in addition to *Respecting Us*, *Reassuring Us*, and *Advocating For Us*. For example, Calhoun (1994) investigated helping parents deal with the loss of an infant. Supportive actions consisted of acknowledging the baby's importance to the parents, providing information, updates, and referrals, and providing emotional support in terms of communication, being present, attending to parents' physical and spiritual needs, and changing visiting rules. Additionally, the Nurse Parent Support Tool (NPST) (Miles et al., 1999) was developed to evaluate the nursing support received by parents of hospitalized children. These authors noted that examining supportive behaviours, both direct and indirect, was one way of better understanding the interpersonal role of the nurse, who was considered a vital component of the metaparadigm of environment as described by Kim (1987). The NPST includes 28 items, and assesses four dimensions of support. All dimensions are addressed within *LIGHTENING OUR LOAD*:

1. "Supportive communication and ongoing information", are analogous to *Communicating with us.*
2. "Support of parental esteem" through respecting, enhancing, and supporting the parental role, are analogous to *Acknowledging us* and *Respecting Us.*
3. "Emotional support" is analogous to *Reassuring Us.*
4. "Caregiving support", referring to the quality of care provided to the infant, is analogous to *Being accountable to us.*

The similarities between the results of the studies with parents of hospitalized children and the current study with family members of critically ill adults, underlines the pivotal role of the patient-family member relationship - no matter what the age of the patient.

There is considerable overlap when the dimensions of the Supportive Care Model for palliative care oncology patients proposed by Davies and Oberle (1990) and Oberle and Davies (1992) from the nurse's perspective, are compared to the phases of *LIGHTENING OUR LOAD*. *ENGAGING WITH US, SUSTAINING US,* and *DISENGAGING FROM US* include dimensions identified in their "Connecting"; *SUSTAINING US* includes all dimensions identified in their "Sustaining the Connection", "Doing for" and "Empowering"; *Facilitating Us Moving On* includes dimensions of their "Finding meaning". *LIGHTENING OUR LOAD* to help family members get through the critical care experience, shares similarities in meaning with the core category of their "Preserving integrity" in terms of the patient and family. Preserving the integrity of the nurse (Davies & Oberle) however, is not specifically identified in the current theory, although there is reciprocity inherent in *Getting Acquainted With Us*, *Sharing responsibilities with us*, and *Negotiating with us.* Additionally, Heslin and Bramwell (1989), and Larson (1986) investigated the supportive nursing interventions of palliative care nurses with oncology patients. Results included psychological support for families as being considered supportive to patients. These authors do not expand on this support. Nonetheless, psychological support is implicit in all three categories of *LIGHTENING OUR LOAD,* from *ENGAGING WITH US, SUSTAINING US,* to *DISENGAGING FROM US.*

Research conducted to determine supportive care behaviours with family members of terminally ill adult patients, revealed results that are all subsumed within the grounded theory of *LIGHTENING OUR LOAD.* Similar to the current findings, Hampe (1975) reported that spouses of the terminally ill felt supported when the nurse was courteous, friendly, and focussing care on the patient, analogous to *Welcoming us* and *Being competent*. Previously, Irwin and Meier (1973) had concluded that families of terminally ill patients identified the following as supportive behaviors: being honest, giving clear explanations and information about the patient's condition, making the families and patients comfortable, and showing interest by answering questions. These behaviours are subsumed under *Respecting Us*, *Communicating with us,* and *Promoting our self-care*.

The findings of the next two studies with patients are included with the discussion of the findings about nursing support for family members in the current study, as support for the patient is not isolated from support for the family. Based on the premise of the interconnectedness among individuals in a family, that which supports one member has a ripple effect on that which supports another member. That which informs us about one member may serve to inform us about another. The acute care patients surveyed and interviewed by Gardner and Wheeler (1987) about nurses' supportive care identified eight factors as supportive to patients that are compatible with and indeed included within the theory of *LIGHTENING OUR LOAD* as supportive to family members:

1. "Availability"- the physical and psychological presence of the nurse corresponds with *Letting Us In* and *Being there for us.*
2. "Physical care"- patient treatment and comfort measures corresponds with *Being accountable* and *Advocating For Us.*
3. "Individual care"- responding to the patient as an individual corresponds with *Respecting Us* and *Relating to us.*

4. "Control"- helping patients maintain control corresponds with *LIGHTENING OUR LOAD* to support family members in regaining some control.
5. "Confidence"- helping promote the patient's confidence in care corresponds with *Being accountable to us.*
6. "Problem solving"- providing advice and promoting self-awareness for the patient corresponds with *Guiding our decisions.*
7. "Information"- providing orientation information, and advance notice of changes corresponds with *Orienting us, Communicating with us,* and *Preparing us.*
8. "Moral support and encouragement" corresponds with *Reassuring Us.*

Subsequently, Geary, Formella, and Tringali (1994) discovered that critical care patients' perceptions of nurses' supportive behaviors included providing information, nurses' waving from the doorway, and holding the patient's hand. This is the only study in which specific greeting behaviours, as presented in the current study as *Welcoming us*, are identified as supportive, albeit for patients rather than for family members.

Gardner and Stewart (1978) defined supportive care for families experiencing critical care, as taking the "form of [nurses] providing information and education, encouraging expression of feelings, making environmental interventions" (p. 106). They discussed the importance of contact with family members as soon as possible following admission of the patient, in order to begin establishing a co-operative, trusting rapport. Again, *Letting Us In*, *Reassuring Us*, and *Advocating For Us* include all behaviours noted by Gardner and Stewart. As well, critical care nurses meeting family needs was determined by Millar (1989) to be providing support. Furthermore, Kleiber et al. (1994) investigated behaviours labeled by family members as supportive over the time span of a relative's (infant to adult) critical care hospitalization. The researchers defined support as "an action perceived by family members to relieve anxiety and facilitate coping" (p. 71). General supportive behaviours nurses exhibited were identified: a caring attitude (including concern, helpfulness, friendliness, understanding, positive attitude, and reassurance); truthful and understandable information; presence; communication; assistance; comfort measures; empathy; and spirituality. These behaviours are incorporated under *Getting Acquainted With Us*, *Respecting Us*, *Reassuring Us*, *Promoting our self-care*, and *Helping us find meaning*. When family members of burn patients were asked "What is helping you get through this hospitalization?" the support of family and friends, followed by the support of the burn team, was identified as crucial and involved nurses providing information, reassurance, and guiding family members (Thompson et al., 1999). Being with the patient was supportive to family. These points are subsumed within *Letting Us In*, *Reassuring Us*, and *Guiding our decisions*. Finally, *LIGHTENING OUR LOAD* was compared to the Nursing Support with Families Framework (NSWF) developed to help guide interventions with family members in the critical care situation (Vandall-Walker, 2002) based on the Supportive Care Model (Davies & Oberle, 1990). Four categories of nursing support were proposed: "connecting", "being instrumental", "promoting empowerment", and "discovering meaning". These categories correspond to four dimensions of nursing support: emotional support, instrumental nursing support, informational nursing support, and spiritual nursing support. All are subsumed within *Getting Acquainted With Us*, *Respecting Us*, *SUSTAINING US*, and *Facilitating Us Moving On*. Interestingly, *Letting Us In* and *Easing Our Departure* were not aspects specifically addressed within the NSWF.

LIGHTENING OUR LOAD and Social Support

Chen (1990), Gale et al. (2001), McNiven et al. (1992), and Vandall-Walker (2002) provide evidence of a significant shift in the discussion of nursing support. They infer by the terminology used, that nursing support is comprised of components of social support. In part, this inference is influenced by the expansion of knowledge about social support, from both the social sciences and nursing, which began in the 1980's. This shift in the discussion has further confused the understanding of nursing support. The theory identified in this study, with the core category of *LIGHTENING OUR LOAD,* helps clarify some of the ambiguity. The phases, *ENGAGING WITH US, SUSTAINING US*, and *DISENGAGING FROM US*, together explain the process that critical care nurses are involved in when they support family members working to get through the critical illness of a relative. The support nurses provide occurs both in response to, and in anticipation of, a family member's reaction to the stressors of uncertainty and fear due to a crisis. The admission of the patient into a critical care unit is the starting point of the process of nursing support.

Laireiter and Baumann's (1993) review of social support research noted that in the community, professionals were considered less significant providers of social support than in clinical settings. During crisis, the core support system was less effective for providing all the supports necessary for dealing with the situation. As a result, individuals with specific knowledge pertinent to the situation (professionals) became more significant providers of social support than did social intimates. Significantly, patients found nurses to be the most important supporters for meeting psychological and instrumental needs (Laireiter & Baumann). Based on a review of social support research, Stewart et al. (1997) defined social support as "interactions with family members, friends, peers, and health professionals that communicate information, esteem, aid, or emotional help" (p. 85). Taken together, the perspectives of Laireiter and Baumann and Stewart et al. provide the necessary rationale for the link between nursing support and social support. Certainly, the components of social support noted by Stewart et al. and further refined by Langford, Bowsher, Maloney, and Lillis (1997), consisting of the attributes of emotional, instrumental, informational, and appraisal support, correspond with the proposed grounded theory of *LIGHTENING OUR LOAD*.

However, Rook and Dooley (1985) had earlier maintained, "social support achieved through [professional] interventions should not be assumed to be equivalent in its form or effects to social support normally available from one's family and friends" (p. 10). In the current study, the form and effects of the process of nursing support are about *LIGHTENING OUR LOAD*. This is indeed different from those aspects of social support proposed by Langford et al. (1997) that involve reciprocity or mutual assistance, social intimacy, and exchanges of resources. If one accepts their argument, then nurses cannot be providers of social support for three reasons: (a) mutual assistance is not a requirement for the nurse/patient relationship (Norbeck, 1981; Lenrow & Burch, 1981); (b) nurses are not social intimates (Gottlieb, 1983; Norbeck; Lenrow & Burch); and (c) nurses do not enter into the provision of nursing care in expectation of reciprocity (Shumaker & Brownell, 1984) and an exchange of resources. However, one can argue that although mutual assistance is not a requirement, it does frequently occur. As well, although nurses are not social intimates, they are involved with patients and families in very intimate ways. Furthermore, the fact that nurses are paid, albeit in Canada, by the government from taxes, addresses the aspect of exchange of resources. It would appear then, that the differences between social support and nursing support are differences in degree and not in kind. Interestingly, Grossman's (1995) study to identify social support behaviours for critically injured patients and family members indicated that these behaviours occurred only among family members, patients, or friends. Lindsey, Ahmed, and Dodd's (1985) investigation of social support and Egyptian cancer patients produced similar results. However, these findings are contradicted by an investigation of social support for cancer patients, in which helpful and unhelpful behaviours exhibited by family, friends, and health providers were described (Dakof & Taylor, 1990). Possible sources of the differences between these studies as to who provides support, may lie in the domains of culture, research methods, and the impact the diagnosis has due to the nature and duration of the hospitalization.

Hupcey (1998a) proposed a definition of social support based on an extensive review of the literature. "Social support is a well-intentioned action that is given willingly to a person with whom there is a personal relationship and that produces an immediate or delayed positive response in the recipient" (p. 313). One could say that nursing support is hence about *LIGHTENING OUR LOAD,* a well-intentioned process engaged in willingly with a person with whom there is a professional relationship and that produces an immediate or delayed positive response in the recipient.

***LIGHTENING OUR LOAD* and Professional Support**

House (1981) posited that each category of social support; i.e., emotional, appraisal, informational, and instrumental, can be viewed in a matrix, vis-à-vis the source (intimate or professional), the context (general versus problem-focussed), and the perception (objective versus subjective). Additionally, Norbeck (1988) noted that professional support exists within the context of the professional relationship involved in a health care situation, and ends when the professional service is no longer required. This support is primarily solicited during a crisis when the usual providers of social support prove inadequate to sustain the family. If, as suggested, nursing support is different in degree rather than in kind, to social support, it therefore follows that nursing support, as presented in the current study, would constitute one form of professional support, referred to by some researchers as formal support, surrogate support, or objective support. This understanding is based on the "big picture" definition of "social", as relating to human society, rather than the narrower definition of social as referring only to one's social intimates.

Certainly, nurses are professionals, and the current study explores the provision of support by nurses of family members experiencing the crisis of critical illness. Supports external to the family's usual network are required to help family members in their work to get through the crisis. Nurses do this by *LIGHTENING OUR LOAD* for family members. The professional support that is required is of high intensity and of relatively short duration, and consists primarily of emotional or psychological, instrumental, and informational support (Norbeck, 1988). This is supported further by Waters (1999) who identified nursing support as professional support, in the development and application of the Professional Support Questionnaire for Critical Care Nurses Working With Family Members (PSQ), as did Miles et al. (1999) in their development of the Nurse Parent Support Tool (NPST), previously described. It is worth mentioning, that years earlier, Rubin (1968) had stated that "It is in the definition of the situation that one profession is distinguished from another" (p. 210).

Limitations

The key limitation of this study relates to the sample. Most participants self-selected, primarily in response to posters placed in critical care waiting rooms in two teaching hospitals in a large urban Canadian centre. Staff members, who thought the individuals would be valuable informants, referred two of the participants. Family members recruited four individuals, again because these family members thought the additional family members had valuable information to impart. This process resulted in a volunteer sample (Morse, 1989) comprised of all individuals who responded to the poster, and a nominated sample of those referred by critical care staff or other family members, who then agreed to participate. Based on theoretical sampling principles, the emerging theory influenced recruitment of the nominated sample and secondary selection from within the entire pool of participants, once participants' knowledgeability of the topic and ability to articulate their experience, was revealed.

All participants indicated that they had contacted the investigator because they wanted to help improve the situation for other family members in the future. In other words, all who contacted the investigator had something about which they were not satisfied, some more than others. Some participants reported numerous incidences of non-support. However, there were participants whose only suggestions for improvement centred on the provision of amenities such as parking, lockers, and food-dispensing machines. These participants maintained that in all other aspects, nurses were very supportive. This self-selection of individuals with a "bias" may at first glance be viewed as a limitation. However, those participants who reported numerous instances of non-support were viewed as negative cases. Strauss and Corbin (1998) maintain that "building explanations into the theory for them [negative cases] increases the generalizability and explanatory power of the theory" (p.160), as they "represent possible extremes of variation in the concept" (p. 212). Certainly participants, who particularly struggled to be supported by nurses, provided thick descriptions that informed the theory beyond what it might otherwise have been.

Because the investigator did not have complete control over the recruitment of informants, the resultant theory reflects the experience of the participants in this sample of the population of family members experiencing the critical illness of an adult relative. No family members of coronary patients volunteered for the study, although posters were visible in the three waiting rooms connected with these ICUs. In the case where the waiting room was shared between an ICU and a CCU, participants indicated that family members were "free to come and go at will on the coronary side". Access to the coronary patients then, appeared less controlled than access to critical care patients. Did this influence whether or not they even saw the recruitment poster? As well, no family member participants were involved in making decisions to donate organs for transplant. None of the participants' relatives were admitted for injuries sustained because of violence. Additionally, only one participant was from a visible minority group. All participants indicated relative economic stability. These specific situations potentially influenced the family members' perceptions of nursing support as well as their interest in being part of the current study. Further, Hopping et al. (1992) identified that nurses in teaching hospitals have higher education, the authority to control visiting policies, a belief that visiting should be limited for the patient's sake, and were more likely to establish and maintain closed visitation. The two hospitals chosen for this study were teaching hospitals, both practicing nurse-controlled visiting. This factor may have a bearing on the perception of participants that the wall between the waiting room and the ICU was a barrier that had to be breached, and that access was difficult. What bearing this nurse-controlled visiting had on the absence of participants, whose relative was admitted with cardiac-related diagnoses, is unclear.

Morse (1999) indicates that demographic variables alone do not influence the generalizability of a study, because "the knowledge gained is not limited to demographic variables.... it is the knowledge that is generalized (p. 6) to all similar situations, questions, and problems. The purposive selection of participants is key to determining the generalizabilty of the results, or as Strauss and Corbin term this concept, the explanatory power of the theory (1998). As indicated, theoretical sampling having been somewhat constrained, the explanatory power of *LIGHTENING OUR LOAD* is limited to the context of family members of adult critically ill patients in large urban hospitals in Alberta. Additional research on this topic using samples of similar as well as different populations of family members, as well as research from the nurse's perspective, will either confirm that the proposed theory adequately accounts for all possible variation, or will expand, modify, or extend these findings. Additional research should result in a theoretical framework of nursing support that can be applied in a more structured way in the form of a validated questionnaire to guide the formative evaluation of nursing support with families of critically ill individuals

Implications

The results of this study go beyond describing the experience of family members of critically ill adults, the experience of their work in critical care, and what nurses can do to help them. A more abstract explanation of the process of nursing support from the perspective of family members is revealed. This level of abstraction has resulted in a substantive theory, but with explanatory power limited by constraints to sampling, to the specific population from which the sample was drawn (Strauss & Corbin, 1998). The grounded theory reported does not offer nurses a prescription for supporting families of critically ill adults. Rather, the findings of this study do provide information to increase a critical care nurse's sensitivity about nursing support for this cohort, and offers one explanation of this process. Additional exploration of the process of nursing support is indicated, using theoretical sampling that is more systematic and widespread than was possible in the current study, and potentially drawn from populations of expert critical care nurses as well as critical care family members from community hospitals, other provinces, and other countries. This process of nursing support can be investigated with non-ICU nursing and patient populations as well.

The three phases of *LIGHTENING OUR LOAD: ENGAGING WITH US, SUSTAINING US,* and *DISENGAGING FROM US* can serve as focal points around which to design nursing support assessment and evaluation tools for family members, thus providing a family-centred framework for developing subsequent interventions. The matter of assessment is significant, as this activity not only provides the family context to the critical care situation, but serves as an opportunity for the family and nurse to begin engaging. Moreover, the overarching call from participants for access to the bedside should not be ignored. Ample evidence about critical care visiting currently exists beyond the current study, sufficient to encourage nurses to critically examine their practices. Nurse administrators may choose to focus attention on the provision of amenities, as again, previous research has addressed the value of these supports for family members experiencing the critical illness of an adult relative. This grounded theory can also sensitize health professionals to the important and necessary *'work'* of family and the role nurses can play in supporting family members in their *'work'*. The value to family members of nurses' welcoming behaviours, and being included in the provision of personal care to the patient, revealed in the current study, has been well-documented previously, and should therefore be considered by critical care nurses when dealing with family members.

LIGHTENING OUR LOAD represents the voices of family members, the recipients of nursing support, not the voices of nurses, the providers of nursing support. Contextual elements of time, critical care environment, patient, nurse, and the family and their *'work'* of *'getting through'*, trigger movement through *ENGAGING WITH US, SUSTAINING US, to DISENGAGING FROM US*. Decreased patient length of hospital stay and increased family member comfort, knowledge, empowerment, resiliency, and partnership, may be positive outcomes of mitigate the negative potential outcomes of *LIGHTENING OUR LOAD*. On the other hand, increased patient length of hospital stay, family member morbidity including depression and post traumatic stress disorder, may result when the family perceive a lack of support for their *'work'* of *'getting through'* the critical care experience. The current study can both inform and be a catalyst for future research targeting patient and family outcomes.

A number of research questions to investigate based on what is now known about *LIGHTENING OUR LOAD* are suggested:

1. What is the process of working that families engage in to get through the critical illness of a relative?
2. How do critical care nurses perceive the process they engage in to support family members of critically ill adults?
3. What is the significance of spirituality, ethnicity, and economic status to nursing support with family members of critically ill adults?
4. Is there reciprocity between the nurse and family when nursing support is provided?
5. When different professionals act together with family members on their behalf, how does this "collaborative support process" look?
6. Is there a connection between a therapeutic relationship and nursing support?

Furthermore, as no instruments currently exist to measure nursing support from the perspective of family members, the grounded theory of *LIGHTENING OUR LOAD* can inform instrument development about the provision of nursing support, and family satisfaction with the critical care experience. Gardner and Wheeler (1981b, 1987) have developed a Nursing Support Scale (NSS) from the perspective of expert nurses, to rate the support nurses provide patients. As well, Miles et al. (1999) developed the Nurse Parent Support Tool (NPST) for parents of young children to assess the nursing support they received. *LIGHTENING OUR LOAD* could be used as a framework to expand and adapt one or both of these scales for use by family members in rating the support they have received, and their overall satisfaction with the critical care experience, at various points in time during and after the hospitalization. Is "caregiver burden" post-discharge, influenced by the level of nursing support that family members experience during the ICU stay?

Conclusion

Notwithstanding the fact that support is viewed as a dominant caring concept, and frequently cited as a nursing intervention, little was known about how nurses effect the provision of support, and even less, about the perceptions of families regarding nursing support. This phenomenon was examined in terms of nursing with family members of a critically ill adult. In the current study, the overarching response of family members was to '*work*' to '*get through*' their relative's critical care hospitalization. Their workload was comprised of all the tasks they performed, taken together. This workload was found to be more comprehensive than has been reported previously in the literature, wherein the meaning ascribed to the event, as well as family member hardiness, enduring, stress responses, needs, satisfaction with care, and coping styles have been identified. One specific aspect of family members' work, that of gaining the trust and respect of nurses so as to be taken seriously by nurses and physicians, has not been previously reported in the literature.

LIGHTENING OUR LOAD emerged as the core category of the process of nursing support, comprised of three interrelated, overlapping, and recurring phases: *ENGAGING WITH US*, *SUSTAINING US*, and *DISENGAGING FROM US*. Although this grounded theory shares characteristics with previously reported research, unlike much of the research with family members of critically ill patients, *LIGHTENING OUR LOAD* emerged from a qualitative investigation from the perspective of family members rather than from the perspective of nurses. As well, *LIGHTENING OUR LOAD* is inclusive of the family members' perspective from the patient's admission to ICU, to discharge or death, and beyond.

Comparisons made between the grounded theory of *LIGHTENING OUR LOAD* and extant research about family needs revealed similarities. First, the needs perceived by family members of the critically ill adult, reported using CCFNI$^{©}$ instruments in study after study and now considered to be universally experienced, are not only addressed in *LIGHTENING OUR LOAD* but are extended to include needs heretofore unidentified.

These instruments have not captured the entire phase of *DISENGAGING FROM US*, and the categories of *Trusting us*, *Communicating with us*, and *Being accountable to us*. As well, recent non-CCFNI research about relocation anxiety and bereavement has been closing the gaps in research related to *DISENGAGING FROM US*. *DISENGAGING FROM US* throughout the entire ICU admission however, has only been addressed in the current study. Furthermore, no other research specifically identified the significance to family members, of ICU nurses *Welcoming us*, and only a few alluded to *Saying goodbye*. However, participants in the current study did not report that nurses had the power to heal or that nurses were guided by a higher power, as identified by Warren (1994).

When *LIGHTENING OUR LOAD* was compared with general and specific conceptualizations of caring, comfort, supportive care, social support, and professional support, many shared characteristics were found, dependent on the context. More significant was the fact that these comparisons exposed the relationships among these concepts. Social support results from humans caring for each other, based on various levels of social connection. Professional support however, refers to those aspects of social support provided by professionals in response to specific needs that cannot be met by social intimates. Nursing support is the specific form of professional support provided by nurses to family members in response to the critical illness of a relative. Comfort is one outcome of the provision of nursing support. This grounded theory of nursing support, *LIGHTENING OUR LOAD*, revealed from the perspective of family members, is specific to families of critically ill adults in their '*work*' to '*get through*' the experience, and constitutes one step in the development of theoretical nursing knowledge about the process of nursing support.

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APPENDIX A:

RESEARCH NOTICE

DO YOU HAVE A LOVED ONE IN ICU??

WOULD YOU CONSIDER PARTICIPATING IN A RESEARCH STUDY?

Purpose: The information you provide will be useful for understanding the ways nurses can help individuals experiencing the critical illness of a loved one.

Contact: Virginia Vandall-Walker, RN, PhD Candidate

<<<Tear off form affixed here>>>

(form has Virginia Vandall-Walker's name, email address, and phone number)

APPENDIX B:

INFORMATION LETTER FOR PARTICIPANTS

Title of project: Delineating the Process of Nursing Support with Family Members of the Critically Ill

Investigators:

Virginia Vandall-Walker, RN, PhD Candidate
Faculty of Nursing
University of Alberta
Edmonton, AB T6G 2G3
Cell Phone: 780-497-2882

Louise Jensen, RN, PhD
Supervisor
Faculty of Nursing
University of Alberta
Edmonton, AB T6G 2G3
Phone: 780-492-6795

Purpose: The purpose of this research is to learn how nurses can most effectively support individuals with a loved one in intensive care. This information will be useful for understanding the ways nurses might ease the family's distress.

Procedure: I will be asking questions about your experience. The interview will take about an hour to complete and will be done privately. The interviews will be tape-recorded. During the interview you may choose not to answer certain questions or discuss certain topics. A decision not to participate will not affect the care you or your loved one receive.

Discomforts or Risks: No discomforts or risks will be associated with the interview. Care will be taken to protect your identity and the identity of your family.

Benefits: There will be no direct benefits to you or your family because of your participation. However, you may find it helpful to talk about your experiences. The information you provide may help nurses working with families in critical care in the future.

Statement of Confidentiality: All written notes and tape recordings will be treated as confidential material. No name will be attached to or written on the tapes or transcripts. I will assign a code number for each participant that only I will know. The consent forms, tapes, transcripts, code book, and notes will be kept locked in two separate, secure, filing cabinets. If this research is published, no personal information about your identity will be used. Something you said might be quoted but no one reading the information will be able to identify you.

Freedom to withdraw: You may change your mind about participating at any time. Doing so will not affect the care you or your family receive. To withdraw, please call or mail a note to either of the individuals noted above.

Contacts: If you have any questions or comments about this research, please feel free to contact Virginia Vandall-Walker at (780) 497-2882. If you have any concerns about any aspect of this study, you may contact the Patient Concerns Office of the Capital Health Authority at 474-8892. This office has no affiliation with the study investigator.

APPENDIX C:

INFORMED CONSENT

Title of project: Delineating the Process of Nursing Support with Family Members of the Critically Ill

Investigator:	Virginia Vandall-Walker, RN, PhD Candidate Faculty of Nursing University of Alberta Edmonton, AB T6G 2G3 Cell Phone: 780-497-2882	Louise Jensen, RN, PhD Supervisor Faculty of Nursing University of Alberta Edmonton, AB T6G 2G3 Phone: 780-492-6795

	Please circle one
1. Do you understand that you have been asked to take part in a research study?	Yes / No
2. Have you received a copy of, and read the Information Letter (attached)?	Yes / No
3. Do you understand the benefits and risks involved in taking part in this research study?	Yes / No
4. Have you had an opportunity to ask questions and discuss the study with the interviewer?	Yes / No
5. Do you understand that you do not have to participate and that you may withdraw from the study at any time?	Yes / No
6. Do you know that if you do not participate, or if you withdraw from the study, the quality of care you or your loved one receive will not be affected?	Yes / No
7. Has confidentiality been explained to you?	Yes / No
8. Do you understand what it means?	Yes / No
9. Do you understand who will have access to the information you provide?	Yes / No

This study was explained to me by:

____
Name of person

I agree to take part in this study:

____________________________ ____________
Signature of research participant Date

____
Printed name

____________________________ ____________
Signature of witness Date

____
Printed name

I believe the person signing this form understands what is involved in the study and voluntarily agrees to participate.

____________________________ ____________
Signature of Investigator Date

APPENDIX D:

DEMOGRAPHIC DATA FORM

Title of project: **Delineating the Process of Nursing Support with Family Members of the Critically Ill**

Participant # __________

Spokesperson's Relationship to the Patient (circle one)

Husband Wife Partner Mother Father Daughter Son Friend
Other (specify) ____________

Who constitutes the patient's family (those individuals most significant to the patient)?

____

Personal Information

Participant: Age: _____ Gender: ______ Marital status: ______

Occupation: _________________________ # Yrs.________

Experience with critical care? (When? Where? Why?)

____

Patient: Diagnosis: ____________________Age ______ Gender: ______

Date of Admission: _____________

Children: Number of: __________ Number of Children at Home:_______

Ages: __________ Gender s: __________

Social Network of Participant and Family Unit
(make a general statement based on whether the participant reports that the individual and family networks are large and strong, small and weak, or in, fact non-existent etc...)

APPENDIX E:

SAMPLE RESEARCH QUESTIONS

1. Tell me what it has been like for you since your (   ) has been in ICU?

2. What has helped you deal with this experience?

3. What has not been helpful?

4. Did you feel helped by nurses?

5. Can you tell me what you mean by the word support (if used)?

6. What support did you expect?

7. What has been supportive for you as an individual in dealing with this experience?

8. What has been supportive for your family as a whole in dealing with this experience?

9. During the ICU experience was there a change in what you expected from nurses?

10. During the ICU experience was there a change in how the nurses were with you?