

IMPORTANCE OF FAMILIES IN NURSING CARE

Running Head: IMPORTANCE OF FAMILIES IN NURSING CARE

Nurses' Attitudes about the Importance of Families in Nursing Care:

A Survey of Canadian Critical Care Nurses

Working in Adult ICUs

By

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Abstract

The purpose of this study was to identify Canadian critical care nurses' attitudes about the importance of families in nursing care in adult intensive care units (ICUs), explore their perceptions of family-centered care (FCC), and examine policies and practices in place that promote FCC in adult ICUs. A web-based survey was used with a sample of members (N = 207) of the Canadian Association of Critical Care Nurses. Using the Families Importance in Nursing Care: Nurses' Attitudes (FINC-NA) instrument, it was found that age and years of ICU experience were positively related to more positive attitudes (n = 193), while direct care providers had lower scores than nurses in other roles. Nurses identified benefits for patients, families, and staff associated with FCC, but also outlined challenges in implementing FCC, including comfort of nurses and a lack of support from team members. Nurses' responses to questions about FCC policies and practices illustrated concerns with the implementation of FCC in the units the nurses worked in. The results of this study have implications for practice, education, and research.

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Dedication

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Chapter One: Introduction

The admission of a family member into a critical care unit is often a crisis for that patient and his/her family (Leon & Knapp, 2008). Almost 20 years ago, Molter (1994) wrote that she believed “there is a moral obligation to do no harm to patients; that separating patients from those they depend on for support, strength and love can do harm” (p. 2). Family-centered care (FCC) has become the norm in most pediatric settings in North America, but the same cannot be said for adult settings. The focus of this study is on two factors in the movement towards FCC: nurses’ attitudes toward patients’ families in the adult intensive care unit (ICU); and the presence or absence of structures in critical care settings to promote family-centered care.

In this first chapter of the thesis, a problem related to the implementation of FCC in adult ICUs is identified and the purpose of the study and research questions are outlined. In chapter two, the literature is explored related to the roles of families in ICU, the needs of family members of critically ill patients, visiting in the ICU, nurses’ attitudes toward families, implementation of FCC in adult ICUs, and the positive outcomes that have been documented as a result of implementing strategies to promote FCC in the ICU. The methods for this study are presented in chapter three, followed by the results in chapter four, and discussion of the results in the final chapter.

Background to the Problem

In a report created for the Institute for Family-Centered Care in Bethesda, Maryland and the Institute for Healthcare Improvement, Conway et al. (2006) described patient- and family-centered care as placing an emphasis on:

Collaborating with patients and families of all ages, at all levels of care, and in all health care settings. Further, it acknowledges that families, however they are defined, are

essential to patients' health and well-being and are allies for quality and safety within the health care system.... Family members are more than surrogates to be called on when the patient is unable to make decisions on their behalf; they are essential members of the care continuum and care-giving team. (p. 6)

Family-centered care as a philosophy and method of care delivery originated in pediatric health care environments. In the 1920s in England, Sir James Spence wondered why parents were excluded from the care of hospitalized children. He began to admit mothers with their children to hospitals (Shields, 2007). In the 1940s, two New Zealand surgeons showed that admitting mothers with their children did not increase the incidence of infection, which was the primary argument to exclude parents. Family-centered care developed after research in the 1950s showed that children were emotionally disadvantaged when separated from parents during hospitalization (Shields, 2007).

In the 1960s, Fagin began to write about her perceptions of the health care systems of the time. Fagin (1962) believed that parents of hospitalized children were treated as "the natural enemy rather than an integral part of the patient's life" (p. 78). The separation of parents and child during the hospitalization resulted in the child feeling deserted and isolated, and Fagin (1962) advocated for the presence of parents in the hospital to decrease anxiety caused by the hospital environment and to maintain as little disruption in the lives of hospitalized children as possible. Fagin and Nusbaum (1978) wrote that "the evidence has been convincing that the presence or absence of the mother figure is itself a condition of the greater significance in determining a child's emotional state" (p. 24), even when mothers were found to have questionable parenting skills. Fagin's research resulted in recommendations to change parental visiting privileges in pediatric units to include permitting parents to visit with their hospitalized

child 24 hours a day (Fagin & Nusbaum, 1978). Interestingly, one of the observations made by Fagin (1962) in relation to adopting FCC in pediatric settings, and later reinforced by Shelton, Jeppson, and Johnson (1987) in their FCC guide, was that changes in nurses' attitudes were required for families to be included in care.

FCC in pediatric ICUs.

In 1997, Bruce and Ritchie reflected on what was then the 30-year development of FCC in pediatric ICUs. They noted that there had been a shift towards increasing the involvement and responsibility parents have in the coordination of care for their critically ill child (Bruce & Ritchie, 1997). This involvement of parents has had positive outcomes. For example, Evans (1996) evaluated in-hospital care provided by mothers of hospitalized children with cancer who had been taught to administer intravenous antibiotics to their children. Successful participation by mothers in their children's care resulted in a sense of control felt by the mothers which helped promote adaptive coping (Evans, 1996, p. 143). Hurst (2006) found that communication between parents and health care professionals in neonatal ICU improved when parents attended programs that promoted the inclusion of parents in the care of and decision making for their child. And in a study of an education program for children with asthma and their family members, attendance at the program resulted in a significant decrease in the number of visits children made to the physician as well as a decrease in the numbers of children who required emergency care (Lewis, Lewis, Leake, Monahan, & Rachelefsky, 1996).

Today, it is widely accepted that the hospitalization of a critically ill child is a stressful experience for the child and parents. Hospitals have adopted policies to decrease this stress by "allowing unrestricted parental visiting, providing rooming-in facilities for parents and involving parents in the care of their child" (Coty, Larocque, & Koren, 2001, p.10). FCC in PICU includes

adopting the view that parents' relationship with professionals is one of collaboration and partnership (Caty et al., 2001). Nurses who implemented FCC into pediatric practice with the least amount of difficulty included nurses in specialty units, nurses with more education, and nurses supported by their administration (Bruce & Ritchie, 1997; Caty et al., 2001; Harrison, 2010).

Patient-centered care becomes FCC in adult ICUs.

Up until fairly recently, the focus in adult ICUs has been on patient-centered care. The concept of patient-centered care was introduced into the literature over 40 years ago. British psychoanalyst Enid Balint (1969) provided an early definition of this concept: "understanding the patient as a unique human being" (p. 269). After an extensive review of the literature related to patient-centered medicine in the period between 1969 and 1998, Mead and Bower (2000) identified that this approach was characterized by: a biopsychosocial perspective of illness; an understanding of the personal meaning of illness for the patient; a more egalitarian relationship between the patient and health care providers; a therapeutic alliance between the patient and health care providers; and recognition of the influence of the personal qualities of health care providers on the relationship. More recently, Hughes, Bamford, and May (2008) reviewed the literature in the period from 1987 to 2006 on five different types of centeredness in health care (i.e., patient, person, client, family, and relationship). These authors identified the following recurring themes related to these concepts: respect for people as individuals; the unique perspective of each person; therapeutic alliance; the importance of relationships (including family relationships); an inclusive model of health; acknowledgement of expert lay knowledge; shared responsibility; communication; autonomy; and the professional as a person.

Patient-centered care translates into family-centered care in critical care because of the compromised, vulnerable conditions of critically ill patients, who often cannot make decisions on their own behalf and require family members to partner with the health care team to advocate in the patients' best interest. Central to this approach is the tenet that the patient and his/her family are included as a unit in the plan of care (Henneman & Cardin, 2002; Hinkle, Fitzpatrick, & Oskrochi, 2009; Shields, 2007).

An extensive review of the literature in FCC in critical care determined there is a significant gap in the acceptance and implementation of this approach to care in adult ICUs as compared to pediatric intensive care units (PICUs). While there is evidence on hospital and government web-sites in Canada of some movement toward adopting this philosophy of care in adult ICUs (Government of Saskatchewan, 2010; Mount Sinai Hospital, 2012; St. Michael's Hospital Trauma Services, 2007; St. Paul's Hospital, 2010), it has not yet been widely adopted across the country. There are likely a number of reasons why this is the case in Canada. Benzein, Johansson, Arestedt, Berg, and Saveman (2008) have argued that factors such as organizational structures, finances, and nurses' attitudes toward families may prevent the implementation of family nursing. This study explored two of these factors: a) nurses' attitudes toward families, extending the work of Benzein, Johansson, Arestedt, and Saveman (2008); and b) the presence or absence of structures (e.g., policies and procedures, clinical guidelines, education programs) in critical care settings to promote family-centered care.

Purpose and Research Questions

The purpose of this study was to identify Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs, explore Canadian critical care nurses

perceptions of FCC in adult critical care, and examine policies and practices that are in place that promote FCC in adult critical care units. The specific research questions were:

1. What are Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs?
2. What are Canadian critical care nurses' perceptions of FCC in adult critical care?
3. What policies and practices are in place in adult ICUs in Canada to promote FCC or involvement of the family in the care of patients?

Guiding Framework

To understand why it is helpful to explore nurses' attitudes about the importance of families in nursing care, one can draw on Ajzen's (1991) work related to planned behavior. Icek Ajzen is a professor of psychology at the University of Massachusetts whose interests focus on attitudes and research in personality and social psychology (Ajzen, n.d.). Ajzen (1991) developed the *Theory of Planned Behavior* and linked the concepts of attitude, intention, and behavior.

Intentions to perform behaviors of different kinds can be predicted with high accuracy from attitudes toward the behavior, subjective norms, and perceived behavioral control; and these intentions, together with perceptions of behavioral control, account for considerable variance in actual behavior. (Ajzen, 1991, p. 179)

The *Theory of Planned Behavior* is "designed to predict and explain human behavior in specific contexts" (Ajzen, 1991, p. 181). The theorized links between attitudes, intentions, and behaviors will be used as a guiding framework for this study. Ajzen's theory supports the idea that attitudes are important to study given their links to behaviors. Benzein and colleagues have argued that nurses' attitudes must be supportive in order for them to include families in nursing

care (Benzein, Johansson, Arestedt, & Saveman, 2008). This finding is supported by Ajzen's theory which proposes that attitudes influence people's intentions and behaviors.

In Ajzen's (1991) theory, attitude is a behavioral, normative and control belief about a behavior, however, the exact nature of the relationship between attitude and behavior is uncertain. If an individual has a positive attitude about a behavior there is an increased chance he/she will perform that behavior. Ajzen believes that attitude and personality traits can predict behavior. In this study attitudes were examined, defined by Ajzen (1991) as "the degree to which a person has a favorable or unfavorable evaluation or appraisal of the behavior in question" (p. 188). Attitudes are generally assumed and form a continuum that extends from a negative evaluation at one end to a positive evaluation at the other end (Ajzen, 1991). Whether an individual has a positive or negative attitude towards the behavior affects whether the individual will perform the behavior. A positive attitude increases the chance of the individual performing the behavior where a negative attitude decreases the chance of the individual performing the behavior. Therefore, understanding attitudes can serve as a point of focus in attempts to change behavior (Ajzen, 1991, p. 206).

Assumptions

- FCC is a philosophy that has applications to or relevance for adult ICUs.
- Based on Ajzen's theory, there is a relationship between attitudes and behaviors; therefore, it is important to study attitudes.
- Based on Ajzen's theory, an individual's attitude towards a phenomenon may be a place to focus in attempts to change behavior.
- Transformation of an attitude towards a patient in an intensive care unit requires that a patient be treated as a biological and social being (Danuseviciene &

Jurkuvienė, 2010). The patient and their family must be perceived as a unit in order to provide a high level of patient-centered care (Molter, 1979, p.239).

Significance

There is a need to increase our knowledge regarding Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs. Nurses' attitudes, whether they are supportive or not supportive of FCC, may serve as a beginning point to help us understand possible barriers and facilitators to implementing FCC in adult ICUs. Benzein and colleagues have argued that a supportive attitude is important to invite and engage families in nursing care, to improve interaction between families and nurses, and to establish good relationships with families and provide good nursing care (Benzein, Johansson, Arestedt, Berg, & Saveman, 2008). It is also important to learn more about structures that promote or inhibit FCC, including policies and procedures, clinical guidelines, and educational programs that support the presence of family in the ICU.

Chapter Two: Literature Review

In this chapter, the literature related to families in ICU is examined. In particular, the following topics are explored: the impact on families of the hospitalization of a loved one, the role of families in ICU, the needs of family members in the ICU, the evolution of visiting practices and policies related to families in ICU, and nurses' attitudes about the importance of families. Databases used to examine the literature were PubMed and Cumulative Index for Nursing and Allied Health Literature (CINAHL). The years included in the search were 1962-2013.

The Impact on Families of the Hospitalization of a Family Member in an ICU

Studies have demonstrated that families experience depression, anxiety, and post-traumatic stress disorder (PTSD) as a result of the hospitalization of a loved one in an ICU (Curtis, Ciechanowski, Downey, Gold, Nielsen, Shannon et al., 2012; Kross et al., 2011; McAdam, Dracup, Whilte, Fontaine, & Puntillo, 2010). These responses have long-term significance for family members and this section will look at factors that may precipitate these symptoms and strategies suggested for health care providers to minimize these detrimental outcomes.

The symptoms experienced by family members of ICU patients who were at high risk for dying were studied by McAdam et al. (2010). This prospective cross-sectional study examined 74 family members of ICU patients with grave prognoses. The purpose of the study was to assess the level of traumatic stress, anxiety, and depression of family members of ICU patients four days after the patient's admission to the ICU. The results determined that family members had a significant risk of experiencing symptoms of PTSD; most family members in the study experienced moderate to high levels of traumatic stress and moderate to high levels of anxiety

and depression. The researchers suggested that family members experiencing these psychological symptoms may: have difficulty making decisions with the health care team; be unable to estimate how effective treatment options are for the patient; not understand information provided to them; require information to be repeated in many different ways (i.e., inter-professional communication with the team, only the most critical information in order to prevent information overload); and require more time to process information (McAdam et al., 2010). Interventions such as structured family meetings and helping families anticipate what they may see, hear, and experience while visiting the ICU may minimize these symptoms and prevent long-term negative consequences (McAdam et al., 2010).

Kross et al. (2011) used a randomized trial to study an interdisciplinary quality improvement intervention that was conducted in eleven hospitals in Washington State. A total of 226 family members of patients who had been in ICU for at least 6 hours and who had died in the ICU within 30 hours of being transferred out of the ICU were surveyed at least 6 months after the patient's death to assess for symptoms of PTSD and depression. These symptoms were previously detected in this group but the patient characteristics associated with PTSD and depression in family members were not known (Kross et al., 2011). The researchers found that 14% of family members had PTSD and 18.4% had depression, while family members of older patients had lower scores for PTSD. Family members who were present when the patient died and who had a family conference in the first 72 hours of the ICU admission had higher scores for symptoms of PTSD. Family members of patients who received palliative care services had a significantly lower burden of depression (Kross et al., 2011). Awareness of these results may encourage health care providers to ensure palliative care is in place at end of life to ease the burden of decision making (Kross et al., 2011).

Azoulay et al. (2005) studied the risk of post-traumatic stress symptoms in family members of intensive care unit patients. Twenty-one ICUs in France that used homogeneous practices regarding end-of-life care and FCC participated in this longitudinal study. The study sample consisted of 284 family members. Approximately 33% of family members who participated in this study indicated that they had post-traumatic stress reaction (PTSR) and were at significant risk for developing post-traumatic stress disorder (PTSD). A higher score on the survey that was used to measure PTSR indicated a higher risk of developing post-traumatic stress disorder. Higher scores were found in families if they were dissatisfied with the information they received or if they participated in end-of-life decisions, if their loved one was in an ICU with a larger number of beds, in females and children, in families who had a family member with cancer in the ICU, and in families of patients who had severe acute illnesses (Azoulay et al., 2005).

Symptoms of depression were found more often in family members of patients who died in ICU. Anxiety and depression were found to be associated with a severe post-traumatic stress reaction that resulted in a decreased quality of life for up to three months after the discharge or death in ICU (Kentish-Barnes et al., 2009). Factors associated with PTSD symptoms included the patient's death and end-of-life decisions. Severe symptoms of PTSD in relatives were associated with higher rates of anxiety and depression and decreased quality of life (Kentish-Barnes et al. 2009). Family-centered care and psychological support were recommended for family members of patients in ICUs. Strategies are needed to diagnose PTSD and complicated grief disorder early. This may be done by preventive interventions such as communication strategies, family meetings and end-of-life family conferences with written information provided

to family members, psychological support, and appropriate medications (Kentish-Barnes et al., 2009).

Paparrigopoulos et al. (2006) studied the short-term psychological impact on family members of the hospitalization of loved ones in ICU. A sample of 32 family members of ICU patients who were admitted to the ICUs of two general hospitals participated in the study. Family members' psychological reactions were assessed one week after the patient's ICU admission and three days before the patient's discharge from the ICU. Symptoms of anxiety and depression, characteristics of PTSD, were high during the first assessment indicating severe anxiety and depressive reaction. Approximately 80% of the sample was likely to meet the diagnostic criteria for PTSD (Paparrigopoulos et al., 2006). After the second assessment, the stress reaction decreased significantly, but 87.5 % of the sample met the criteria for depression and 59.5% for post-traumatic stress reaction (PTSR). Significant correlations were found between the patient's age or the family member's age and the degree of anxiety, depression, PTSR, or PTSD. Females were found to have more intense emotional reactions than males in the first assessment and had higher scores on all measures of psychopathology. Spouses had higher levels of anxiety during the first assessment. Family members with a low level of education had higher scores indicating PTSR (Paparrigopoulos et al., 2006).

Choi et al. (2013) studied health risk behaviors in family caregivers during patients' stays in ICUs. The purpose of this study was to explore how family caregivers' health risk behaviors were related to the preexisting care needs of the patient and the caregivers' depressive symptoms and burden. Dyads of caregivers and patients were recruited for a sample of 50 caregivers and 47 patients. The researchers found that 94% of caregivers had one or more health risk behaviors such as inadequate rest (70%), inadequate exercise (38.7%), and skipping meals (62%).

Caregivers also were found to be unable to slow down or rest when they were sick, had difficulty taking their medications or scheduling and keeping doctor appointments. Caregivers who were smokers were found to smoke more than they normally would (Choi et al., 2013, p. 43).

The family members of patients who are hospitalized in an ICU experience stress that may result in emotional problems that lead to PTSD. It is important for health care workers to be aware of the stress experienced by families as well as be familiar with ways to assess the degree of PTSD that families may experience.

The Roles of Families of Adult Patients in ICUs

For some time, people have recognized and written about the importance of relationships and interactions among nursing staff and families of adult patients. As noted in chapter one, critical care patients are often compromised and vulnerable and may not be able to communicate given the nature of their illnesses. Tapp (2000) identified that a “relational stance” (p. 89) is important in nursing, a stance that understands that the professional knowledge of the nurse must be applied to the individual circumstance of the patient and family. Nurses must respect that in order to help families they must engage and learn with them how to best meet their individual needs and not assume that our nursing knowledge makes us the expert (Tapp, 2000). Some have argued that the patient and family ought to be perceived as a unit in regards to nursing care (Molter, 1994). In this next section of the chapter, literature related to families in ICU is reviewed, including literature related to the family as a source of information, as decision-makers for patients unable to make decisions for themselves, and as a support to critically ill patients.

The family as a source of information.

For a number of reasons, including the nature of their illness or injury and the treatment for same, many patients are unable to communicate in ICU. In their seminal work related to

critical care nurses, Benner and colleagues (Benner, Tanner, & Chesla, 1996) wrote about the importance of “knowing the patient”. The concept of “knowing the patient” brings to life a value which perceives the person as a holistic being. Researchers have determined that knowing the patient is comprised of the nurse understanding the patient and developing an individualized plan of care that includes nursing interventions based on this understanding. The experience and expertise of the nurse, the time nurses spend with patients and their family members, and how nurses engage with patients during care are factors that influence how well nurses know their patients. Nurses’ abilities to know the patient may result in positive outcomes for patients (Radwin, 1996). Crocker and Scholes (2009), for example, in an ethnographic study on weaning patients from mechanical ventilation, identified that nurses (N = 12) described “knowing the patient” as a necessity to develop an individualized plan of care.

One of the ways nurses come to know patients in ICUs is through the family members who visit patients during their critical illness. Benner et al. (1996) describe how engaging with family members of critically ill patients can result in ICU nurses having increased knowledge about their patients and may improve clinical judgment. Establishing a relationship with the family of a critically ill patient, a patient who may be mentally compromised, provides the ICU nurse with knowledge about the patient’s past, present, and future. Information received from establishing a relationship and engaging with the patient’s family helps nurses come to know the patient and family and may result in an emotional connection with the family. The nurse obtains more detailed information about the patient’s past and understands how the family is impacted by the illness, allowing the nurse to plan individualized care for the patient and his/her family members based on their identified needs (Benner et al., 1996).

Tanner (2006) reinforces the importance of knowledge of the patient in an article examining the growing body of nursing research on clinical judgment. The term clinical judgment is defined by Tanner as “an interpretation or conclusion about a patient’s needs, concerns, or health problems, and/or the decision to take action (or not), use or modify standard approaches, or improvise new ones as deemed appropriate by the patient’s response” (p. 204). One of Tanner’s conclusions is that: “sound clinical judgment rests to some degree on knowing the patient and his or her typical pattern of responses, as well as an engagement with the patient/family” (p. 204).

Understanding the importance of nurses knowing their patients is reinforced by understanding that negative outcomes occur when nurses do not know patients. According to Whittemore (2000), in the absence of knowledge of the patient, it is possible for patients to be denied compassion and empathy and for nurses to have difficulty fulfilling the role of patient advocate. In addition, the essence of nursing practice, which includes understanding the patient as a holistic being, may be lost. Knowing the patient requires that nurses spend time with their patients and patients’ family members (Whittemore, 2000).

In an ICU setting, because of the vulnerable and compromised condition of the critically ill patient, the nurse often comes to know the patient through the family. The nurse who provides holistic care and perceives the patient and family as a unit must know something about the family and its members’ needs related to the hospitalization of the patient. The literature supports the need for the ICU nurse to engage with patients and their families to enhance knowledge of the patient and promote positive patient care outcomes.

Family members as decision-makers.

A second role assumed by patients' family members in the ICU is that of substitute decision-makers (SDMs). Families of ICU patients are often placed in the role of making decisions for their loved ones due to the compromised cognitive condition of many critical care patients. In Canada, legislation regarding surrogate decision-making for those unable to make decisions for themselves varies from province to province. The Manitoba Law Reform Commission (2004), in the report *Substitute Consent to Health Care*, identified the gap in the law in Manitoba given the "absence of statutory authorized substitute decision makers. Although health care practitioners consult with family members, this practice does not carry legal authority and therefore may result in conflict, confusion and potential liability for health care professionals" (Manitoba Law Reform Commission, 2004, p.2). The report advises Manitoba health care workers that Canadian courts do not have formal laws regarding the legal status of an in-family substituted consent for patients that are not competent. The Commission advises, however, that it is likely that family consent would meet with approval of the legal system. Therefore, it was recommended that health care professionals seek consent from family members for patients who are not competent. It was further recommended that physicians in particular ensure that SDMs are indeed "seeking to protect the patient's interest" (Manitoba Law Reform Commission, 2004, p.2).

Ontario does have specific legislation that determines what may happen when an individual is not mentally capable of making independent decisions. Ontario has published a document entitled *A Guide to the Substitute Decisions Act* (Province of Ontario, 2000), which summarizes the most significant issues of the Ontario Substitute Decisions Act (SDA). The SDA describes the process that must be followed when appointing a decision-maker for an

individual that is not mentally competent. The SDA has two sets of procedures and rules. One set applies when an individual is not capable of making his/her own decisions regarding his/her property or finances, the second set applies if the individual is incapable of managing personal matters, for example, health care or housing. According to this statute, a hierarchy of family members includes the incapable person's spouse, partner or relative, the person's attorney for personal care, or a guardian who is appointed by the court who must be 18 years old. The family will make personal care decisions on behalf of a patient who is not capable of independent decision making (Province of Ontario, 2000).

Heyland et al. (2003) provide an interesting discussion about the perspectives of patients' families in ICUs. The purpose of the study was to determine the variables that are associated with family members' satisfaction with the decision-making process in the ICU. This prospective cohort study was conducted in six Canadian hospitals that had university affiliation. A sample of 1,123 SDMs was given a self-administered questionnaire that assessed 21 aspects of communication and decision making of SDMs of ICU patients that had been mechanically ventilated for more than 48 hours (Heyland et al., 2003). The study found that families needed to share the role of decision making with the physician to feel satisfied in their role as SDM in the ICU. Families also needed good communication with their health care workers to ensure they received adequate information about patients in order to make decisions and advocate on their behalf. Family members reported increased satisfaction if they knew the patient was receiving quality care and that the patient's caregivers provided family members with support (Heyland et al., 2003). The researchers also found that although the majority of SDMs wanted to share decision-making responsibilities with the physician, a significant number preferred that physicians make decisions alone. The researchers concluded that families must be asked which

role they prefer and that health care institutions must improve quality of care related to the decision making process; this can be done by developing structures or processes to support SDMs through a challenging time (Heyland et al., 2003).

Johnson, Bautista, Hong, Weissfeld, and White (2011) provided support for the significance of understanding the perspectives of family members in the role of SDMs. They add to the argument by addressing the significance of trust between families and health care providers. This prospective cohort study of SDMs for critically ill patients was conducted in four ICUs at the University of California, San Francisco Medical Center. The sample consisted of 175 patients and 230 SDMs. Eligibility required that SDMs were making decisions for incapacitated adult patients that were mechanically ventilated and had respiratory failure. Each patient could have more than one SDM; 40 patients in this study had more than one SDM (Johnson et al., 2011).

The findings provide insight on how SDMs with low levels of trust preferred to retain the right to have the final authority in making decisions that were value laden, such as whether to continue with life support. It is argued by the researchers that it is important that health care providers establish collaborative relationships with SDMs and be mindful of the fact that a loss of trust can undermine the collaborative decision-making process (Johnson et al., 2011). The study recommends that physicians determine the level of involvement that the SDMs would prefer to have in the decision-making process and allow SDMs different levels of authority for decisions based on this preference and the clinical context (Johnson et al., 2011, p. 919).

The role of the family as decision makers in the ICU is complex. As noted above, legislation regarding substitute decision making varies from province to province. It has been advised that health care professionals include families in the decision-making process (Manitoba

Law Reform Commission, 2004). Ontario and other provinces have specific legislation regarding the appointment of SDMs (Province of Ontario, 2000). A recent case in Ontario actually takes this issue one step further by determining that physicians cannot make unilateral decisions that exclude SDMs.

Hassan Rasouli was a patient who had a substitute decision maker, Parechehr Salasel, his wife. The patient was hospitalized at the Sunnybrook Health Sciences Centre in October, 2010 after having surgery to remove a benign brain tumor. As a result of postoperative complications the patient developed bacterial meningitis; this infection left him with severe brain damage. He was placed on a mechanical ventilator and received nutrition and hydration through a tube placed in his stomach. The doctors concluded the patient would never regain consciousness and that his case was hopeless, and they wanted the patient removed from life support and administered palliative care until his death. The family, however, did not consent to the discontinuation of treatment and palliation. The family remained hopeful and did not accept that his unconsciousness was irreversible. The court ordered that the proposal to stop medical treatment be referred to the Ontario Consent and Capacity Board and further ordered that until this board had made a decision the physicians were not allowed to withdraw mechanical ventilation or transfer the patient to palliative care (*Rasouli v. Sunnybrook Health Sciences Centre*, 2011). Interestingly, the wishes of the family, as the patient's SDM, regarding end-of-life care were upheld when they differed from those of the physicians until a decision could be made by the Consent and Capacity Board. This landmark case was appealed and is currently before the Supreme Court of Canada, and provides insight into the power of SDMs to advocate and be involved in the decision-making process.

In summary, research has determined that health care professionals should determine how involved SDMs wish to be in the decision-making process and incorporate policies in health care institutions to guide staff (Heyland et al., 2003). Maintaining trust in a collaborative relationship with families is also extremely important in supporting families in the role of substitute decision makers in the ICU (Johnson et al., 2011).

Families as a support to critically ill patients.

Families have historically played an important role in the care of their critically ill family members. Critically ill patients have psychosocial needs which are often overlooked because of communication problems related to the severity of their illness. It is important that family members be allowed to participate and provide their family members with emotional support in ICU (Davidson et al., 2007).

There is considerable benefit to allowing families to visit in the ICU. Visiting the patient has been shown to decrease stress and anxiety in family members of critically ill patients (Garrouste-Orgeas et al., 2008). The presence of family members has been found to have a positive effect on critically ill patients if they are supportive, reassuring, calm, and provide comfort to the patient (Livesay, Gilliam, Mokracek, Sebastian, & Hickey, 2005). Family visits in the ICU have been found to: reduce sensory overload and sensory deprivation for critically ill patients; provide support to the patient; improve communication between the nurse and the family member; and help meet the needs of the family of the critically ill patient (Plowright, 2007; Roland, Russell, Richards, & Sullivan, 2001). Molter (1994) stated that families provide support, strength, and love to critically ill patients. Allowing family members to visit in the ICU has been found to help educate the family (Roland et al., 2001). Encouraging family visits is one

of the first steps towards decreasing psychological stress in ICU patients and their families (Vandijck et al., 2010).

A study of the experiences of patients, families and their nurses in the ICU (Cypress, 2010) supports the argument that families are supportive to critically ill patients. The study used phenomenology as a research method. The sample included five ICU nurses, five patients, and five family members. Participants were interviewed twice for one hour and the interviews were audio-taped. The findings were categorized into themes that included physical care, physiological care, psychosocial support, and transformation. The study findings support the inclusion of the family in all aspects of patient care. The researcher recommended that this inclusion be purposeful, that nurses receive education that focuses on the individual's experience with illness, and that nurses become patient centered rather than focused on disease.

Olsen, Dysvik, and Hansen (2009) investigated how critically ill patients experience the presence of their family during their critical illness. The sample consisted of 11 ICU patients in a university hospital in Norway. The qualitative method used involved interviews and then content analysis to analyze the data collected. The identified categories were: "support of the patient, stress for the patient, stress for the patient and the family and support of the family" (Olsen et al., 2009, p. 194). The researchers identified that participants found the presence of their families to be an important source of support to them during their critical illness as it helped to create a sense of being cared for and helped them feel safe, relaxed, and like they belonged. The ways the participants stated they experienced support from their family was when family provided information to help them fill in gaps in their memory and feeling the presence of their family as brightening their day (Olsen et al., 2009).

The Evolution of Practices and Policies Related to Families in Adult ICUs

As noted above, the literature provides a good overview of the roles assumed by families of patients in ICU (e.g., providers of information, substitute decision makers, providers of support to the patient). Another important area of the literature when considering nurses' attitudes towards families is the evolution of practices and policies related to families in the ICU. In this section of the chapter, literature related to the needs of family members in the ICU and visiting practices and policies are explored.

Needs of families in adult ICUs.

In the late 1970s, Molter published what has become a landmark study related to the needs of family members of critically ill patients. She believed that admission of a family member to an ICU was a crisis for that family. If this crisis was left unresolved, patient outcomes could be affected in a negative way. Molter (1979) felt that it is important to consider the patient as a member of a family unit and that patient needs must be assessed "within a framework of the concept of total patient care" (p. 332). She wrote that based on this assumption, research must be done to understand the needs of the relatives so that health care professionals are not misguided and to ensure total patient care is provided.

With this view of the patient and family as a unit, Molter conducted her study for the purpose of identifying the needs of relatives of critically ill patients to ensure that health care professionals provide holistic patient care that family members need as identified by the family and not the nurse. Molter used an exploratory, descriptive research design for her study. The sample consisted of 40 family members of critically ill patients. This small sample size is a weakness identified in the study. She found that family members of critically ill patients identified their own needs as: needing to have hope, to receive honest information, and to feel

that staff members were concerned about the patient. Family members stated that they did not expect that health care professionals would care for them, only the patient. These findings were disturbing to Molter who believed treating the patient and family as a unit results in positive patient outcomes. The most significant findings of the study were the identification of the needs of family members of critically ill patients and the statements by family members that reflect the fact the health care delivery at the time was patient focused and not family and patient focused (Molter, 1979).

Leske, working in the 1980s, built on Molter's work. Leske believed that hospital staff either did not allow families access to their critically ill family members or severely restricted their visiting time. She began researching the needs of families of critically ill patients in 1982 and found that families of critically ill patients need to discuss their feelings about their loved ones' critical illness in order to help them manage their stress. She also found that families needed time with patients and that this did not negatively impact the patient's condition. Leske understood that family members of critically ill patients experience anxiety. High anxiety levels may prevent family members from providing adequate support to critically ill patients and result in the transfer of anxiety from the family to the patient. Family anxiety may result in lost trust of the health care team, noncompliance with patient care, anger, dissatisfaction, and lawsuits. Leske's work focuses on interventions to decrease anxiety to improve outcomes for the family, patient, and healthcare team (Leske, 2002).

Leske partnered with Molter to develop the Critical Care Family Needs Inventory (CCFNI). The CCFNI is an instrument that consists of 45 needs statements that family members rate on a Likert scale (Molter, 2007, p.32). The CCFNI has been used broadly in research internationally to assess the needs of family members of critically ill patients. Verhaeghe,

Defloor, Van Zuuren, Duijnste, and Grypdonck (2005), in a review article on the needs of family members in critical care, classified these needs into four categories: cognitive needs (e.g., information and knowledge); emotional needs (e.g., hope and reassurance); social needs (e.g., proximity); and practical needs (e.g., comfort, visiting hours). Research has shown that the needs for information, hope, and reassurance are commonly ranked by family members as their greatest needs (Verhaeghe et al., 2005).

Adopting the philosophy of family-centered care in critical care requires that nurses assess the needs of family members of critically ill patients and provide the care that they require (Bailey, Sabbagh, Loiselle, Boileau, & McVey, 2010; Hinkle et al., 2009). Yet there is evidence that nurses' perceptions of the needs of families and family members' perceptions of their needs differ (Maxwell, Stuenkel, & Saylor, 2007). This mismatch of perceptions is occurring even in the presence of considerable research in this area.

A study by Maxwell et al. (2007) used a descriptive exploratory design to survey 30 critical care nurses and 20 family members. The purpose of the study was to "explore differences in the perceptions of the needs of family members of critically ill patients and nurses' perceptions and the extent to which these needs were met" (Maxwell et al., 2007, p. 370).

Nurses and family members were in agreement with only 5 out of 12 needs. These were:

- (1) to have questions answered honestly,
- (2) to be assured that the best possible care was being given to the patient,
- (3) to have explanations given in terms that are understandable,
- (4) to feel there was hope and
- (5) to talk to the doctor every day.

(Maxwell et al., 2007, p. 370)

Nurses and family were not in agreement on the needs related to knowledge of the patient's prognosis and condition, how the patient was treated and why, communicating with the nurse

each day, and information regarding daily progress or transfer plans. Family members rated these items as more important than the nurses in the study. Family members also felt their needs had been met to a greater degree than nurses had perceived family members' needs had been met.

It is important for nurses working in critical care to be aware that the needs of family members of critically ill patients and nurses' perceptions of family members' needs differ when compared. The implication for nursing is that nurses must assess the needs of families as perceived by the family members of critically ill patients in order to develop a plan of care to best meet those needs (Maxwell et al., 2007). If family members' needs are not met this may result in anxiety, decreased confidence in the health care system, and negative patient outcomes (Maxwell et al., 2007).

Hinkle and Fitzpatrick (2011) extended the research on family needs in ICU by adding physicians to their sample. The relatives, physicians, and nurses were working with the same group of critically ill patients. This approach (i.e., the addition of physicians) was recommended in the study by Maxwell et al. (2007). The sample consisted of 101 relatives of ICU patients, 28 physicians, and 109 nurses from 6 adult ICUs in a large American tertiary care medical centre (Hinkle & Fitzpatrick, 2011). The 45-item Critical Care Family Needs Inventory (CCFNI) was used to survey study participants. One goal of the study was to compare differences between family members, physicians, and nurses in perceptions of needs. Data were analyzed by calculating the five subscales for relatives, physicians, and nurses and analyzing the differences in the mean scores in three subscales. The top five needs identified by each of the subgroups differed, but three needs were ranked in the top five by family members, physicians, and nurses (Hinkle & Fitzpatrick, 2011, p. 223). The three needs were "to have questions answered

honestly, to be assured that the best care possible is being given to the patient and to feel the hospital personnel care about the patient” (Hinkle & Fitzpatrick, 2011, p.223). Key differences in responses related to the scores for information, support, and comfort needs. Family members rated the need for information higher than physicians and nurses, while physicians rated the needs for support and comfort higher than family members or nurses. The study found that families of critically ill patients would be best served by having visiting policies that were more open, suggesting that the issue of visitation in adult ICUs must be further explored (Hinkle & Fitzpatrick, 2011).

Visiting in the ICU.

Studies on family needs have found that families want to spend time with their loved ones in ICU. Historically, access to patients has been controlled through visiting policies. The restriction of visiting hours in American hospitals started in the late 1800s, for patients who did not pay for services, in an attempt to ensure that order was maintained on general wards. Before the late 1800s visiting hours were not restricted. Patients, who could pay, however, were allowed to have unrestricted visitors (Berwick & Kotagal, 2004). In the late 1960s, American hospitals began to introduce ICUs and restricted visitors for paying and non-paying patients in ICUs and the general wards in an attempt at establishing order on wards. Visitors were restricted to allow patients and their family members time to rest. Berwick and Kotagal (2004) state that most American hospitals today have liberal visiting policies in intermediate care units but strict visiting policies remain in the ICUs even though research has determined that families should be included in patient care and that patients have the right to informed decision making (Berwick & Kotagal, 2004). Nurses are the primary gatekeepers to the ICU. The ICU nurses decide who can visit the patient, how many visitors can come in at one time, and for how long these visitors can

stay, and are not often consciously aware of the power they have (Farrell, Joseph, & Schwartz-Barcott, 2005).

Historically, organizations have benefitted from restricted visitation policies rather than patients. The last 40 years have brought arguments that advocate for more liberal visitation policies, however, it has been argued that the trend seems to be returning to restricting visiting hours (Plowright, 2007). ICU nurses have been found to have negative attitudes about open visitation in the ICU and support the restriction of visiting hours. An older telephone survey of ICUs in England provides evidence of the negative attitudes nurses have had about open visiting hours in the ICU (Plowright, 1996). These negative attitudes, about, for example, open visiting hours contributing to making the ICU busy and visitors taking up a significant amount of nursing time and getting in the way, continue in the presence of an increasing awareness of how family members contribute to the patient's well-being and no evidence to support the exclusion of families from the ICU (Plowright, 2007).

Vandijck et al. (2010) examined visiting practices in ICUs in Belgium, including rules related to visiting, the way family meetings were organized, the type of information provided to families, and the availability of a website. A total of 57 (out of 76 ICUs) completed the survey. All of these ICUs had restricted visiting policies in terms of time of day, number of visitors at one time, and number of visits per day. In 11 ICUs (19.3%), visiting was restricted to "immediate relatives" (Vandijck et al., 2010, p. 138), and in 26 ICUs (45.6%) visiting was extended beyond family to include friends. Six of the ICUs had no waiting area for visitors, 31 used a notice board in the waiting room to provide family with information and an information leaflet, and 25 had a website. In 42 (73.7%) of the ICUs a family meeting was held within 24 hours of admission.

According to Berwick and Kotagal (2004), the reasons physicians and nurses support restricted visitation in the ICU are: (1) concern over “physiologic stress for the patient, (2) barriers to provision of care and (3) exhaustion of family and friends” (p. 736). If the patient and family are viewed as a unit then perhaps the question is “who is visiting who” (Berwick & Kotagal, 2004, p. 736)? Perhaps health care professionals ought to see themselves as visitors in the lives of their patients, and not the other way around (Berwick & Kotagal, 2004).

Farrell et al. (2005) have argued that “nurses are the primary gatekeepers in the ICU” (p. 19). The role of the nurse in facilitating open visitation must be clear. The nurse must be educated and aware of the “philosophy, policy and procedure at the organizational level before they can be clear at the unit level” (Livesay et al., 2005, p.188). Open visitation is interpreted differently among nurses which leads to varying practices and may result in inconsistencies and frustrated patients, visitors, and nurses. Inconsistencies may cause conflict in the nurse-visitor relationship. The role of nurses is to communicate effectively with other nurses and be knowledgeable about hospital and unit visitation policies so they can facilitate consistent implementation of these policies with visitors (Livesay et al., 2005).

Livesay et al. (2005) explored health care team members’ perceptions of open visiting hours in a 10-bed neuroscience intensive care unit. The sample consisted of 26 health care team members (22 RNs and 4 personal care assistants). The participants were asked nine questions to determine what perceptions nurses had about visiting hours (Livesay et al., 2005). The hospital did provide a clear policy regarding visiting hours and place; however, the results of the survey indicated that respondents interpreted this policy differently. All of the health care team members responded in ways that demonstrated confusion regarding the policy; open visitation was mentioned in only 7 of the 26 surveys. Some felt open meant at all times, others understood

open to mean more flexible visitation that was specific to the patient. Respondents varied in their reasons for asking family to leave the bedside; some examples of reasons included patient suctioning, codes and emergencies, neurological assessments, or if families had been at the bedside for too long. Twenty-five respondents felt family visits had both a negative and positive effect on patients. Positive effects included support, reassurance, calmness, and comfort provided to the patient by the family. Negative effects of visitation were described as a result of family members upsetting the patient and causing physiologic changes in the patient, including, for example, increases in blood pressure and heart rate. The researchers recommended that nurses in ICU need a clear policy and procedure that was specific to visiting in the unit that could be implemented by all staff. Education was also recommended to review current visitation policies and it was identified that teaching materials need to be provided by the hospital and used consistently to help nurses implement the inclusion of families in patient care (Livesay et al., 2005).

Farrell et al. (2005) explored the experience of ICU nurses who are “experts at working with visitors in a critical care unit” (p. 19) as selected by the unit manager. Eight nurses were selected. The purpose of the study was to identify and describe strategies that expert nurses used to include families into their practice. The study found that nurses did not have a plan to include visitors into their nursing care. There was an expected pattern when visitors arrived and many strategies were used to manage visitors. All nurses agreed that each family was unique and needed to be managed on an individual basis. Strategies that nurses used in relation to allowing visitors access to the critically ill patient and approaches nurses used when requesting the family leave the ICU were discussed in the study (Farrell et al., 2005). The rules for visiting required the family to call before coming in, imposed a two-visitor limit, and allowed for 5 to 10 minute

visits at a time. Only immediate family members were allowed to visit. Not all nurses agreed with this policy or enforced it (Farrell et al., 2005). Strategies nurses used to care for families of critically ill patients included greeting family members and introducing themselves, discussing patient goals and their plan of care, and answering family members' questions. Nurses included families in patient care by suggesting they hold the patient's hand and do small tasks such as mouth care. All of the nurses asked families to leave the unit during times when they needed to completely focus on patient care and could not divide their attention between the family and an unstable patient (Farrell et al., 2005).

The study provides us with a good description of the difficult task ICU nurses face when they are required to provide support and care for family while managing complicated nursing interventions and technology. The primary issue the study raises is the difficulty that nurses have providing visitors with information about and access to their family members while safely managing care for a critically ill patient. The question that must be asked is: Is it appropriate to expect that ICU nurses be able to simultaneously provide care for medically complicated critically ill patients while supporting the needs of an emotional and anxious family? The study suggests that perhaps a new role is required in the ICU. The study does not recommend a specific health care professional or educational preparation for this new role, but the researchers do recommend that the role of the family caregiver be filled by one who is knowledgeable about the needs of the family to allow the nurse to focus on providing patient care (Farrell et al., 2005).

Garrouste-Orgeas et al. (2008) examined the perceptions of nurses, physicians, and family members of a 24-hour visiting policy in the ICU over a period of 1 year. Patients were examined over a period of 5 days. To be included in the study patients had to have been in the unit for at least three days. The setting for the study was a 460 bed tertiary care hospital in Paris,

France. The ICU had 10 private rooms with a private waiting room for families. The policy on visitation was that the ICU physician held an organized meeting with the family upon or soon after admission to assess the distress of the family, provide information about the patient, and identify a strategy to support the family. The family was to receive a leaflet that explained general information about the ICU. Family members, which included relatives and friends of the patient, could visit the patient any time of the day or night and stay as long as they wished (Garrouste-Orgeas et al., 2008).

The sample included 209 patients, 30 nurses, 13 physicians and 149 families. Data were collected over the first five days after admission. The ICU nurses escorted family members into the patient's room and recorded the time they came and left and the number of visitors present in the room (Garrouste-Orgeas et al., 2008). The research found that of 209 patients on days one to five, the following had at least 1 visitor: on day one, 112 patients; on day two, 150 patients; on day three, 141 patients; and on day 5, 98 patients. Most visits occurred between 2 p.m. and 8 p.m. Family members seldom visited at night. Only two family members slept in their loved one's room. Four patients had a cardiac arrest while family members were present and three of the four family members decided to remain during the resuscitation (Garrouste-Orgeas et al., 2008).

The 30 ICU nurses who participated in the study returned 155 of the 209 surveys. The 13 physicians who participated in the study completed 136 of the 209 surveys. "Item scores assigned by nurses and physicians were similar for the following: 'never' for unease and delay when examining the patient; 'occasionally' for family stress and family integration and 'often' for family trust" (Garrouste-Orgeas et al., 2008, p. 33). Physicians reported they never changed

their behavior in front of a family member. Nurses reported that they did alter their behavior in front of family members (Garrouste-Orgeas et al., 2008).

The 149 family members surveyed perceived that unregulated visitation allowed them time to get to know the healthcare team better, provided them with enough time to engage with nurses and physicians, and decreased their anxiety. Families did not have to wait to see the patient. The most significant findings were that unrestricted visitation policies in the ICU resulted in families being present in the unit only 1-2 hours per day, and not large numbers of family members, and increased family satisfaction. In addition, there was moderate evidence of family members experiencing anxiety and depression. Most family members (75.5%) believed that the open visitation policy decreased their anxiety. The study does not comment on the effect that open visitation policies have on depression in family members of critically ill patients. Open visitation was not found to interfere with the provision of care (Garrouste-Orgeas et al., 2008).

Nurses have many reasons to be reluctant about open visitation in the ICU. Lee et al. (2007) studied the reasons nurses want restrictions on family visitation and provided strategies for nurses to include families in patient care in an ICU with open visitation. The researchers began with a survey and found that only 62 of the 171 ICUs that participated had open visiting hours. Most ICUs had an age restriction of 12 years and allowed only 2 visitors at a time. Three initial focus groups, identified as session one, were held to discover nurses' perspectives on visiting hour policies in the ICU. The focus groups were held within a single center that had experience with open and unrestricted visitation policies. The goal was to identify positive and negative effects of open visitation in the ICU. The goal of the second three focus groups, identified as session two, was to determine solutions to the barriers found in the focus group from the first session.

The study was conducted in a 719 bed tertiary care centre with 92 ICU beds. The medical ICU had 18 beds and was a closed administrative model for nurses and physicians. In 1998, the medical ICU changed their visitation policy from restricted hours to an open visitation policy and allowed families' access to the ICU that was unrestricted 24 hours a day. Two family members were allowed to visit at one time. The sample consisted of 16 nurses in session one and 22 nurses in session two. Nurses from one day shift, one evening shift, and one weekend night shift were included in both sessions to identify the different barriers that may be present during different shifts. The findings in session two revealed that the barriers to open visitation in ICUs were:

space which included concerns about lack of privacy, compromising confidentiality, visitors creating a physical barrier to patients; communication and conflict which included concerns about visiting disrupting nursing care, risk of physical and emotional assaults from difficult visitors, recognizing patients' need for recovery, inconsistency among nurses in setting limits with visitors, variable communication skill among nurses; and burden which included concerns about difficulty managing emotional needs of patients and visitors, pressure for visitors to be at bedside given lack of set visitation time and attending the physical needs of both the family and the patient (Lee et al., 2007, p. 499).

This study adds to the literature on promoting visitation by offering strategies to help nurses practice in an ICU that has an open visitation policy, including recommendations related to enhanced security (e.g., monitored entrances); communication and conflict (e.g., education for staff, brochures for families, liaison workers); and self-care for families (Lee et al., 2007).

As explored in the Lee et al. (2007) study, family-centered care and patient-centered care begin with an awareness of the significant role families may play in caring for a critically ill patient and progresses to inclusion of the family on the health care team. Open visitation policies are grounded on believing that such policies will facilitate communication and increase patient and family satisfaction. It is evident that the concerns of nursing may alter the adoption of open visitation policies in ICUs.

Nurses' Attitudes About Families

Increasingly, the literature points to the importance of establishing collaborative relationships with families. This is important for the reasons discussed already: families are often knowledgeable about their ill family members and can provide information to the health care team about their loved ones (Astedt-Kurki et al., 2001a; Astedt-Kurki et al., 2001b); and family members act as surrogate decision-makers as appropriate. It is also the case that maintaining the family unit through collaboration can provide family members with the strength to endure the emotional suffering that results from experiencing a critical illness (Eggenberger & Nelms, 2007). It has been argued that their inclusion into the development of the plan of care improves the quality of care the health care team can deliver and has the potential to improve the well-being of the entire family (Astedt-Kurki et al., 2001b).

So what is known about nurses' attitudes regarding family in the ICU? Researchers have examined nurses' attitudes about family generally and then more specifically related to family presence during resuscitation and invasive procedures. In this section of the chapter, literature will be examined related to nurses' attitudes about the importance of family in nursing care and then more particularly related to critical care nurses' attitudes and perspectives about family in

the ICU. Literature that examines the importance of education on the attitudes of critical care towards families will also be reviewed.

Nurses' attitudes about the importance of families in nursing care.

Benzein, Johansson, Arestedt, and Saveman (2008) surveyed Swedish nurses to understand nurses' attitudes about the importance of families in nursing care. The Families Importance in Nursing Care – Nurses' Attitudes (FINC-NA) instrument (Benzein, Johansson, Arestedt, Berg, & Saveman, 2008) was used to measure attitudes (Benzein, Johansson, Arestedt, & Saveman, 2008). The study sample consisted of 634 RNs, out of a possible total of 1000 randomly selected registered nurses (RNs) from the register of the Swedish Association of Health Professional Nurses, and all were employed as nurses in patient care (i.e., 66% in hospital care, 18% in primary health care, 13% in community care, and 3% in other settings). The results of the study demonstrated that nurses had “a supportive attitude about the importance of families in nursing care” (Benzein, Johansson, Arestedt, & Saveman, 2008, p. 169). Interestingly, RNs working in hospitals and those with no general approach to family care in their workplaces had lower scores (i.e., were less supportive) on the subscale related to family as a resource in nursing care; male RNs, new graduates, and those with no general approach to family care had lower scores on the family as conversational partner subscale; and new graduates and those with no general approach to family care in their workplaces had lower scores on the family as burden subscale.

Benzein and colleagues suggested that a supportive attitude is required for nurses to invite and engage with families in nursing care. The researchers indicated that if nurses have a supportive attitude they will be more likely to collaborate with families to provide nursing care. Collaboration of families and nurses results in improved satisfaction and patient care outcomes.

The researchers also acknowledged that a supportive model of supervision that reflects on the provision of family-focused care may challenge new RN graduates. They argue that nursing education must include a family-focused perspective to guide clinical practice of new graduate RNs. A general approach to families at the workplace must be provided as this has been found to increase supportive attitudes toward families. A shift is needed to focus on the formation of collaborative relationships with families who must be perceived as experts of the illness of the family member (Benzein, Johannson, Arestedt, & Saveman, 2008, p. 177).

Oliveira et al. (2011) adapted and validated the FINC-NA instrument for use in Portugal. A sample of 136 nurses working in primary health care from two centers in Portugal took part in the study. The researchers found that most nurses had supportive attitudes towards families. The results showed high values, which indicate positive attitudes, in the subscales family as a conversation partner and family as a resource in nursing care. Concern was expressed over the small number of items in the burden scale which was also discussed in the Swedish study, however, internal consistency was considered reasonable in the burden subscale in both the Portuguese and the Swedish study. The researchers recommended that strategies to encourage supportive attitudes in nursing care be developed in order to improve collaboration and family health (Oliveira et al., 2011).

Sveinbjarnardottir, Svavarsdottir, and Saveman (2011) used the FINC-NA to evaluate the attitudes of nurses about the importance of family in psychiatric care at a university hospital in Iceland before and after they had participated in an education and training program (ETI-Program) on family systems nursing. A quasi-experimental study design was used. The ETI-Program was implemented by nurses and consisted of a one-day seminar. The supervision component of the ETI-Program consisted of three to five supervised sessions within a four month

period that occurred once the nurses started applying family nursing in their clinical practice. The sample consisted of 81 nurses who responded to the FINC-NA before and after they had participated in the ETI-Program. The researchers found: females had more supportive attitudes than males in the subscale family as own resource in nursing care; more experienced nurses had higher scores (more positive attitudes) than less experienced nurses in the family total score and family as burden sub-scale (inverted scores); and nurses who had the experience of a serious illness in their family had higher inverted scores on the family as burden sub-scale than nurses who had not had this experience. Nurses' attitudes improved in all of the subscales in the survey after participating in the ETI-Program. The inverted mean value of the subscale family as a burden increased significantly indicating that nurses felt families were less of a burden after they had participated in the education program. These results indicate that education is a strategy that may improve nurses' attitudes about the importance of family in nursing care.

Other researchers have identified that education is important in making changes to nurses' attitudes about care of the family. Steginga et al. (2005) used a quasi-experimental, longitudinal, pretest/post-test design with a six week follow up to examine nurses' (N = 53) attitudes toward and skills related to the psychosocial care of patients with cancer and their families before and after an education course. The findings of the study reinforce the importance of education for nurses on making positive changes in the attitudes of nurses. The studies examined in this section suggest that education for nurses may be a strategy that contributes to nurses developing more supportive attitudes towards families.

Critical Care Nurses' Perspectives about Family in the ICU

A study by Engstrom and Soderberg (2007) explores the perspectives of critical care nurses about close relatives in ICU. The purpose of the study was to describe the experiences

that critical care nurses (CCNs) have with close relatives in ICUs. The study design was qualitative and the researchers used thematic content analysis to help describe the CCNs' experiences with close relatives in ICUs. Focus groups were held to collect data and encourage group interaction among participants. The sample of 24 CCNs, who were all female with specialist training in ICUs, had worked in an ICU for at least two years. The focus groups consisted of five to seven CCNs (Engstrom & Soderberg, 2007).

The researchers found that the CCNs felt that relatives were important both for the patient and the staff; however, they felt that relatives were taken for granted. The CCNs stated that they asked relatives to leave the room and did not allow their involvement in situations that compromised the integrity of the patients' care, for example during bathing. During emergency situations, CCNs felt they had to concentrate on the patient, however, did not object to having relatives present during resuscitations. They did feel that they would like a staff member to support the family during these crisis situations (Engstrom & Soderberg, 2007). This study provides insight into the perspectives that CCNs have about close relatives in the ICU. The study indicated that nurses understand that good relationships with relatives are important. Results determined that nurses believe that establishing relationships with relatives contributes to information gathering and good nursing care and helps meet the needs of patients. However, nurses have difficulty providing care for both patient and family. Interestingly, the study does not provide a discussion of how nurses ought to involve and include relatives in nursing care in ICUs (Engstrom & Soderberg, 2007).

Garrouste-Orgeas et al. (2010) assessed the "opinions of caregivers, families and patients about involvement of families in the care of intensive care unit (ICU) patients" (p. 634). This study was done in a 10-bed medical-surgical ICU in a tertiary care centre in France. Families

were allowed to visit 24 hours a day with no restrictions and could stay as long as they liked. The ICU offered many FCC interventions including a waiting room, information for family members who came to the ICU, including printed information, and via phone for family who could not visit in person, and a family meeting with the physician upon admission to the ICU. The printed information stated that families could participate in care if this was their wish. The activities that family members were allowed to participate in were carefully chosen by ICU staff members with the goal of not being too technical, respecting patient privacy, and not causing adverse events (Garrouste-Orgeas et al., 2010).

A total of 101 patient-relative pairs were enrolled in the study; 21 nurses, 7 nursing assistants, and 17 physicians returned questionnaires related to these 101 patient-relative pairs. The results show that the greatest support from ICU staff members for family participation in care was for wiping the patient's eyes, moistening the oral cavity, hydrating the patient's lips, and preventing pressure sores by massages (Garrouste-Orgeas et al, 2010, p. 637). "Physicians and nursing assistants were more favourable than nurses to family participation in care" (p. 639). Nurses (10%) who were "unfavorable to care" (p. 639) identified concerns related to interacting with families while providing care and possible adverse events (Garrouste-Orgeas et al., 2010, p. 639). The findings suggest that these concerns may be related to these nurses' limited experience in the ICU (Garrouste et al., 2010, p. 639). The study found that ICU staff members were favourable to the participation in care and this may be the result of 10 years of experience with a 24-hour open-visitation policy. The findings also suggest that ICU staff may have limited family participation in care related to time constraints and concerns regarding being perceived as disorganized by family members (Garrouste-Orgeas et al., 2010).

Engstrom, Uusitalo, and Engstrom (2010) used a qualitative descriptive approach to explore critical care nurses' experiences with the involvement of relatives in nursing care. The findings were presented in two main categories: those that acknowledged the significance of relatives' involvement and those that demonstrated obstacles to relatives' involvement (Engstrom et al., 2010). CCNs believed that relatives were important in nursing care of the ICU patient. Nurses believed that relatives were knowledgeable about the patient and were important in the ICU patients' lives. CCNs stated that relatives provided information that helped the nurse have a picture of the ICU patient that was important in order for the nurse to provide quality patient care. Relatives helped the nurses establish improved relationships with the ICU patient (Engstrom et al., 2010). The CCNs also believed it was important that relatives be allowed to be close to patients and encouraged them to be involved in their nursing care, while they were aware that relatives' ability to participate in patient care varied and it was important to respect relatives who did not feel comfortable participating in patient care (Engstrom et al., 2010).

Nurses found that relatives' involvement in the nursing care of patients in ICU was important to CCNs and that relatives were viewed as important resources, however, there were obstacles. Obstacles the CCNs described included relatives interfering with patient privacy during nursing care in regards to patients being exposed during nursing care. CCNs were concerned about relatives' presence interfering with patients' rest and staff communication with other staff members (without the presence and potential interruption of relatives). CCNs had concerns about conflict arising with relatives, the fast pace required in ICU causing relatives to have trouble participating in nursing care, and about relatives being overwhelmed by technology (Engstrom et al., 2010). Overall, relatives' involvement in nursing care of ICU patients was found to positively contribute to improving relationships between nurses and patients and helped

CCNs perceive patients as holistic persons rather than just patients. This study concludes with the recommendation that further research be done to explore nurses' opinions about relatives' involvement in the nursing care of ICU patients (Engstrom et al., 2010).

Agard and Maindal (2009) examined ICU nurses' perspective of their interactions with relatives in ICU. Of particular interest was the study's examination of nurses' attitudes "towards involving relatives in care-related tasks and allowing relatives to be with the patient during critical situations" (Agard & Maindal, 2009, p. 264). The purpose of the study was to provide a description of nurses' perception of self-efficacy; the second aim of the study and the focus of this review was to "explore the relationship between self-efficacy and outcome expectations and the nurses' attitude towards involving relatives in care-related tasks and allowing relatives to be with the patient during critical situations" (Agard & Maindal, 2009, p. 264). The study was cross-sectional and explorative and used data from a questionnaire that was self-administered. The study was conducted in a 13-bed medical/surgical adult ICU at a university hospital in Denmark. The sample size was 110 ICU nurses who provided direct patient care. Nurses were asked "about their attitude towards actively involving relatives in a number of everyday nursing tasks and towards allowing relatives to witness treatment and care in critical situations" (Agard & Maindal, 2009, p. 265).

The results indicated that nurses do feel they are required to care for the patient and their families. A total of 108 of the 110 nurses surveyed strongly believed it is important to become involved in the psychosocial problems of relatives even though it was emotionally demanding. Interestingly, the results determined that nurses would involve relatives in patient care that was related to the psychological well-being of the patient, for example, sitting at the patient's bedside. However, there were significant differences among nurses' attitude towards relatives'

presence at critical events such as cardiac arrest or acute intubation. The study results showed that nurses were not in agreement regarding which activities relatives could be involved in. The researchers believed that these differences were reflections of the “complex nature of nurses’ decision-making concerning the presence of relatives and their participation in caring activities” (Agard & Maindal, 2009, p. 268).

Nurses’ Attitudes About Family Presence During Resuscitation in ICU

Recent studies have explored nurses’ attitudes and beliefs about family presence during resuscitation and invasive procedures. Duran and colleagues used a descriptive survey design with open-ended qualitative comments to explore this topic. Emergency departments, neonatal intensive care units, medical, surgical, neurosurgical and burn/trauma intensive care units (adult ICUs) at the University of Colorado Hospital participated in data collection (Duran, Oman, Abel, Koziel, & Szymanski, 2007). The sample consisted of 202 health care providers (i.e., 98 physicians, 98 nurses, 6 respiratory therapists), 72 patient’s family members, and 62 patients. The study found that 54% and 69% of health care workers supported family presence during resuscitation and invasive procedures respectively, with nurses having more positive attitudes toward the practice than physicians. Nurses supported the development of policies to support family presence more than physicians. All healthcare providers believed that a policy on the presence of family was required. Family members felt they had the right to attend resuscitations and invasive procedures and wanted the option of being present, feeling it would help them understand the patient’s condition. Patients also felt the presence of family members during resuscitations and invasive procedures would be comforting. Potential barriers identified by health care providers included patient and family safety, concern for the emotional health of family members, and performance anxiety of healthcare providers. This study makes a

significant contribution to the literature by reinforcing the need for hospital policies to reinforce the option of allowing families to be present in the care of their loved ones (Duran et al., 2007).

Olsen et al. (2009) contribute to the literature on family presence in ICUs by exploring the meaning of family members' presence during the ICU stay using a descriptive qualitative study design. The study was carried out in a 12-bed ICU at a university hospital in Norway. The sample consisted of 11 patients. Qualitative content analysis was used to analyze the data. Although attitudes are not the focus of this study, participants did "express ambivalent attitudes to visits. On one hand, the presence of their loved one meant a lot to them, but on the other hand they described stressful episodes from the ICU stay" (Olsen et al., 2009, p. 193). An understanding of the attitudes that patients have about the presence of their family during the critical illness is important. The implications this has for nursing practice is that the ICU nurse must be aware that although families have been found to be a support for ICU patients, patients do not always find the support helpful. It is important the nurses determine the attitude the individual patient has towards the presence of their family in ICU (Olsen et al., 2009).

Howlett, Alexander, and Tsuchiya (2010) add to the literature about health care provider attitudes regarding family presence (FP) during resuscitation by providing a review of the literature in this area. The literature review consisted of 13 articles that met the inclusion criteria of research studies that addressed the attitudes of health care providers toward the presence of family during adult resuscitation. These authors determined that: health care providers have been found to be supportive towards FP; nurses have been found to have a more positive attitude towards FP than physicians; and nurses working in areas such as emergency departments have more experience with FP during nursing care, which may result in them having more positive attitudes than other nurses (Howlett et al., 2010). Differences within the discipline of nursing

were found regarding attitudes towards FP. More favourable attitudes were associated with higher education, professional certification, belonging to a professional organization, and working in emergency departments (Howlett et al., 2010). The perceived burden placed on staff regarding FP was related to their concerns over “stress, environmental issues, litigation and family interference” (Howlett et al., 2010, p.167). Health care providers stated concerns about not having a staff person assigned to provide support for families during crisis situations such as resuscitations.

A descriptive study Hayajneh (2013) surveyed 200 Jordanian nurses’ to determine their attitudes about family presence during CPR of adult patients. The results showed that Jordanian nurses had negative attitudes about the presence of family members during resuscitation of adult patients. The study recommends that the attitudes and experiences of patients and relatives regarding family presence during resuscitation should be determined before hospital policies about family presence during resuscitation are implemented. These findings are different from previous studies which found that nurses had positive attitudes or a combination of positive and negative attitudes about family members present during adult resuscitation.

Conclusion

It has been argued that the patient and family ought to be perceived as a unit in regard to nursing care (Molter, 1994). The concept of the family and the patient as a unit in critical care is significant as it is the family who must act as decision-makers for patients who are unable to make their own decisions for themselves and as a support to critically ill patients. It is also the family that guides the nurse to know the patient (Radwin, 1996). Benner et al. (1996) add that engaging with family members of critically ill patients can increase ICU nurses’ knowledge about their patients which may improve clinical judgment. Evidence exists to illustrate that

families indeed are a support to critically ill patients and researchers have suggested that nurses must take the time to assess the needs of critically ill patient's family members (Verhaeghe et al., 2005). Understanding the needs of family members is essential when adopting a family-centered care philosophy in critical care (Bailey et al., 2010; Hinkle et al., 2009).

Understanding nurses' attitudes about families is important. The literature includes discussions about critical care nurses' experiences with family in ICU and nurses' attitudes about family presence during resuscitation and invasive procedures in ICU, however, knowledge of nurses' attitudes about the importance of family in nursing care in critical care settings is a gap that must be addressed. Benzein, Johansson, Arestedt, and Savemen (2008) have carried out research related to nurses' attitudes about the importance of families in nursing care; however, their study does not include countries other than Sweden, Portugal, and most recently Iceland, or the clinical area of ICU. This study investigated Canadian critical care nurses' attitudes about the importance of family in Canadian adult critical care units. Benzein, Johansson, Arestedt, and Saveman (2008) supported and encouraged this research when they expressed uncertainty about whether or not the results of their study "can be generalized to RNs in other countries" (p. 177).

Chapter Three: Methods

In this chapter the design of the study will be described. In addition, the methods used to recruit the sample and collect and analyze the data will be outlined. The chapter will end with a discussion of the ethical considerations for the study.

Design

A survey design was used in this study. This approach allows researchers to “obtain information about the prevalence, distribution and interrelations of variables within a population” (Polit & Beck, 2008, p. 322). Survey design was chosen as it provided a means by which to ask a large number of critical care nurses questions that they could answer briefly in order to gain information about individuals’ attitudes (Polit & Beck, 2008). In particular, an on-line survey was used. This type of survey is effective when surveying specific populations, such as members of professional associations who have high rates of internet access and skill levels (Dillman, Smyth, & Christian, 2009). The survey was administered using FluidSurveys, a Canadian company.

Optimizing Web-Based Survey Response Rates

As internet access becomes more widely available web-based surveys are a promising method of data collection (Chizawsky, Estabrooks, & Sales, 2009). Much has been written about optimizing web-based surveys. Dillman et al. (2009) have discussed the importance of asking good questions to motivate respondents to answer accurately. Choosing open-ended questions is also a way in which to optimize responses to a web-based survey because it allows the responder to “freely answer the question as they want without limiting their response” (Dillman et al., 2009, p.72).

The visual design of a web-based survey is an important consideration to optimize response rates. Guidelines to pay attention to when choosing words and forming questions for web-based surveys include: ensuring the questions are relevant to the respondent; asking only one question at a time; using reasonably simple and concrete words; using sentences with simple structure; ensuring you are clear about yes and no questions; and ensuring your questions are specific to the response you are requesting (Dillman et al., 2009, p.72). Ekman, Klint, Dickman, Adami, and Litton (2006) suggested that “the degree of difficulty of questions in a web-questionnaire and the order in which they are presented does affect drop out” (p. 295). By gradually increasing the difficulty with the easiest questions at the beginning of the survey and the most difficult questions at the end of the survey their response rate increased by 6% (Ekman et al., 2006, p. 295).

The literature provides many ways to optimize the response rates of web-based surveys to ensure an adequate sample size and reliable results. The following strategies were implemented in this study to optimize participation. This study used the FINC-NA instrument which is an instrument that has been developed, tested, and retested by skilled a skilled team of researchers, all experts in the field of family nursing (Benzein et al., 2008). This study used a sample from a professional association of critical care nurses and offered nurses two opportunities to provide written comments in addition to the FINC-NA survey questions. As well, easy demographic questions were placed at the beginning of the survey, followed by more challenging questions, and attention was paid to the design of the survey in FluidSurveys.

Procedures

The population of interest for this study was critical care nurses working in ICUs in Canada. In statistics for the year 2009 released by the Canadian Nurses Association (2011),

there were 19,096 nurses working in critical care in Canada, representing approximately 7% of all Canadian registered nurses (with a total of 266,341). In order to obtain a readily available sample of critical care nurses from across the country, permission was sought from the Canadian Association of Critical Care Nurses (CACCN) to gain access to their membership. The CACCN is a national organization that was formed in 1981. Membership criteria for the CACCN are that the member is a registered nurse who is employed or has a background in critical care nursing. At the time the study was carried out, the organization had 11 chapters across Canada in British Columbia, southern Alberta, Edmonton, London, Manitoba, Montreal, New Brunswick, Nova Scotia, Ottawa region, Saskatchewan, and Toronto (CACCN, 2011).

The research protocol was submitted to the Education and Nursing Research Ethics Board at the University of Manitoba for ethical approval. After obtaining research ethics board approval (Appendix A), a letter was sent to the Board of Directors of CACCN requesting permission to send out an e-mail message to all registered nurses who are members of CACCN and this permission was granted (Appendix B). A representative of CACCN sent out the link to the survey via email to members of the organization who had provided CACCN with a contact e-mail address. The e-mail message included the following information: an introduction to the investigator, the name of the thesis project, the purpose of the study, and a statement informing the participants that the study had been approved by the Education and Nursing Research Ethics Board at the University of Manitoba (Appendix C). Participants were also provided with the link to FluidSurveys.

An initial email message and three reminder email messages were sent out by CACCN at one-week intervals to encourage additional responses (Appendixes D to G). The reminder e-mail messages to CACCN members contained similar information to the invitation message and were

informed that recruitment had not closed and they still had time to participate in the study. The last e-mail message included the date the survey would close.

The Instruments

The survey was divided into four parts: demographic questions (Appendix H); questions regarding visiting policies and FCC (Vandijck et al., 2010) (Appendix I); the Families' Importance in Nursing Care-Nurses' Attitudes (FINC-NA) instrument (Benzein, Johansson, Arestedt, Berg, & Saveman, 2008; Saveman, Benzein, Engstrom, & Arestedt, 2011) (Appendix J); and an open-ended question regarding FCC (Appendix K). The demographic section of the survey (Appendix H) included questions to determine: participant's age, sex, years spent working as a nurse; the type of hospital the participant worked in, for example, tertiary or community; what type of ICU the participant worked in and the size of the ICU; the presence of a general approach to the care of families in the participant's workplace; and if the participant had a family member who had experienced a serious illness.

The FINC-NA instrument (Appendix J) was used in this study. It was developed by Benzein, Johansson, Arestedt, Berg, and Saveman (2008) and modified by Saveman et al. (2011). Benzein and colleagues argued that historically the patient has been the unit of care for nurses, but families are increasingly present in nurses' practice settings. The question they posed was: "Is the nurse able to recognize families not only as care providers to their ill family member but as important to include as the unit of care" (Benzein, Johansson, Arestedt, Berg, & Saveman, 2008, p. 98)? The FINC-NA was developed to explore nurses' attitudes about providing care to families.

Benzein and her colleagues reviewed the literature related to nurses' attitudes about the importance of families in nursing care and found "no adequate existing instrument" (Benzein,

Johansson, Arestedt, Berg, & Saveman, 2008, p. 98) to explore these attitudes. Based on their review of the literature, 117 items were constructed and a group of eight researchers with expertise in this area were asked to discuss and critique the items, resulting in an 82-item tool. A second group of nine researchers with both content and tool development expertise critiqued the instrument. These nine researchers, all of whom had a background in family nursing and experience with developing instruments, determined that the items of the instrument examined nurses' attitudes about caring for family members. Their critique of the items resulted in an instrument that has 78 items. The instrument was further examined for content validity by 19 practicing nurses who had post-graduate education. This group excluded 19 items that required too many alternatives in responses making choices difficult to differentiate. This resulted in 59 items remaining that had Yes or No response alternatives. The instrument was completed by 21 nursing faculty members, all of whom were provided with the same information about the instrument.

The FINC-NA instrument was psychometrically tested using a random sample of 979 registered nurses from Sweden. The RNs' participation was voluntary and anonymous; questionnaires were sent in the mail, completed, and returned. The demographic characteristics of the participants were analyzed using descriptive statistics. Nonparametric statistics were used by researchers to analyze participant responses to the instruments. Psychometric properties were analyzed using item analysis and analysis of the principal component. This led to development of a scale that was internally consistent. In the first survey the item total correlations were greater than 0.4 except for item 2 ("The presence of family members holds me back in my work") and item 23 ("The presence of family members makes me feel that they are checking up on me"). Both of these items belong to the family as burden subscale. Benzein et al. (2008)

found that no improvement in internal consistency was detected if these two items were removed from the subscale (Benzein et al. 2008, p. 317). With the exception of these two items, the range in item-total correlations varied from 0.44 to 0.68.

The final version of the FINC-NA was validated with the goal of analyzing the scales dimensionality as a means of testing for construct validity. To decide how many factors to remove, a scree plot was used to analyze and determine how items and factors could be simplified. The sample was divided into two equal samples to cross-validate the factor structure. Items were analyzed on the final instruments by performing item-total correlations for the entire scale and the subscales. The responses were analyzed by calculating the share of those who had weakest and strongest possible scores on each item. Correlation analyses were performed between the FINC-NA scales to evaluate validity. Cronbach's alpha reliability coefficient was used to provide an estimate of internal consistency of the FINC-NA (Benzein, Johansson, Arestedt, Berg, & Saveman, 2008).

Saveman et al. (2011) modified the instrument by replacing the original four-point scale for items with a five-point Likert scale in order to increase the variability in the response to items on the FINC-NA. The goals for refinement and reevaluation of the FINC-NA included: "(a) score distribution, (b) homogeneity, (c) dimensionality, (d) stability, and (e) internal consistency" (p. 314). Psychometric testing included several statistical tests. Evaluation of floor and ceiling effects was done by calculating the highest and lowest scores that were possible for the items. Item analysis was performed to evaluate homogeneity and discrimination ability of the items in the FINC-NA. Exploratory factor analysis was used to test if the refined version of FINC-NA could reproduce "factor structure of the original version of FINC-NA" (Saveman et al., 2011, pp. 315-316). Ordinal regression modeling was performed to evaluate the differences

between items and between the subgroups. Cronbach's alpha was used to estimate the internal consistency and reliability of the FINC-NA. The authors concluded that: "the variability of the scores and the homogeneity [were] improved" and "all FINC-NA scales showed good reliability" (Saveman et al., 2011, p. 313). Permission was granted by Dr. E. Benzein to use the instrument in this study.

The third part of the survey (Appendix I) was composed of questions related to visiting policies in the ICU, as developed by Vandijck et al. (2010) after an extensive review of the literature, and used in a study of Belgian ICUs. Content validity of Vandijck et al.'s (2010) questions was assessed by eight Belgian ICU nurses (e.g., head nurses, nurses with post-graduate degrees) and face validity was assessed by seven other Belgian ICU nurses. In this part of the survey, questions were asked to determine ICU nurses' knowledge about visiting policies, restriction of visits, adaptation of visiting policies to individual cases, waiting rooms, family meetings, information provided to visitors and the inclusion of families in discharge planning. Permission was granted by Dr. Dominique Vandijck to use the questions which were developed for her research in FCC in Belgian ICUs. Some additional questions were added to this section based on a review of the literature and the recommendations of my thesis committee members.

The fourth part of the survey was an open-ended question (Appendix K) related to perceptions of FCC in adult critical care. Perceptions are involved in one's view of the world; these are unique to an individual as one can only draw on or describe what is known by one's self (McDonald, 2011). In a concept analysis of perception, McDonald (2011) identified that a defining attribute of perception is "sensory awareness or cognition of the experience" (p. 5). As revealed in the literature review, FCC is an emerging concept in adult critical care (Government of Saskatchewan, 2010; Mount Sinai Hospital, 2011; St. Michael's Hospital Trauma Services,

2007; St. Paul's Hospital, 2010), and this question offered survey respondents the opportunity to provide comments about their perspectives on this approach to care.

Data Analysis Procedures

Once a respondent completed the survey, data were initially stored on the FluidSurveys site and then moved to a file on a private computer. Data were analyzed using Statistical Package for the Social Sciences (SPSS) Version 20. A statistician was consulted during the development of the proposal and identification of possible statistical tests for data analysis and then as data were analyzed the statistician was consulted to run a regression analysis in SAS software (statistical analysis software).

Appropriate descriptive statistics were used to describe the sample. In particular, means, medians, standard deviations, and ranges were calculated for data from the demographic section of the survey (e.g., age, gender, years working as a RN and in ICU). To determine Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs, the critical care nurses' responses to the FINC-NA items were analyzed using methods similar to those described by Benzein, Johansson, Arestedt, and Saveman (2008). Before the data analysis was carried out, the scores on the burden scale were inverted. The items on the burden scale are negative statements about the family; therefore they have been labelled family as a burden (Benzein, Johansson, Arestedt, Berg, & Saveman, 2008, p.106). The scores for the other scales of the FINC-NA demonstrated that "the higher the score, the more supportive is the nurse's attitude towards families" (Benzein, Johansson, Arestedt, & Saveman, 2008, p. 167). Inverting the burden scale ensured that scoring of the instrument was uniform throughout all the subscales.

The scores from the FINC-NA total scale and the subscales were treated as ordinal data. Pearson's r test was used to determine correlations between the subscales of the FINC-NA and

the demographic variables of age, years of nursing experience, and years of experience in ICU. The t-test for independent samples was used to examine differences between comparable groups (Polit & Beck, 2008). T-tests were carried out on total scores and subscale scores of the FINC-NA using the variables of gender, age of 50 years or less compared to age greater than 50 years (as used by Benzein, Johansson, Arestedt, and Saveman, 2008), 5 years or less of experience in ICU compared to greater than 5 years of ICU experience, presence or absence of a general approach to the care of families in the workplace, and whether or not the RNs had a member of their family as a patient in an ICU. Multiple regression analysis was used to examine the effect of several independent variables on nurses' attitudes among the subgroups and items on the FINC-NA. The following independent variables were placed in the regression model: years worked as a registered nurse, gender, current role, type of hospital worked in, and whether or not a family member had been seriously ill. In order to determine what policies and practices were in place in the nurses' units to promote FCC or involvement of the family in the care of patients, data were analyzed using descriptive statistics (e.g., frequency). In addition, t-tests were used to compare attitudes of nurses working in units with less than four FCC policies and practices in place and with four or greater FCC policies and practices in place.

Cronbach's alpha was the method used to evaluate the internal consistency of the items and scales of the FINC-NA to determine the extent to which different subparts of an instrument are reliably measuring the critical attribute, which is nurses' attitudes. Internal consistency reliability is the best way of assessing whether or not all the items of the FINC-NA measure the same trait (Polit & Beck, 2008).

Content analysis is a research method that allows a systematic approach to organizing data obtained through open-ended questions by condensing the data under study using categories

(Elo & Kyngäs, 2008). Responses to two open-ended questions were analyzed using content analysis. The first question was a request for comments that appeared at the end of the FINC-NA instrument. The word “Comment” was written and several lines were provided to encourage participants to write their comments. The second question read: “What are your perceptions of family-centered care (FCC) in adult ICUs?” Each of the comments was read carefully by both me and my supervisor and categories were identified to organize the data. To ensure rigor, the content analysis process described by Elo and Kyngäs, (2008) was followed. The process of analysis was divided into three phases: preparation, organizing, and reporting (Elo & Kyngäs, 2008, p. 109). The preparation phase began with my advisor and me both agreeing on an initial strategy for organizing the data. The purpose of this phase was to immerse ourselves in the data. For example, the comments for the perceptions of FCC were first divided into those that supported and agreed with FCC or those that represented challenges of FCC. The material was read again by both my advisor and me and we wrote down potential coding categories from the comments (Elo & Kyngäs, 2008, p. 109). Some of these categories were collapsed based on our discussion, if my advisor and I were in agreement, and these categories are reported based on the frequency of responses within each category.

Ethical Considerations

This research project operated within the guidelines established by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences and Humanities Research Council of Canada [SSHRC], 2010), the purpose of which is to “promote the ethical conduct of research involving humans” (p. 5). The core principles outlined by the Tri-council Policy Statement were followed. These were respect for

persons, concern for welfare, and justice. Respect for persons was maintained by providing detailed information about the survey to enable participants to make an informed decision regarding their participation in this study. Participation in the study was voluntary. Completion and return of the survey was considered respondents' consent for participation in the study. With regard to concern for welfare, the respondents' names or e-mail addresses were not known and were not collected, so responses could not be linked to a specific individual. The privacy policy of FluidSurveys, which is a Canadian company, ensured that the data collected would not be shared or used by FluidSurveys. Once removed from the Fluid Surveys web-site, electronic data files were stored on a password-protected computer that only the researcher has access to, and only me, my committee, and a statistician from the Manitoba Centre for Nursing and Health Research had access to the data. Justice was maintained by ensuring that the inclusion criteria fit with the research questions posed and that participation in the study was voluntary (CIHR, NSERC, & SSHRC, 2010).

No harmful effects or risks were perceived by participating in the study. Information gained from the survey may provide potential benefits to patients, their family members, and members of the health care team. The information gained from this study may also guide future research in this area which also may provide future benefits of FCC to patients, family members and members of the health care team. The proposal was submitted to the Education and Nursing Research Ethics Board (ENREB) at the University of Manitoba and permission of the Board of Directors of the CACCN was sought to distribute the link to the survey to its members.

Chapter Four: Results

This chapter will provide the results of the survey and provide answers to the following three research questions:

1. What are Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs?
2. What are Canadian critical care nurses' perceptions of FCC in adult critical care?
3. What policies and practices are in place in adult ICUs in Canada to promote FCC or involvement of the family in the care of patients?

The Sample

The link to the survey was sent out by the Canadian Association of Critical Care Nurses (CACCN) on October 31, 2012 and data collection closed on November 21, 2012. A total of 207 registered nurses who worked in critical care and were members of the CACCN responded to the survey (see Table 1). On October 8, 2012 the CACCN had a membership of 1138 registered nurses. One hundred members did not have electronic mail addresses. A total of 1038 emails were sent out and 207 responses were received to the survey, for a response rate of 20%. The mean age of study participants was 45 years, with a range from 23 to 64 years. The mean years of experience as a registered nurse was 21 years and the mean years of experience working in intensive care settings was 16.13 years, with a range from 1 to 40 years. Significantly more female nurses (92.8%) than male nurses (7.2%) participated in the survey. The majority of the nurses in the study (92.3%) worked in mixed medical/surgical ICUs as direct care providers (72%). Most nurses (81.6%) stated that the ICUs they worked in had a general approach to the care of families in their place of work and 79.2% had the experience of having a family member seriously ill and in need of professional care.

Table 1: Demographics for Sample

Demographics (N = 207)	
Age (years)	Mean 44.61 (10.725 Standard Deviation [SD])
Gender	
Female	n = 192 (92.8%)
Male	n = 15 (7.2%)
RN Experience (Years)	Mean 21.07 (11.336) Range (2-42 years)
Experience in ICU (Years)	Mean 16.13 (10.744) Range (1-40 years)
Experience with ill family member	
Yes	n = 164 (79.2%)
No	n = 43 (20.8%)
Current role	
Direct care provider	n = 149 (72%)
Educator	n = 25 (12.1%)
Manager	n = 18 (8.7%)
APN ^a (CNS ^b , NP ^c)	n = 11 (5.3%)
Other	n = 4 (2%)
Type of Hospital	
Quaternary Care	n = 39 (18.8%)
Tertiary Care	n = 98 (47.3%)
Community	n = 59 (28.5%)
Rural	n = 2 (1%)
Other	n = 9 (4.3%)
Type of ICU	
Mixed Medical/Surgical	n = 191 (92.3%)
Surgical	n = 7 (3.4%)
Medical	n = 7 (3.4%)
Other	n = 2 (1%)

Note: a. Advance Practice Nurses; b. Clinical Nurse Specialists; c. Nurse Practitioners

Critical Care Nurses' Attitudes About the Importance of Families

The first research question was: What are Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs? The FINC-NA questionnaire,

containing 26 items and using a 5-point Likert scale, was used to answer this question. Scores with this instrument can range from 26 to 130. The higher the score, the more positive the respondent's attitude about the importance of families in nursing care. A total of 193 nurses responded to all of the items on the FINC-NA, with a mean total score of 102.23, standard deviation of 13.416, score range of 68 to 130, and Cronbach's alpha of 0.931. The scores for the family as burden scale are inverted so that negative statements, which reflect a negative attitude, are given a lower value on the scale to correlate with the scoring of the rest of the subscales of the FINC-NA (Benzein et al., 2008)

The mean score for the subscale family as a resource in nursing care (Fam-RNC) was 38.91, with a standard deviation of 5.908, and a score range of 23 to 50 (with a possible range of 10 to 50) (see Table 2). Fam-RNC included items such as: "I gain a lot of worthwhile knowledge from families which I can use in my work" (mean score of 4.18); "a good relationship with family members gives me job satisfaction" (mean score of 4.48); and "the presence of family members is important for the family members themselves" (mean score of 4.42). The means of items within this subscale ranged from 2.81 to 4.48. The item "the presence of family members eases my workload" had the lowest mean score on this scale, and of all items on the FINC-NA, at 2.81.

The mean score for the subscale family as a conversational partner (Fam-CP) was 32.73 (possible score range of 8 to 40), with a standard deviation of 3.99 (see Table 3). Items in this subscale deal both with engaging families in conversations to gather and exchange information and inviting families to take part in care. Mean values for items in this subscale ranged from 3.57 for the item "I invite family members to actively take part in the patient's care" to 4.81 for the item "it is important to find out what family members a patient has".

Table 2. Family as a Resource in Nursing Care (Fam-RNC) Subscale (n = 193)

Items	Item Mean (M), Standard Deviation [SD]	Subscale N=193 M(SD)	Cronbach's Alpha
Subscale Total Score		38.91 (5.908)	.883
10 The presence of family members eases my workload	2.81 (1.00)		
07 The presence of family members gives me a feeling of security	3.19 (.942)		
05 The presence of family members is important to me as a nurse	4.17 (.848)		
04 Family members should be invited to actively take part in the patient's nursing care	3.80 (.988)		
11 Family members should be invited to actively take part in planning patient care	3.82 (.976)		
03 A good relationship with family members gives me job satisfaction	4.48 (.727)		
20 Getting involved with families gives me a feeling of being useful	3.71 (.918)		
21 I gain a lot of worthwhile knowledge from families which I can use in my work	4.18 (.714)		
13 The presence of family members is important for the family members themselves	4.42 (.664)		
22 It is important to spend time with families	4.22 (.746)		

Note: Possible score range: 10-50

Table 3. Family as a Conversational Partner (Fam-CP) Subscale

Items	Item M[SD]	Subscale N=193 M[SD]	Cronbach's Alpha
Subscale Total Score		32.73 (3.999)	.793
14 I invite family members to have a conversation at the end of the care period	3.67 (.973)		
06 I ask family members to take part in discussions from the very first contact, when a patient comes into my care	4.21 (.799)		
12 I always find out what family members a patient has	4.28 (.750)		
19 I invite family members to speak about changes in the patient's condition	4.25 (.631)		
24 I invite family members to speak when planning care	3.86 (.801)		
06 It is important to find out what family members a patient has	4.81 (.434)		
15 I invite family members to actively take part in the patient's care	3.57 (.943)		
09 Discussion with family members during first care contact saves time in my future work	4.05 (.866)		

Note: Possible score range: 8-40

The mean score for the subscale family as a burden (Fam-B) was 14.86 (possible score range of 4 to 20), with a standard deviation of 3.308 (see Table 4). The items on this subscale deal with concerns related to time for caring for families, the stress families cause nurses, and the impact of families on the progress of nurses' work. The scores on this scale have been inverted so that negative attitudes receive lower scores. Items on the Fam-B included "the presence of

family members holds me back in my work” (mean score of 3.50) and “I do not have time to take care of families” (mean score of 3.83).

Table 4. Family as a Burden (Fam-B) Subscale

Items	Item M[SD]	Subscale N=193 M[SD]	Cronbach’s Alpha
Subscale Total Score		14.86 (3.308)	.833
23 The presence of family members makes me feel that they are checking up on me	3.79 (.996)		
26 The presence of family members makes me feel stressed	3.71 (.994)		
02 The presence of family members holds me back in my work	3.50 (1.057)		
08 I don’t have time to take care of families	3.83 (1.034)		

Note: Possible score range: 4-20

The mean score for the subscale family as own resource (Fam-OR) was 15.74 (possible score range of 4 to 20), with a standard deviation of 2.34 (see Table 5). The items on this subscale deal with families’ coping and use of their own resources and the nurse as a support to families. Specific items include: “I encourage families to use their own resources so that they have the optimal possibilities to cope with situations by themselves” (mean score of 3.54); and “I see myself as a resource for families so that they can cope as well as possible with their situation” (mean score of 4.34).

Table 5. Family as Own Resource (Fam-OR) Subscale

Items	Item M[SD]	Subscale N=193 M[SD]	Cronbach's Alpha
Subscale Total Score		15.74(2.34)	.657
17 I encourage families to use their own resources so that they have the optimal possibilities to cope with situations by themselves	3.54 (1.041)		
25 I see myself as a resource for families so that they can cope as well as possible with their situation	4.34 (.593)		
18 I consider family members as co-operating partners	3.86 (.814)		
16 I ask families how I can support them	3.99 (.827)		

Note: Possible score range: Family as own resource (Fam-OR) 4-20.

Cronbach's alpha was the method used to evaluate the internal consistency of the items and scales of the FINC-NA. Internal consistency reliability is the best way of assessing whether or not all the items of the FINC-NA measure the same trait, which in this study is nurses' attitudes. The normal range of values for Cronbach's alpha is between .00 and +1.00 (Gliem & Gliem, 2003; Polit & Beck, 2008, p. 455). According to Gliem and Gliem (2003), the following rules apply when interpreting Cronbach's alpha values: less than or equal to .5 the reliability is unacceptable, greater than or equal to .5 the reliability is poor, greater than or equal to .6 it is questionable, greater than or equal to .7 it is acceptable, greater than or equal to .8 it is good, and greater than or equal to .9 it is excellent. The values of Cronbach's alpha ranged from 0.657 to 0.833. The Fam-OR scale score of 0.657 is low. The remaining subscales range from acceptable to good. The Cronbach's alpha results indicate the reliability of the FINC-NA in all of the

subscales is acceptable with the exception of the Fam-OR scale which is questionable. Cronbach's alpha score for the Fam-B subscale was 0.833, with 4 items on this subscale, and 0.657 for the Fam-OR sub-scale, which also had 4 items. These scores are important because the number of items in the scale and the mean of the inter-items correlations determine the size of alpha. The low number of items in the subscale Fam-OR may have resulted in a questionable reliability score of 0.657.

Relationships.

Statistical tests were carried out to explore relationships between scores on the FINC-NA and the demographic variables. Pearson correlation (product-moment correlation coefficient) or Pearson's r is calculated with variables that are measured on an interval or ratio scale. Pearson's r is a correlation coefficient that describes the direction and magnitude of the relationship between some of the demographic variables and the subscales of the FINC-NA. An r of .70 would be considered high and perfect correlations of +1.00 and -1.00 are rare (Polit & Beck, 2008, p. 455). A positive relationship indicates that as one variable increases there tends to be associated increases in the other variable. A negative relationship indicates that two variables are inversely related and increases in one variable are associated with decreases in the second variable (Polit & Beck, 2008, p. 453).

The relationships between age, years of nursing experience, and years working in ICU and the scores on FINC-NA (i.e., total scores and sub-scale scores) were examined (see Table 6). There is a significant positive correlation between age and the subscales of the FINC-NA and the total score (as age increases, so do attitudes) as follows: Fam-RNC, $r = .162$, $n = 193$, $p < .05$; Fam-CP, $r = .269$, $n = 193$, $p < .01$; Fam-B, $r = .313$, $n = 193$, $p < .01$; Fam-Total, $r = .248$, $n = 193$, $p < .01$. A weak relationship is indicated by a correlation of less than .20 and a medium

relationship is indicated by an r value of between .30 to .49. Significant weak positive correlations were also found between years of nursing experience and years working in ICU (as experience increases, so do attitudes) and scores on FINC-NA in the Fam-CP, Fam-B, and Fam-Total scores.

Table 6. Pearson r Correlations Between Demographic Variables and FINC-NA

	Fam-RNC	Fam-CP	Fam-B	Fam-OR	Fam-Total
Age	.162*	.269**	.313**	.112	.248**
Years of Experience	.129	.225**	.283**	.069	.207**
Years in ICU	.068	.207**	.252**	.032	.159*

Note: Sample size = 193 nurses

*p < .05 (2-tailed)

**p < .01 (2-tailed)

The Kruskal-Wallis Test was used to compare total scores on the FINC-NA instrument for four different nurse roles. A statistically significant difference in scores was found across the groups (Gp1, n = 10: CNS and NP; Gp2, n = 25: Educator; Gp3, n = 19: Manager and Other; Gp4, n = 139: Direct Care Providers), chi-square (3, n = 193) = 29.90, p = .00. The Educator group (Md = 99.0) and Direct Care Providers group (Md = 101.00) had lower median scores than the Manager and Other group (Md = 112.0) group and the CNS and NP group (Md = 122.5).

Table 7. Kruskal-Wallis Test Examining Nurses' Roles and Scores on FINC-NA

	Role	n	Mean Rank
Fam-Total	CNS and NP Role	10	155.30
	Educator	25	97.76
	Manager and Other	19	144.53
	DCP	139	86.17

Independent-samples t-tests were done to examine the impact of gender, age (nurses over 50 years of age compared to those 50 years of age or younger), ICU experience (greater than 5 years of experience compared to 5 years or less), presence or absence of an ill family member, and presence or absence of a general approach to care of families in the nurses' units on scores on the FINC-NA instrument (Table 8). There were no significant differences in scores found with gender, presence or absence of an ill family member, or presence or absence of a general approach to care. There was a significant difference found in total scores on the FINC-NA between nurses 50 years or younger ($M = 100.65$, $SD = 12.97$) and those over 50 years of age ($M = 105.07$, $SD = 13.83$; $t(191) = -2.22$, $p = .028$, two-tailed). The mean difference between the groups was -4.42 . Significant differences in these two groups were also found in the Fam-CP and Fam-B sub-scales. Significant differences were noted in total scores on the FINC-NA between the nurses who had 5 years or less of ICU experience ($M = 97.02$, $SD = 12.75$) and those who had more than 5 years of ICU experience ($M = 103.73$, $SD = 13.27$; $t(191) = -2.95$, $p = .004$, two-tailed). The mean difference was -6.70 . In addition, significant differences in scores between these two groups were identified on the Fam-CP, Fam-B, and Fam-OR subscales.

Table 8. Summary of Demographic Variables and FINC-NA Mean Scores

FINC-NA	n (%)	Fam-RNC M (SD)	Fam-CP M (SD)	Fam-B ^a M (SD)	Fam-OR M (SD)	Total M (SD)
All	193	38.9 (5.9)	32.7 (3.9)	14.8 (3.3)	15.7 (2.3)	102.2 (13.4)
Gender						
Female	179 (92.7)	39.0 (5.6)	32.8 (3.9)	14.8 (3.1)	15.7 (2.2)	102.4 (12.7)
Male	14 (7.3)	37.0 (8.7)	31.5 (4.8)	14.9 (4.9)	15.3 (2.8)	98.8 (20.1)
p value ^b		.401	.261	.957	.531	.516
Age						
50 years or less	124 (64.2)	38.4 (5.8)	32.2 (3.8)	14.3 (3.3)	15.6 (2.3)	100.6 (12.9)
>50 years	69 (35.8)	39.7 (5.9)	33.6 ^b (4.0)	15.7 ^b (3.0)	15.8 (2.3)	105.0 ^b (13.8)
p value ^b		.125	.018	.005	.472	.028
ICU experience						
5 years or less	43 (22.3)	37.8 (6.0)	30.6 (3.8)	13.3 (3.6)	15.0 (2.2)	97.0 (12.7)
>5years	150 (77.7)	39.2 (5.8)	33.3 ^b (3.8)	15.2 ^b (3.0)	15.9 ^b (2.3)	103.7 ^b (13.2)
p value ^b		.189	.000	.001	.041	.004
Ill family member^c						
Yes	153 (79.3)	39.0 (6.1)	32.8 (4.0)	14.9 (3.3)	15.8 (2.4)	102.6 (13.9)
No	40 (20.7)	38.5 (4.8)	32.1 (3.5)	14.5 (3.1)	15.4 (2.0)	100.6 (11.3)
p value ^b		.647	.283	.507	.430	.411
General Approach^d						
Yes	160 (82.9)	38.8 (5.7)	32.9 (3.9)	15.0 (3.0)	15.7 (2.3)	102.6 (13.2)
No	33 (17.1)	39.3 (6.7)	31.5 (4.1)	13.7 (4.1)	15.6 (2.1)	100.3 (14.4)
p value ^b		.627	.055	.096	.853	.373

NOTE:

- a. Inverted items
- b. Independent samples t-test – significant level of $p < .05$
- c. Has a member of your family ever been seriously ill and in need of professional care?
- d. Is there a general approach to the care of families at your place of work?
- e. M = mean score
- f. SD = standard deviation

Regression Model

A regression model was also used to examine relationships between variables. The variables entered into the model were: years worked as a registered nurse; gender – male and female; current role – advanced practice nurse (APN), including clinical nurse specialist and

nurse practitioner, direct care provider (DCP), educator (EDC), manager (MNG); type of hospital – community hospital, other, quaternary care centre, tertiary care hospital; presence of a seriously ill family member – yes and no. The coefficients show how strongly each independent variable is associate with the dependent variable.

Table 9. Regression Model for FINC-NA Total Score

R-Square for Model – 0.189

Parameter		Estimate	SE	t Value	p	95% CI
Intercept		106.97	5.095	21.0	<.0001	96.9 to 117.0
Years Worked as RN		0.103	.087	1.19	0.23	-0.07 to 0.27
Female		2.23	3.59	0.62	0.53	-4.86 to 9.33
Role	APN	8.37	4.83	1.73	0.09	-1.16 to 17.9
	DCP	-10.95*	3.38	-3.24	0.001	-17.6 to -4.29
	EDC	-7.66	4.03	-1.9	0.06	-15.6 to 0.29
Hospital	Community	0.81	2.17	0.38	0.71	-3.46 to 5.08
	Other	-1.06	4.16	-0.25	0.80	-9.27 to 7.16
	Quaternary	-3.65	2.48	-1.47	0.14	-8.54 to 1.24
Ill family Member		-0.43	2.304	-0.19	0.85	-4.97 to 4.12

Note:

a Estimate

b Standard error

*Significant at p<.05 – 95% confidence limits

The R-square value for the family total was 0.189. This result indicates the proportion of variance that was accounted for by the combined and simultaneous influence of the following independent variables: years as a registered nurse, gender, current role, type of hospital and have you ever had a family member seriously ill. Family total was reflective of all the dependent

variables and the subscales family as a resource in nursing care, family as conversational partner, family as burden, and family as own resource. The direct care provider role was the only variable in the model making a statistically significant contribution to the total score on the FINC-NA. The role of direct care provider has a co-efficient of -10.947 and a p-value of 0.0014. Analysis of each independent variable determined that the direct care provider role made a statistically significant contribution to the scores in all of the FINC-NA subscales. The APN role was found to be significant in the Fam-OR subscale; the educator role was found to be significant in the Fam-CP subscale; and years of experience as a RN was found to be significant in the Fam-B subscale.

Comments after the FINC-NA

After responding to the last item on the FINC-NA, nurses had the opportunity to provide a comment on that aspect of the survey and 49 nurses did so. Each of the comments was read carefully by both me and my supervisor and agreed upon categories were identified to organize the data (see Table 10). Of the comments provided, 33 related directly to the FINC-NA instrument or items on it. For example, 17 nurses indicated that their responses would vary depending on the families they were caring for at the time. As one nurse stated:

Many of these questions can be answered completely differently depending on the specific family you are working with. Some families are considerate, knowledgeable, polite and thankful for the care being provided while others can be extremely overbearing, uncooperative, unreasonable and even hateful which definitely has a huge impact on not only the nurse's experience but patient care and workplace morale. I believe in family-centered care with most families who are reasonable and appreciate (sic) of the care we provide, while others, despite working with them extensively and

attempting to appease them at all times, are simply unreasonable and there is 0% chance to have a nurse-family relationship that contributes to positive nursing care for their family.

Twenty-one comments related to specific items on the FINC-NA. For example, in response to item 15, “I invite family members to actively take part in the patient’s care”, one nurse wrote:

In intensive care, family is very limited in providing care to the patient, I will show them how to do oral care, provide oral suction, etc. but outside of those very simple tasks given the patient population we serve, it is difficult to get family to assist with care.

Another nurse provided this response to item 26 of the FINC-NA, “the presence of family members makes me feel stressed”:

The presence of family members only gives our team the feeling of stress when they threaten lawsuits, or going to the CEO, etc., without the vision of potential natural occurrence of death to their family member. This type of flagrant dissociation with the reality of impending death actually creates a barrier of care for their loved ones by the health care team.

Thirteen comments were more general in nature and these tended to focus on either the nurses’ support for or the challenges associated with providing family-centered care. One nurse wrote: “I have difficulty with large numbers of persons visiting, with little consistency and no commitment from any.” Another indicated:

I am very passionate about patient AND family-focused care. I feel that I try to incorporate the family into as much care as possible and try to spend time helping them but at the same time if you have a sick patient and are busy with them, you don't have time to adequately care for the family as well. I have lots of thoughts on this subject.

Table 10. Open-ended Comments Post FINC-NA (49 responses)

Responses Specific to FINC-NA Instrument	33
Response to Questions Would Vary Family to Family	17
Item: Families Taking Part in Care	5
Item: Families Taking Part in Planning Patient Care	3
Items: Families as a Stressor for Nurse	10
Item: Inviting Families to Have a Conversation	3
Meaning of Middle Column on Likert Scale	1
Concerns with FCC	6
Support for FCC Interventions	7
Other	3

Note: Some comments contained information that fit into two categories, so the numbers do not total 49.

Summary of Results related to the FINC-NA

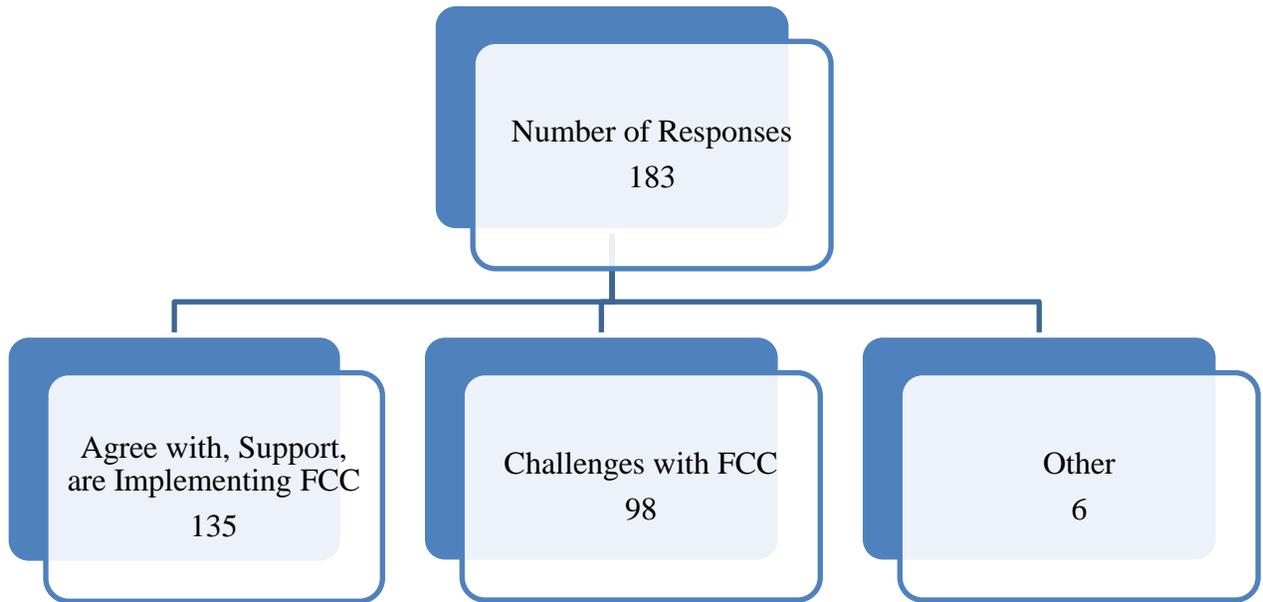
In summary, the results of the FINC-NA determined that, generally, nurses who were members of CACCN working in Canadian critical care units have supportive attitudes towards the involvement of families in nursing care. The relationships between age, years of nursing experience, and years working in ICU and the scores on FINC-NA (i.e., total scores and sub-scale scores) were examined (see Table 6). Significant correlations determined that as nurses age their attitudes towards the importance of families in nursing care were found to be more positive. Significant weak positive correlations were also found between years of nursing experience and years working in ICU and attitudes, indicating that as experience increases, nurses' attitudes towards families also become more supportive. When nurses' roles were

examined, direct care providers were found to have a less supportive attitude about the importance of families in nursing care than nurses in other roles.

Perceptions of FCC

The second research question was: What are Canadian critical care nurses' perceptions of FCC in adult critical care? This question was addressed in two ways: a) using an open-ended question on the survey; and b) using a question that asked nurses to assess their units' ability to provide FCC. A total of 183 nurses responded to the open-ended question, "What is your perception of family-centered care?" As per the qualitative content analysis process outlined by Elo and Kyngäs (2008), these responses were read in their entirety by me and my supervisor, broad coding categories were identified independently, and then we agreed upon coding categories to organize the data. Initially, the comments were separated into two categories: a) agree with, support, or are implementing FCC; and b) challenges of FCC. Then all of the comments within each broad category were read carefully and sub-categories were identified to code and further organize the comments (see Figure 1 and Table 11). The results for the nurses' assessment of their units' ability to provide FCC, based on a scale of 1 to 10, was a mean score of 7.1, with a standard deviation of 1.49, with a range from 1 to 10. This suggests that generally the nurses believed that FCC was being provided at a good level in their units.

Figure 1. Open-ended Responses Regarding Perceptions of FCC (183 responses)



Note: Responses could contain information that fit with more than one category.

Table 11. Open-ended Responses Regarding Perceptions of FCC (183 responses)

Agree with, Support, or are Implementing FCC	135
General Comments Agreeing with FCC	77
Comments Regarding Why They Agree	
Benefits Patient	41
Benefits Family	21
Benefits Staff	23
Challenges of FCC	98
General Comment that FCC is Challenging	21
Comment Re: Nature of Challenge	
Difficult Families	25
Comfort of Nurses/Staff with FCC	27
Families Stressed/Unable to Participate	14
Workload for Nurses	9
Lack of Resources for FCC	11
Comfort of Physicians with FCC	6
Family as a “Bother”	13
Privacy Concerns	6
Best Interests of Patient a Concern	12

Note: Responses could contain information that fit more than one category.

Agree with, support, or are implementing FCC.

One hundred and thirty-five nurses provided comments that indicated that they agree with, support, or are implementing FCC. Within this group of comments, 77 nurses wrote general, often very brief, comments indicating that they agreed with FCC. Comments included: “I believe [FCC] is important” and “In most cases [FCC] works well.” Some of the comments provided more detail than agreement or support for FCC, indicating that FCC provided benefits to the patient (41 comments), the family (21), and/or the staff (23). Some of these comments described specific FCC interventions that have been implemented in the units (i.e., family meetings, brochures, a family website, voluntary co-primary nursing, family meeting record, quality care committees, bedside updates to provide families with information about the patient, unrestricted visits).

Two examples of comments provided by nurses and categorized as agreeing with FCC are provided below:

“Family should be allowed to be present in ICU and resources to support families should be available.”

“This is an approach that is pivotal to delivering high quality, compassionate, collaborative and family based care.”

Two examples of nurses’ comments outlining FCC strategies being used in their units follow:

We have worked very hard in the unit where I work to promote family-centred care. We introduced unrestricted visiting > 20 years ago and have many strategies in place to support families (brochure, family website, voluntary co-primary nursing, a family meeting record and quality care committee).

Not all ICUs allow families to be as involved as our unit. A community-based hospital has a culture of family and patient-centred care. We have always allowed families to be present during resuscitation and provide a staff member to support them at that time. For select families they have been present for invasive procedures. Many families do not wish to stay for these procedures but we would evaluate this on a case by case situation.

Some nurses referred in a general manner to the presence of families (i.e., during resuscitations, invasive procedures, rounds). These nurses provided comments that gave the reader the sense they agreed with FCC and provided examples of FCC strategies, however, they did not go into detail about how they felt about the concept of FCC or families. Their discussion of families was limited to general statements indicating that: they support family presence; families should be allowed to visit with some restrictions; families are important during end-of-life care; families need information and are valuable sources to provide information; or families are important and not utilized enough in the ICU. Comments about patients were also limited and generally indicated that families should be included in care if the patient agrees because the patient and family should be considered “a unit.”

Some nurses provided more detail in their comments and these were categorized in terms of the benefits of FCC to patients, families, or staff. Nurses who described the benefits that FCC provided to patients included reasons such as: families provide healing for patients; families provide information and help nurses get to know the patient better; FCC ensures patients receive holistic care and improves patient outcomes; families provide support for patients, advocate for them, decrease anxiety, and improve patients’ sense of well-being. One nurse provided the following response outlining the benefits of FCC:

“Families are an integral part of the care team. They provide support and advocacy for patients, as well as providing necessary information to the health care team”.

Another nurse responded in the following manner indicating she believed FCC had benefits for patients:

I believe that families can be an integral part of the healing for the patient.

Allowing the family access to care gives them the sense of responsibility. I find it is better for a collaborative approach. Patients for the most part respond better when their loved ones are present.

A total of 21 comments contained information about the benefits of FCC for families.

Nurses felt that FCC: empowers families; improves family outcomes; helps build trust between families and the health care team; improves communication with family members; decreases family stress; allows families to see the work of the health care team; helps families with decision making; and helps families cope with their loved one’s critical illness. The following two responses illustrate how nurses believed that families benefit from FCC:

FCC is a good concept for adults ICUs. It decreases family and pt anxiety, it reduces incidents of mistakes since family can always provide healthcare providers with information related to pt history, it builds trust between caregiver and the family, decreases family and healthcare giver incidents of misunderstanding, and it can also decrease incidents of legal issues.

I believe that families are important part of plan of care. Having families active participants in all care, allows for positive open communication, and facilitates clearing any misunderstandings. They are able to see the patient calm, sedated but

rather how critically ill their loved one is and all that we are trying to accomplish to save their loved one's life. Also, they are able to appreciate my professional role as a nurse not just a handmaid to a doctor.

Twenty-three comments provided information about nurses' perceptions of the benefits of FCC for staff members. Nurses identified that families: provide information about what patients were like before their critical illness; help determine the patient's needs; provide knowledge that helps with decision making; decrease mistakes made by the health care team by providing information about medications; help the health care team understand cultural differences; and provide insight into the patients' values and beliefs. For example, one nurse stated:

I believe that the integration of families in ICU is an essential aspect to patient care. The family will know the patient in their pre-hospital status and are important resources to help the health care team work to get the patient back to that status. Also, once the patient leaves the ICU the family are a constant, and will be the ones taking care of the patient at home.

Another nurse commented:

Often in the ICU the patients are unable to speak for themselves due to intubation or disease processes. It is important to have contact with family members so that they're able to advocate for their loved one. They can also provide information on patient history and lifestyle.

The comments of nurses provide us with insight into why nurses perceive FCC to be beneficial. The nurses' perceptions of FCC provide us with information about specific strategies that are being used in intensive care units to implement FCC and detailed information on how

nurses' perceive that patients, families, and the health care team may benefit from this philosophy of health care delivery.

Challenges of providing FCC.

Ninety-eight nurses provided comments that indicated providing FCC was challenging. Within this group, 21 nurses wrote general comments that FCC is challenging and 77 nurses wrote more specific comments indicating the nature of the challenge. The challenges nurses identified included: difficult families (25 comments); the comfort of nurses and other team members with FCC (27 comments); working with families who were stressed and/or unable to participate in FCC (14 comments); the workload for nurses created by FCC (9 comments); the lack of resources available for FCC (11 comments); the comfort of physicians with FCC (6 comments); viewing the family as a "bother" (13 comments); privacy issues (6 comments); and concerns about the best interests of the patient (12 comments).

One group of comments provided by nurses related to what the nurses described as challenging or difficult families (25), while another group related to the notion of the family as a "bother" (13). Nurses described the nature of these challenges in the following ways: families expecting things done now and taking things for granted; family members who may not have the best interest of the patient in mind; families asking many questions; families interfering with patient care; family members who want to be present continuously in the ICU and who become exhausted; stressed and dysfunctional families that make nurses feel stressed; and families that dictate what needs to be done and are difficult to get along with. One nurse commented:

[Families] can be time consuming. Many feel threatened so if the entire team is not on board then you end up with good nurse/bad nurse. Consistency is a must. The family unit may be so dysfunctional that they cannot be invited to participate.

Another wrote:

I find families often have unrealistic expectations. It is hard to provide FCC when the requests or hopes of the family are not in line with the patient's status. I think we often prolong the lives of patients unnecessarily to give families time to cope. I see the effects of this on the patient, and subsequently resent family members for pushing to keep their loved one alive at all cost despite clear suffering.

Some nurses (27) described concerns with their own or other nurses' level of comfort with FCC. For example, nurses identified that some nurses are not comfortable with family presence or their own expertise, feel like families are watching them, or feel threatened. The comfort of nurses/staff with FCC is discussed in the following response:

I think many nurses are uncomfortable with family presence and make them wait unnecessarily simply because they think they are being watched. Maybe they are, but they need to feel confident enough in their expertise that this should not matter.

Another nurse indicated:

Behaviours of health professionals in the intensive care inhibit family-centred care... They become the barriers; health care professionals state that time and workload inhibit their ability to involve and discuss care with families, old practices of keeping the family waiting behind closed doors are maintained despite education and changing policy. Everything is set up for success but yet we fail our families routinely within patient/family satisfaction surveys.

Other nurses (14) commented that they felt families are stressed and unable or unwilling to participate in care. As one nurse wrote:

Family have a difficult time in coping/dealing with ICU admission/health condition of their loved one to even think about participating in patient's care.

Some felt participation in patient care may increase family members' stress, while others thought that families do not have the knowledge to participate.

Nurses commented (9) that FCC can be difficult to implement in relation to their heavy workload, with 11 nurses indicating that they felt they lacked resources to effectively implement this approach to care. A particular concern was the lack of support from other members of the health care team. One nurse wrote:

FCC is important but harder to manage when the workload is so high that one barely has time to look after the patient's needs let alone look after their families and answer their questions etc. Certainly not the most ideal situation but when the budget and saving money has become more important than the patients, that's what happens. Sad but true, at least where I work.

Another nurse commented on the lack of an inter-professional approach to FCC:

I believe that families are not utilized and embraced enough; however, I myself find it difficult at times to include them, especially when things are really busy. I think FCC is important in the face of critical illness but it requires support from multiple disciplines which are often not readily available at my place of work - nurses can't possibly do everything. In this case, FCC suffers.

Also lacking were appropriate places for family conferences, space for families to gather, and adequate supports for families.

Nurses perceived that FCC is challenging if physicians are not comfortable with this philosophy. They gave examples of how the comfort of physicians with FCC affects families.

For example, nurses described how family presence at rounds and family conferences was based upon the decision of the physician, some physicians still need to be “dragged” in to family conferences, and inconsistencies could occur between and among physicians. One nurse commented:

Definitely room for improvement as far as planning for family conferences go. There can be inconsistencies with physicians and availability to meet with families to discuss care; as well as inconsistencies between physicians from week to week regarding what the treatment plans are. Families can get confused if a doctor wants to do a certain test (i.e., CT scan) on their week, but when the next week's physician takes over they see the test as unnecessary so it is cancelled. As a nurse it can be difficult to explain the rationale for why changes happen when we don't fully understand ourselves why they make the decisions they make.

In their comments nurses were found to have the perception that protecting patient privacy was a challenge of FCC (6). The concerns they addressed in relation to privacy and FCC were as follows: the challenges of preserving patient confidentiality; family members were stopped from coming in during shift change or rounds as they were listening to other patient's information and conveying this to others outside of the patient/family; patient-related information is easily heard throughout an open unit; and patients may lose their dignity and privacy with families participating in care.

The last category addresses nurses' perceptions of FCC affecting what is in the best interest of patients. These comments (12) focused on the fact that family members may not have the best interest of the patient at heart. As one nurses stated:

It is dependent on the family, some are rational and some are not. Some do not understand the complexity of cases, and refer to the internet to get answers to things that are not textbook and families do not have the medical knowledge to support their decisions even though they have been given recommendations from the critical care staff. Sometimes families' decisions are to suit their needs not the patient's needs or wishes.

Another nurse wrote:

I am not convinced that family-centered care benefits the patient. In some circumstances, it would. However, in my experience a lot of unnecessary stress on the patient and staff is caused by the family members dictating how the nurse, physician and the rest of the healthcare team should practise. In our facility, family meetings are routinely done throughout the patient stay and at the critical stages in the treatment, so they have always had a crucial role in the treatment. I agree that they are essential members of the care continuum but they do not always have the best interests in the patient.

In summary, nurses' comments to the open-ended question "What is your perception of FCC?" offer insights into why they agree with or support FCC and what is working well, as well as descriptions of the FCC strategies that have been implemented. The challenges nurses experience with FCC were also described.

Policies and Practices

The third research question was: What policies and practices are in place in adult ICUs in Canada to promote FCC or the involvement of the family in the care of the patients? The total number of respondents for the questions in this section of the survey was 207 nurses and the results are reported in Table 12. It is important to acknowledge that questions were not asked to determine the province, city, or unit the nurses worked in, so it is not known how many Canadian adult ICUs are represented in these responses. Most of the nurses indicated that their units provided information packages to families on admission (73.9%) and that families had access to a social worker (94.2%) and spiritual care providers (96.1%). Only 27.1% of nurses reported that a family conference was held after admission to their unit, with 46.4% of nurses indicating that families were given a bereavement package upon the death of their loved one. Close to half of the nurses reported that their units had open visiting hours and most (66.7%) indicated that their ICUs had locked doors so that families were required to ask permission to gain access to visit a loved one. Open-ended responses to the types of restrictions present in the nurses' units were categorized and the results are presented in Table 13.

Table 12. Policies and Practices – Information, Meetings, and Access to Resources (N=207)

Policy or Practice	Frequency (number of nurses)	Percent (%)
Information Package on Admission		
Yes	153	73.9
No	48	23.2
Do not know	6	2.9
Family Conference After Admission		
Yes	56	27.1
No	143	69.1
Do not know	8	3.9
Families Given Bereavement Package After Death of Their Loved One		
Yes	96	46.4
No	86	41.5
Do not know	25	12.1
Families have access to a social –worker		
Yes	195	94.2
No	10	4.8
Do not know	2	1.0
Families have access to Spiritual Care		
Yes	199	96.1
No	6	2.9
Do not know	2	1.0

With regards to the questions about family presence, 62.3% of nurses indicated that families were always or usually asked to leave during nursing care or procedures in their unit. Approximately one-quarter of the nurses reported that family are always or usually permitted to be present during resuscitation and 15% indicated that family are always or usually permitted to attend rounds.

Table 13. Policies and Practices – Visiting and Presence (N = 207)

Policy or Practice	Frequency (number of nurses)	Percent (%)
Open or Restricted Visits		
Open	98	47.3
Restricted	109	52.7
Doors Locked so Families Need Permission to Gain Access		
Yes	138	66.7
No	69	33.3
Quiet Time When No Visitors are Allowed		
Yes	52	25.1
No	155	74.9
Families Asked to Leave during Nursing Care and Patient Procedures		
Always	15	7.2
Usually	114	55.1
Sometimes	73	35.3
Rarely	5	2.4
Family members permitted to be present during resuscitation		
Always	15	7.2
Usually	37	17.9
Sometimes	86	41.5
Rarely	52	25.1
Never	17	8.2
Family included in rounds		
Always	12	5.8
Usually	19	9.2
Sometimes	49	23.7
Rarely	55	26.6
Never	72	34.8

Ninety-five of the 109 nurses who identified that visiting restrictions were in place in their units wrote comments that provided a simple description about the type of restriction. Out of the 95 nurses that provided comments several of these nurses provided more than one type of

restriction. The different types of restrictions were placed into categories and the frequencies in each category are illustrated in the table below (Table 14).

Table 14. Type of Restrictions to Visiting

Categories	Frequencies (out of 95 responses)
Not during report	45
Not at certain predetermined hours	20
Two visitors at a time	18
Call before entering	8
Bedside nurse determines restrictions	5
Not during procedures	5
Patient condition	3
Restrictions lifted if patient is dying	3
Length of visits	2
Adults only	2
Not during rounds	2
No visitors immediately post op	1

Note: Numbers do not add up to 95 as some responses fit into more than one category

While the results do not provide clear information about the policies and practices in place in ICUs across Canada, they do allow for comparisons between the number of FCC policies and practices in place in the nurses' ICUs and attitudes as measured by the FINC-NA instrument. Two groups were created, those reporting the presence of less than four FCC policies or practices and those reporting four or greater FCC policies or practices in their units. The following eight FCC policies and practices were included: 1. a family conference is held after admission (yes or no); 2. an information package is provided on admission (yes or no); 3. open visiting (yes or no); 4. unlocked doors, so families do not need permission to gain access (yes or no); 5. no quiet time in the unit when visitors are prevented from visiting (yes or no); 6. family members are not asked to leave during patient care and invasive procedures (rarely or never); 7. family members are permitted to remain during resuscitation (always or usually); and 8. family members are included in rounds (always or usually). Independent samples t-tests were

done to examine the impact of the number of FCC policies (i.e., less than four FCC policies or four or greater FCC policies) on scores on the FINC-NA instrument. There were no significant differences found between the groups in the Fam-RNC, Fam-B, or Fam-OR subscales or in the FINC-NA total score. There was a significant difference in scores in the Fam-CP subscale for the less than 4 FCC policies and practices group ($M = 32.24$, $SD = 4.054$) and the 4 or greater FCC policies and practices group ($M = 33.66$, $SD = 3.76$; $t(191) = -2.38$, $p = .019$, two-tailed).

In addition, independent samples t-tests were done to examine the impact of the number of FCC policies (i.e., less than four FCC policies, four or greater FCC policies) on the nurses' assessment of their units' ability to provide FCC. There was a significant difference in scores for the less than 4 FCC policies and practices group ($M = 6.73$, $SD = 1.59$) and 4 and greater FCC policies and practices group ($M = 7.53$, $SD = 1.112$; $t(184) = -3.596$, $p = .002$, two-tailed). A Pearson r correlation test revealed that there was a significant positive correlation between the number of FCC policies (0 to 8) and how the nurse assessed the units' ability to provide FCC as follows: $r = .380$, $n = 186$, $p < .000$. This indicates that as the number of FCC policies in place in the ICU increased, the nurses' assessment of the units' ability to provide FCC increased.

In summary, the responses provided in relation to policies and practices in ICUs indicate that information packages were commonly used in the units these nurses worked in and access to social workers and spiritual care providers was common. A number of nurses reported that families are asked to leave during care or procedures, and few nurses reported that families are regularly present at rounds or usually permitted to stay during resuscitations. Over half of the nurses reported that their units had visiting restrictions. In addition, there was a positive correlation between the number of FCC policies and practices in place in nurses' units and their perception of their units' ability to provide FCC.

Chapter Five: Discussion

Three research questions were explored in this study:

1. What are Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs?
2. What are Canadian critical care nurses' perceptions of FCC in adult critical care?
3. What policies and practices are in place in adult ICUs in Canada to promote FCC or involvement of the family in the care of patients?

In this chapter, the results in relation to each of the research questions will be discussed in the context of the literature. In addition, the limitations of the study will be identified and the implications of the results for nursing practice, education, and research will be examined.

Nurses' Attitudes towards the Importance of Involving Families in Care

Two studies (Benzein, Johansson, Arestedt, & Saveman, 2008; Sveinbjarnardottir et al., 2011) have used the FINC-NA instrument to measure nurses' attitudes towards the importance of involving families in care, so comparisons can be made with those studies in exploring the findings for the first research question (see Table 15). Benzein et al. (2008) examined a sample of randomly selected Swedish RNs who completed the FINC-NA, finding that "a supportive attitude about the importance of involving families in nursing care was held by the majority" of respondents (p. 172). Sveinbjarnardottir et al. (2011) examined psychiatric nurses' attitudes in Iceland before and after an education program and found that: a) attitudes were positive before the education program; and b) families were viewed as less of a burden after the education program.

Table 15. Comparison of Results

Variables	Current study	Benzein et al. (2008)	Sveinbjarnardottir et al. (2011)
	n = 193 Canadian critical care nurses and members of CACCN	N = 634 Swedish RNs	N = 81 psychiatric nurses in Iceland
Gender	No significant differences	Significant difference in Fam-RNC, Fam-CP, and Total score. With logistic regression, being a male predicted a less supportive attitude	Significant difference between males and females on Fam-OR subscale (females had higher scores)
Age (less than or equal to 50 years compared to > than 50 years)	Significant differences in Fam-CP, Fam-B, and Total score (nurses over 50 years had higher scores)	Not reported	No significant differences noted
Experience as a Nurse	Significant differences in Fam-CP, Fam-B, Fam-OR, Total (nurses with less than or equal to 5 years of ICU experience had lower scores)	RNs with less than or equal to 5 years of experience had significantly lower scores than RNs with > 5 years of experience in Fam-CP, Fam-B, Fam-OR, and Total scores	RNs with less than or equal to 15 years of experience had lower scores than those with > 15 years of experience on Fam-B and Total score
General Approach to Care	No significant differences	RNs with no general approach to care of families had significantly lower scores in all scales	Not reported
Experience with Ill Family Member	No significant differences	Significant differences in Fam-CP and Total Score (higher scores for nurses with experience with an ill family member)	Nurses with experience of an ill family member had higher inverted scores than nurses who did not have this experience in the Fam-B subscale

As with the two previous studies, years of experience as a nurse resulted in higher scores or a more positive attitude towards the importance of involving families in care. While Benzein et al. (2008) and Sveinbjarnardottir et al. (2011) found significant differences between males and females and those nurses who had experienced the illness of a member of their own family and those who had not, that was not the case in this study. It is worth noting that the number of males working in critical care who responded to this survey was very small ($n = 14$). Contrary to the findings of Sveinbjarnardottir et al. (2011), critical care nurses over 50 years of age in this study had higher total scores (i.e., more positive attitudes) than nurses 50 years of age or younger.

It is difficult to compare mean or median scores on the FINC-NA instrument between the three studies, as the previous studies used a four-point Likert scale (versus the five-point scale used in this study) and Sveinbjarnardottir et al. (2011) did not report total mean scores or ranges. Benzein et al. (2008) reported a median total score of 88 (maximum possible: 104), with a range of 81 to 94, while the median total in this study was 102.0 (maximum possible: 130), with a range of 68 to 130. The range of scores with Canadian critical care nurses who were members of CACCN and who completed the items on the FINC-NA instrument was much broader than in the Benzein et al. (2008) study, particularly at the lower end of the range. It is not clear why this might be the case. Benzein et al. (2008) had a much larger sample size, used a general population of nurses, and used a four-point Likert scale. This study had a smaller sample size, the sample was a specific population of critical care nurses, and used a five-point Likert scale. There is some evidence that critical care nurses view families as a stressor, which might explain the lower scores (and this will be examined in the next section of this chapter). Further research

on larger samples of critical care nurses would prove helpful in determining if this finding is unique to this sample or is related to working in critical care.

Both a Kruskal-Wallis test and a regression model in this study identified that there was a significant negative relationship between the independent variable current role (i.e., advanced practice nurse, direct care provider, educator, and manager) and scores on the FINC-NA, particularly the role of direct care provider. Previous studies did not examine this variable. This finding may be related to the difficulties nurses who provide direct care face by being physically close to a limited number of patients and their families over an 8- or 12-hour shift or a series of shifts (Peter & Liaschenko, 2004). Nurses in other roles (i.e., ANP, educators, managers) tend to spend limited time at the bedside, so their exposure to families is also limited. This could lead to more positive attitudes towards the involvement of families in care. As noted above, studies have determined that critical care nurses perceive families to be a stressor, which may account for lower scores with direct care providers, and this will be discussed in the next section of the chapter.

Attitudes and age and years of experience.

It was noted in this study that Canadian critical care nurses who were members of CACCN and over 50 years of age had more positive attitudes towards involving families in care than did their younger colleagues. Similarly, Agard and Terkildsen Maindal (2009) studied nurses' (n = 68) perceptions of their interactions with relatives in ICU and found that as the age of the nurse and nurses' experience and seniority in ICU increased, they reported a high level of agreement that they felt capable of gaining the trust of relatives and identified their competence in patient care as very high (p. 266). Nurses' perceptions of personal knowledge and skill and

their expectations about the outcome of their interactions with relatives were positive (Agard & Terkildsen Maindal, 2009, p. 267).

As in the Benzein, Johansson, Arestedt, and Saveman (2008) and Sveinbjarnardottir et al. (2011) studies, this study of Canadian critical care nurses who were members of CACCN found that there is a significant positive relationship between the years nurses had worked in ICU and their attitudes; the differences in this study were noted in the subscales family as a conversational partner, family as a burden, and family as own resource and in the total score. The study by Agard and Terkildsen Maindal (2009), described previously, also found that nurses' experience and nurses' seniority in ICU were positively correlated to their knowledge of the needs of family members, communication with colleagues, and feeling of competence in patient care (p. 266). As experience increased so did knowledge of family needs (Agard & Terkildsen Maindal, 2009). Generally, with experience (and as nurses age), it seems likely that nurses become more skilled in caring for critically ill patients and are better able to divide up their time caring for both patients and families. They may also have an increased understanding of the impact of a critical illness on family members and this may explain their higher scores on the FINC-NA instrument.

The burden subscale and items about families as stressors.

Of particular interest in this study were the results on certain sub-scales of the FINC-NA instrument such as the burden scale and the items about families as stressors. Some of the lowest scores were found in the following items (on a five-point Likert scale): "the presence of family members eases my workload" (2.81); "the presence of family members gives me a feeling of security" (3.19); "the presence of family holds me back in my work" (3.50); "the presence of family makes me feel stress" (3.71); and "the presence of families makes me feel that they are checking up on me" (3.79). Benzein et al. (2008) found that newly graduated RNs and those

who responded that they had no general approach to the care of families at their place of work were more likely to view families as a burden than more experienced nurses or those working in environments with a general approach to family care. In this study, nurses who had less than five years of ICU experience had significantly lower inverted scores on the family as burden subscale than their more experienced colleagues.

The literature provides insight into the specific reasons that families may be stressors for critical care nurses and ways that these stressors may be minimized or managed. For example, using a descriptive approach, Gelinas et al. (2012) described the stressors experienced by nurses ($n = 42$) providing end-of-life palliative care in the intensive care unit. One stressor identified was the availability of space for families at the bedside. In addition, nurses felt it was emotionally stressful to: provide support to families that had not been involved in the planning of care; manage the needs of families on their own; and witness the suffering experienced by patients and their families (Gelinas et al., 2012). Inter-professional collaboration and exchanging information were important ways to develop care and treatment plans and ensure continuity of communication, but when the plan of care or treatment was changed by physicians who rotated through the ICU, difficult conditions were created for the nurses, patients, and family members (Gelinas et al., 2012). Nurses' constant presence at the bedside places them in frequent contact with family members which can make nurses feel uncomfortable about not being allowed to communicate important information to the family (i.e., when the nurse knows the patient is going to die and cannot be honest with family members). Gelinas et al. (2012) found that nurses identified that families have a difficult time understanding information that physicians provide them and expect nurses to explain this further, which adds to the stress of having to bridge the gap between the family and the physician.

Nurses' responses to stressors experienced by nurses caring for families of ICU patients were explored by Stayt (2007). Nurses described less confidence in the emotional aspects of providing family care compared to providing families with information, orientation to the ICU environment, and making sure families were physically comfortable. Nurses felt this was not a valued aspect of care which resulted in various forms of role conflict (Stayt, 2007). Nurses felt that they "were frequently torn between caring for the patient, which they perceived to be their priority, and recognizing their responsibility towards the family" (Stayt, 2007, p. 627). Stayt (2007) encouraged managers to recognize and address potential sources of stress for nurses, to develop interventions to support nurses, and provide a healthy work environment so nurses can continue to provide quality care for families. The findings of the Gelinis et al. (2012) and Stayt (2007) studies may help explain the lower scores found in this study on some items in the FINC-NA.

Direct care providers and attitudes toward families.

Direct care providers were found to have less supportive attitudes toward families in this study when compared to nurses working in other roles (e.g., managers, APNs). Benzein, Johansson, Arestedt, and Saveman (2008) found that RNs working in hospital care had significantly lower scores which corresponded to a less supportive attitude towards families when compared to others within the subgroups (e.g., community and primary care nurses) (p. 88). Astedt-Kurki, Paavilainen, Tammentie et al. (2001a) studied health care providers' perspectives about their interactions with family members of their patients. The study took place in Finland and collected data from a sample of 320 health care providers, some of which were nurses (n = 155) who worked in an acute care hospital. This study found that health care providers in the acute care setting perceived their patients' families to be important, however,

family was seen primarily as information providers about the condition of the patient and the family situation. Interactions between family members and nurses were based upon the “dissemination of information” (p. 371). Interestingly, this study found that hospital staff on pediatric units reported that interacting with family members was very important more frequently than staff working on adult surgical or emergency units.

Peter and Liaschenko (2004) discuss the physical nearness that is inherent in the nurse-patient relationship. Nearness is required when providing care to patients, but this proximity may contribute to problems for nurses, including moral distress and moral ambiguity. Nurses work in a variety of areas in which proximity and length of time of engagement and severity of illness experienced by patients may vary. In critical care settings, nurses may care for one to two patients and their families for the length of their shifts. These authors note that “the quality of relationships with colleagues, the social resources available to both patients and providers, the degree of genuine collaboration with other disciplines, administrative support, and other factors influence the quality and type of relationships between nurses and patients” (Peter & Liaschenko, 2004, p.220). Direct care providers may experience less than optimal working conditions, including staffing issues and mandatory overtime, which can result in an increased workload and a decrease in the amount of energy that nurses have to provide emotional support and engage with patients and their family members (p. 220). These factors may contribute to the development of a less supportive attitude in nurses towards family members.

Advanced practice nurses and attitudes

A significant finding from the regression model was the influence of the role of the advanced practice nurse on scores in the FINC-NA subscale family as own resource.

Viewing families as a resource in nursing care and as their own resource means valuing the presence of families in nursing care, inviting them to take part in the care of their family member, creating a good family-nurse relationship, and considering family members as cooperating/collaborative partners. (Benzein et al., 2008, p. 172)

APNs have in-depth understanding of research and evidence which may indicate an increased understanding of the importance of establishing collaborative relationships with family members, so this is not an unexpected finding.

Critical Care Nurses' Perceptions of FCC

The second research question in this study relates to critical care nurses' perceptions of FCC. A number of the nurses (n = 135) provided comments indicating that they agreed with, supported, or were implementing FCC. Ninety-eight nurses indicated that there were challenges associated with FCC.

Benefits of FCC.

The nurses in this study described many benefits of FCC for patients, family members, and members of the health care team. Benefits to patients identified by the nurses (41 comments) included families providing information to the team for the benefit of the patient, helping nurses to get to know the patient better, ensuring patients receive holistic care, improving patient outcomes, supporting patients, advocating for patients, decreasing patient anxiety, and improving patients' sense of well-being. The benefits of a FCC approach described by the nurses are in keeping with benefits described in the literature. FCC has been found to provide support for patients by, for example, helping patients to feel safe, relaxed, and like they belonged (Olsen et al., 2010) and to have positive physiological effects for patients such as decreased heart rate and blood pressure (Daly et al., 1994). Whittemore (2000) described how families help

nurses know the patient and in the absence of knowledge of the patient, it is possible for patients to be denied compassion and empathy and for nurses to have difficulty fulfilling the role of patient advocate. If family members are supportive, reassuring, calm, and provide comfort to the patient, their presence has been found to have a positive effect on critically ill patients (Livesay et al., 2005). In addition, family visits in the ICU have been found to provide patients with support and a reduction in sensory overload and sensory deprivation (Plowright, 2007; Roland et al., 2001).

The nurses in this study identified in their open-ended comments that FCC also provides benefits to family members (21 comments). Nurses indicated that FCC empowers families, improves family outcomes, builds trust between families and the health care team, provides families with information about their loved one, improves communication, decreases stress for families, allows families to see the work of the health care team, helps families with decision making, and helps families cope with their loved one's critical illness. These types of benefits have been described in the literature. It has been identified, for example, that interventions such as structured family meetings and helping families anticipate what they may see, hear, and experience while visiting the ICU may minimize adverse symptoms in family members and prevent long-term negative consequences such as PTSD (McAdam et al., 2010). Family-centered care and psychological support are associated with less psychological distress in patients and relatives (Kentish-Barnes et al., 2009). Family members have reported increased satisfaction if they knew the patient was receiving quality care and if the patient's caregivers provided family members with support (Heyland et al., 2003). It is also the case that visiting the patient has been shown to decrease stress and anxiety in family members of critically ill patients (Garrouste-Orgeas et al., 2008).

Nurses in this study also provided comments (23) indicating that FCC provides benefits to staff working in ICUs. According to the nurses, families can provide information about what patients were like before their critical illness, help determine the patient's needs, provide knowledge that helps with planning care, decrease mistakes made by the health care team by providing information (i.e., patient medications), help the health care team understand cultural differences, and provide insight into the patients' values and beliefs. These comments are in keeping with benefits described in the literature. Benner et al. (1996) identified that family members help nurses know the patient as a holistic being. Crocker and Scholes (2009) described that "knowing the patient" assists nurses to develop an individualized plan of care for patients. Benner et al. (1996) described how engaging with family members of critically ill patients can result in ICU nurses having increased knowledge about their patients which may improve clinical judgment.

Challenges with FCC.

A number of the nurses (n = 98) provided responses to the open-ended question about perceptions of FCC that indicated there were challenges associated with FCC in ICU settings. The nurses identified that implementing FCC is challenging in the face of difficult families. They also suggested that not all nurses and physicians are comfortable caring for families, there is a lack of resources for FCC, nurses' workload precludes them from providing FCC, and families can be a "bother". There is a growing body of literature exploring the challenges associated with working in critical care settings and the comments from nurses in this study about "difficult" or "challenging families", the lack of perceived support to provide FCC, and the need for a more inter-professional approach to FCC are considered in some of this literature. Two areas of the literature particularly address issues related to challenging or "difficult"

families, conflict in the ICU and moral distress for critical care nurses, and these will be briefly discussed here. This will be followed by a discussion of the lack of resources and supports reported by nurses in this study.

Conflict in the ICU. Azoulay et al. (2009) found that 72% of staff working in ICUs in 24 countries (n = 7358) identified that they had experienced situations of conflict in their practice in a one-week period. One third of conflicts in the ICU were found to occur between staff and patients or their family members, the remainder were within the ICU team (Azoulay et al. 2009). Causes of conflicts between staff and patients/family members were associated with general behaviours and end-of-life care. General behaviours resulted in conflict due to “personal animosity, mistrust, and poor communication within the ICU team” (Azoulay et al., 2009, p. 855). Conflict at end of life was a result of inadequate psychological support for families, no family meetings, and problems in the decision-making process. Edwards, Thronsdon, and Girardin (2012) found that 26.1% of a sample of Canadian critical care nurses (n = 241), also members of CACCN, reported experiencing situations of conflict in the one-week period prior to completion of a survey. The most common types of conflict experienced by nurses were found to be arguments or disagreements between the health care team and family (46.5%) and within the health care team (35.3%) (Edwards, Thronsdon, & Girardin, 2012).

In a small qualitative study on critical care nurses’ roles in situations of conflict (N = 12), Edwards, Thronsdon, and Dyck (2012) found that nurses indicated that conflict exacerbated stress in an environment that was already stressful. It was acknowledged that because nurses worked with the patient and family for an extended period of time (e.g., a full shift or series of shifts), they were dealing with conflict constantly where other team members could speak to the family and then leave. Some nurses reported that one response to conflict with families was

withdrawing from that family in order to protect themselves emotionally; one of the ways to do this was by controlling visitation.

Some of the comments provided by nurses who responded to my survey demonstrated that conflict with patients' family members was an issue in their practice. Given the critical nature of many patients' often unexpected illnesses in ICUs, it is not surprising that conflict may arise between family members and the health care team. The nurses' comments highlight the need for more support in dealing with situations of conflict.

Moral distress in critical care. A number of studies have examined nurses' moral distress in critical care settings and its causes (see, for example, Elpern, Covert & Kleinpell, 2005; Guitierrez, 2005; Hamric & Blackhall, 2007; and Weigand & Funk, 2012). The American Association of Critical-care Nurses [AACN] (2008) defines moral distress as follows: "You know the ethically appropriate action to take, but are unable to act upon it. You act in a manner contrary to your personal and professional values, which undermines your integrity and authenticity" (p.1). Nurses in this study provided comments about families not acting in the best interests of patients (12), and this type of experience could possibly contribute to a sense of moral distress for these nurses. Moral distress is important to understand as it has been found to result in physical and emotional stress resulting in a loss of integrity and job dissatisfaction and contribute to nurses leaving the profession; it may also affect relationships with patients and co-workers and the quality of nursing care (AACN, 2013, p. 1).

Studies have identified a number of causes of nurses' moral distress in critical care settings. Hamric and Blackhall (2009) compared nurses' (n = 106) and physicians' (n = 29) perspectives on the care of dying patients in ICUs to determine how they compare in issues regarding collaboration, moral distress, and ethical climate. They found physicians and nurses

experienced the highest moral distress in situations where they felt pressured to continue unwarranted aggressive treatment. There were interesting differences found between the perceptions of physicians and nurses, with nurses experiencing moral distress more frequently than physicians. In addition, nurses were found to more frequently have considered quitting a clinical position due to the way end-of-life care was managed than physicians (Hamric & Blackhall, 2009, p. 425).

Elpern et al. (2005) studied moral distress of staff nurses (N = 28) in a medical ICU. They found that nurses experienced a moderate level of moral distress; highest levels of distress were found in relation to providing aggressive treatments to patients that were not expected to receive any benefits from that care. Moral distress resulted in negative effects on nurses' job satisfaction and retention, psychological and physical well-being, self-image, and spirituality (Elpern et al., 2005). Wiegand and Funk (2012) distributed open-ended surveys to critical care nurses (N = 49) in order to understand which situations caused nurses to experience moral distress, understand the consequences of moral distress, and see if nurses would change their practice based on their experiences. They found that most of the sample of nurses had experienced moral distress and most of the time this was related to end-of-life care. End-of-life situations that created moral distress for nurses included: "futile medical treatment, organ donation, over and under administration of analgesics, and other end-of-life issues" (Weigand & Funk, 2012, p. 481). The effect of moral distress on the nurses included feelings of "anger, sadness, frustration, psychological exhaustion, helplessness, suffering, distress, disappointment, depression and physical exhaustion" (Weigand & Funk, 2012, p. 483).

Nurses' experiences with moral distress may result in an accumulation of intense feelings of sadness, frustration, and anger. Gutierrez (2005) identified that nurses respond to unresolved

moral conflicts by decreasing their interactions with family members and by not wishing to assume the role of a patient's primary nurses. Primary nursing promotes the development of a deeper relationship between nurses, patients, and their families and helps clarify the needs of and treatment goals for patients and their families. Patients and families do not receive these benefits if nurses are reluctant to assume the role of primary nurses (Gutierrez, 2005). Nurses' moral concerns may be addressed through the inclusion of a social worker on the team, education to "allow for a common language for nurses to discuss moral issues" (Gutierrez, 2005, p. 239), mentorship, assistance to identify moral issues, and development of guidelines for and application of the principles of palliative care.

While the nurses in my study did not specifically comment on experiencing moral distress, some of their responses suggest this could be a concern, particularly in relation to following the wishes of families over patient wishes or perceptions of families not acting in the best interests of the patient. Opportunities to discuss moral concerns and assistance with dealing with moral conflict are needed in the highly charged environment of the ICU.

Perceived lack of resources for FCC. Nurses in this study commented on the perception that there is a lack of resources/supports for FCC (11 comments), including supports for bedside nurses to help them collaborate with families and from other disciplines (e.g., spiritual care, social work, medicine). Nurses identified that some physicians are uncomfortable communicating with families and block them from being present and some physicians fear "malpractice" and do not share information with families. Some of the nurses in this study identified that FCC is challenging because of issues related to end-of-life care and the lack of support in providing this care. The following resources were identified by nurses as lacking: lack of processes, support from spiritual care and social work, family rooms, staff to care for the

family when the bedside nurse is busy providing patient care, a family liaison nurse, education for families, and the availability of a physician/resident to help support families of critically ill patients.

Studies on end-of-life (EOL) care in ICUs have also found that nurses and other health care providers feel that there are inadequate supports available for grieving families and inadequate training for nurses in communication skills related to EOL care (Friedenberg et al., 2012). Nurses in ICUs find that taking care of a dying patient and his or her family is demanding and time-consuming work (Gelinas et al., 2012, p. 34). Beckstrand and Kirchhoff (2005) found that one of the biggest obstacles to care in the ICU is “behaviours of patients’ families that remove nurses from caring for patients” (p.396), including calls from family members other than the designated spokesperson requesting updates on their loved one’s condition. Aslakson et al. (2012) explored nurse-perceived barriers to effective communication regarding prognosis and optimal EOL care for surgical ICU patients in a qualitative study using focus groups with 32 nurses. Nurses in their study reported that they felt they had inadequate skill and training in EOL care and feared conflict.

The research that has been done on conflict, moral distress, and end-of-life care in the ICU highlight some of the factors that cause nurses to experience stress when working with families in the ICU. The findings of previous studies may help explain the reasons nurses view families as a “burden” and “stressor” and their comments regarding a perception of a need for additional support to effectively provide FCC.

FCC Policies and Practices

The third research question in this study was related to policies and practices in place in ICUs to promote FCC. The questions used in this study were similar to questions outlined by

Vandijck et al. (2010) in their study of Belgium ICUs. In the Belgian study, surveys were sent to unit managers of 57 ICUs in that country and the managers completed and returned the questionnaire. The results from my study are based on a sample of 207 ICU nurses who are members of CACCN. This difference does not allow for direct comparisons between the studies, as the unit of measurement in the Belgian study was the specific ICUs in that country and my results were based on nurses' responses to the survey, in the absence of knowledge of which units the nurses worked in throughout Canada. It is not known, for example, if a significant portion of the sample was from a large city such as Toronto, given that a large number of CACCN members are from that chapter, or a small number of units within a given geographic area. This is a limitation of my study.

In this study, the majority of nurses reported that information packages were provided to families on admission (74%) and families had access to a social worker and spiritual care providers (94%). A low percentage of nurses reported that they held family conferences after admission to their unit (27%) or provided families with a bereavement package upon the death of their loved one (46%). Close to half of the nurses reported that their units had open visiting hours and most indicated that their ICUs had locked doors (67%) so that families were required to ask permission to gain access to visit a loved one. The types of restrictions present in units that were reported most frequently included: not during report, not at certain predetermined hours, and only two visitors at a time. Most nurses reported that families were asked to leave during nursing care and few nurses reported that families were allowed to be present at resuscitations or at rounds.

This study found that most families were given information packages on admission to their units. Vandijck et al. (2010) did not ask the question about information packages provided

to family members on admission to their units, however, their study participants indicated that they did provide information by notice board, information sheet, information leaflet, or a visiting card. Implementing ways to meet families and patients need for information such as information brochures to orientate family members to the ICU, its policies, personnel, and equipment have resulted in the following positive outcomes for families: improved understanding of the patients' diagnosis, prognosis, and treatments and increased satisfaction with the information provided (Azoulay et al., 2005).

With regards to bereavement packages, 46% of critical care nurses indicated that their units provided this type of information to family members. A bereavement brochure provided to family during end-of-life care has been found to result in outcomes that decrease clinical symptoms of anxiety, depression, and the risk of post-traumatic stress disorder (Lautrette et al., 2007). These positive outcomes provide us with evidence that the informational needs of family members must be promptly addressed in critical care (Bailey et al., 2010).

In this study nurses indicated that family conferences were not often mandated after admission in their units. In the Belgian study, Vankijck et al. (2010) found that most of the time ICUs had structured family meetings routinely performed on admission of patients to ICU. Family members of critically ill patients identified the need for information and the need for assurance as being most important, which reinforces the need for family meetings and the importance of considering mandating family conferences upon admission of a patient to ICU (Al-Mutair et al., 2013). It has been recommended by a task force established by the American College of Critical Care Medicine that family meetings with the multi-professional team be initiated within 24 to 48 hours after the patients admission to ICU and be repeated as required by

the patients' condition, with feedback from all relevant members of the multi- professional team (Davidson et al., 2007, p. 608).

In this study, 47.3% of nurses indicated their units had open visits and no restrictions, 52.7% of nurses indicated there were restricted visits in their unit. These restrictions to visiting hours in units included: not during report, not at certain predetermined hours, two visitors a time, calling before entering, the bedside nurse determines restrictions, not during procedures, based upon the patient condition, length of visits, only adults are allowed to visit, not during rounds, and no visitors immediately post-operatively. Vandijck et al. (2010) found that all participating ICUs in Belgium had restricted visits. It has been observed that "although restrictions on visiting hours are usually adopted worldwide, descriptive studies, reviews, critical care leaders and best-practice recommendations have recommended open visitations" (Biancofiore et al., 2010, p. 93).

Berwick (2011) makes a rather bold statement recommending that restrictions of visiting hours in the ICU be eliminated. He believes that restricting visits in the ICU are not necessary and may prevent healing and effective communication and jeopardize the safety of patients. Berwick recommends that ICUs implement a two-month trial of entirely open visiting in an ICU and provides the following recommendations: 1. implement a visiting policy in ICU for families, friends, and loved ones that has totally no restrictions; 2. allow patients to request a personal restriction and implement this at the bedside; 3. track what has gone wrong in relation to open visiting as a way to measure negative outcomes of the policy; 4. collect positive information, for example, positive side effects such as innovative ways to include visitors in the care system; and 5. request feedback from visitors by asking them about their experiences with the open visitation policy (Berwick, 2011).

Worldwide organizations' have been found to support open visitation in ICUs (Biancofiore et al., 2010). Twenty-eight ICUs in Italy agreed to participate in a survey to determine the beliefs and attitudes of health care professionals in relation to open intensive care units. The sample consisted of 357 nurses and 102 physicians who had worked in ICU for at least 6 months and physicians who had spent at least 60% of their time working in ICU. Nurses and physicians were found to agree with open visitation. Physicians more often than nurses reported that they felt patients benefited from visits with their family members and that if patients are capable of making decisions they should be in control of who visits them. Nurses strongly disagreed with allowing everyone to visit if the patient agrees, accepting an open visitation policy in their unit, and with the practice of allowing patients to control visitation and adapting the visitation policy to the patients' culture (Biancofiore et al., 2010, p. 97). The analysis of the open-ended question after the survey in their study found that 59% of nurses and 61.1% of physicians felt that patients and their families benefited from an open visitation policy in the intensive care unit but felt the structural and organizational problems in their units would make implementing such a policy challenging (Biancofiore et al., 2010, p. 97).

Gooding, Pierce, and Flaherty (2012) provide us with some suggestions and ideas about visitation in the ICU and share their experience and outcomes working in an ICU that has incorporated patient-and family-centered care (PCFCC). The elements of PCFCC included providing a welcoming environment, respect for patient/family values and expressed needs, patient/family empowerment and collaboration, coordination and integration of care, comfort and support, and access and navigation skills. These core concepts are supported with policies to support patient rights and visitation to include the family in all healthcare settings, including ICUs. Opportunities were provided to allow families to participate in patient care and services

for their individual needs were provided. Feedback from families was collected regularly. Positive outcomes achieved as a result of partnering with family members included good communication and active participation by patient, family members, and health care providers.

Partnering with families in the ICU provides nurses with more opportunities to share information and incorporate families in patient care. In order to monitor outcomes, family participation was encouraged in quality improvement. The concepts of PFCC were applied to the following improvement projects that would encourage the involvement of families in patient care: open visitation, bedside report, manager rounding, family members included in physician rounding, families permitted to call the rapid response team, and families being able to call for an ethics consultation (Gooding et al., 2012).

FCC policies and practices about family presence.

In this study there are interesting findings about policies and processes in relation to family presence during patient care and invasive procedures, resuscitation, and patient care rounds. This study found that most nurses request that families leave during nursing care or procedures in their unit, nurses sometimes allow families to be present during resuscitation, and families were not commonly permitted to attend rounds. These findings appear contrary to trends evident in findings reported in studies in this area.

The findings of this study illustrate that nurses continue to ask families to leave during nursing care or procedures in their unit even though research indicates there are benefits to including families' members in nursing care. Mitchell et al. (2009) found that when family members of critically ill patients partnered with critical care nurses in order to provide basic patient care there were significant improvements in respect and collaboration (Mitchell et al., (2009). Al-Mutair et al. (2013) reviewed the literature to examine family needs and involvement

in the ICU. They found that involving family members in crisis situations in ICU may result in benefits to patients and families.

The results of this study highlight that only a small percentage of the nurses indicate that families are permitted to be present during resuscitation. This is interesting given the growing body of literature related to the benefits of allowing family members to have the option of being present as resuscitation. Benefits include: families know that everything was done for the patient; families' anxiety is reduced; families feel helpful to the patient and staff; information sharing; maintaining relationships between the family and patient; providing families with closure and encouraging grieving (Weaver et al., 2012). Duran et al. (2007) found that family members felt attending resuscitations and invasive procedures would help them understand the patient's condition. Patients also felt the presence of family members during resuscitations and invasive procedures would be comforting. The presence of family meant a great deal to patients during their ICU stay (Olsen et al., 2009, p. 193). Allowing families to be present during resuscitation and visits after death, providing clear communication, and spending time with families when sharing bad news are important ways to decrease the risk of a complicated response to grief (Weaver, Bradley, & Brasel, 2012).

In a survey completed by 202 clinicians, 72 family members, and 62 patients, Duran et al. (2007) found that most health care workers support family presence during resuscitation and invasive procedures, but nurses had more positive attitudes toward the practice than physicians and supported the development of policies to support family presence. All healthcare providers believed that a policy on the presence of family was required. Duran et al. (2007) found that family members felt they had the right to attend resuscitations, wanted the option of being present, and felt it would help them understand the patient's condition. Potential barriers

identified by health care providers included patient and family safety, concern for the emotional health of family members, and performance anxiety of healthcare providers. This study contributes to the literature by reinforcing the need for hospital policies to reinforce the option of allowing families to be present in the care of their loved ones (Duran et al., 2007).

Howlett et al. (2010) reviewed the literature about health care provider attitudes regarding family presence (FP) during resuscitation and found that: generally, health care providers have supportive attitudes towards FP and nurses have a more positive attitude towards FP than physicians. Differences within the discipline of nursing were found regarding attitudes towards FP. More favourable attitudes were associated with higher education, professional certification, belonging to a professional organization, and working in emergency departments. Interestingly, health care providers stated concerns about not having a staff person assigned to provide support for families during crisis situations such as resuscitations (Howlett et al., 2010).

Ganz and Yoffe (2012) studied critical care nurses' perspectives of FCC and attitudes towards family presence with resuscitation. Most nurses agreed that family members' presence during resuscitations may interfere with the resuscitations or result in staff having difficulty concentrating. Nurses did feel that family presence would help families understand that everything was done for their loved one. It was found that older nurses had more positive attitudes towards family presence during resuscitation than younger nurses. The authors of this study recommended more education, research, and policies to improve attitudes toward FCC and presence during resuscitation (Ganz & Yoffe , 2012).

In my study, nurses indicated that they did not always include family members in rounds in ICU. Family presence at rounds has been found to promote discussions between the health care team, the patient, and their family, is an intervention that has been identified as best

practice, and guidelines to support this practice have been developed (Cypress, 2010). Khalaila (2013) found that although it is understood that allowing families to be present during physician rounds improves family members' satisfaction with care and decision-making, meeting these needs of families is not routine practice in ICUs.

In this study, 126 nurses indicated that their units had less than four out of eight identified FCC policies and practices in place. A number of nurses identified challenges to implementing FCC. One of the reasons nurses provided in their comments to the open-ended question on the survey included a lack of an inter-professional approach. Nurses identified that there was a lack of support from physicians, social workers, and spiritual care providers. They also indicated that it would be helpful to have a nurse dedicated for the family when the bedside nurse was caring for a busy patient. There is a need for education for administrators and health care team members regarding the benefits of FCC to facilitate the provision of the support that nurses need in order to implement FCC.

Limitations of the Study

There are clear limitations to this study. These include selection bias, the representativeness of the sample, issues with web-based surveys, and concerns with the use of a survey instrument like the FINC-NA. Each of these limitations will be briefly discussed.

Selection bias and representativeness of the sample.

Bethlehem (2010) discussed selection bias in relation to web-based surveys and provides a description of under-coverage and self-selection as methodological problems of these surveys. Selection bias is "the most common and serious type of systematic error" in research (El-Masri, 2013, p. 10). It happens when study participants volunteer or are selected in such a manner that their characteristics may not represent those of the population being studied (El-Masri, 2013).

Selection bias in my study resulted from the distribution of the web-based survey via FluidSurveys to nurses who are members of CACCN. Given that CNA (2011) has identified that there were approximately 19,096 critical care nurses in Canada in 2009, CACCN's membership (i.e., approximately 1100 members) represents only a small portion of the total number of critical care nurses in Canada. There is some evidence that members of professional nursing organizations are different from nurses who do not belong to such organizations. In 2008, Cybulski published the results of a membership survey for CACCN. At that time, the breakdown in terms of education of members was: 38.2 % diploma-prepared; 45.2 % degree-prepared; 9.7% master's-prepared; and 1.6 % doctorally-prepared (Cybulski, 2008). Canadian workforce data from 2008 (N = 18,440) indicated that 34.35% of critical care nurses were educated at the baccalaureate level and 1.48% at the master's/doctoral level (CNA, 2010). In addition, Cybulski (2008) found that the majority of CACCN members had certification in critical care and also belonged to other professional nursing organizations. A second issue with selection bias is that we do not know how CACCN members who did not respond to the survey differ from those who did respond. A future study that includes a larger representation of the population of critical care nurses in Canada and using a random sample is needed.

Limitations of surveys and improving response rates with web-based surveys.

An interesting finding of this study related to the comments of some nurses that they found it difficult to respond to the items on the FINC-NA instrument in a general sense and that their responses to the items could vary from family to family. The analysis of the open-ended comments did provide more detailed information about nurses' attitudes. This leads us to consider the issues with surveys and the value of incorporating open-ended questions to allow for additional comments. Surveys that have been used in health research to measure attitudes of

participants are prone to “self-report and social–desirability biases” (Colbert et al., 2013, p. 424). Respondents have been found to overestimate their knowledge in surveys or answer in a manner that would make them be perceived in a positive way in order to decrease embarrassment. It is recommended that surveys be created by experts and subject-matter experts are involved in the development of surveys (Colbert et al., 2013). The FINC-NA survey was developed, tested and re-tested by an expert team of nurse scientists including Benzein et al (2008) who were also experts in the area of family nursing which may have limited these issues, but it is evident that there were limitations to the FINC-NA instrument. The presence of open-ended questions added some value to this survey.

The Cronbach’s alpha on the subscale family as own resource on the FINC-NA instrument was low (0.657). An acceptable Cronbach’s alpha score is greater than or equal to 0.70. When refining the FINC-NA, the subscale family as own resource was found to have a Cronbach’s alpha score of .80 and during psychometric testing was found to have “good reliability both in stability and in internal consistency” (Saveman et al., 2011, p. 324). There are only 4 items in the subscale family as own resource. Saveman et al. (2011) found that the subscales family as burden and family as own resource demonstrated the lowest internal consistency. Interestingly, family as burden subscale in this study was found to have a Cronbach’s alpha of 0.833, which is fairly high.

It was noted that there is a mistrust of internet surveys related to an increased number of cybercrimes in recent years. This may have resulted in a decreased number of responses to the survey. Increased credibility was given to the survey, however, by its association with the Canadian Association of Critical Care Nurses (CACCN), a national professional nursing organization (Dillman et al., 2009). The total response rate for this survey was 20% of

membership. This is similar to the study of CACCN members carried out by Cybulski (2008) who had a 23% response rate.

Additional strategies to increase response rates could have been used. Sending the survey to all members of the CACCN by traditional mail and email may have increased the response rate. Surveys sent to CACCN members by email and traditional mail could be paired and coded in order to sort out if someone responded twice. Sending out a reminder messages by both traditional mail and email, personalizing the email invitations by including the name of the CACCN member, and offering a stipend for participating in the survey may also have increased the response rate (Ekman, Dickman, & Litton, 2007). Given privacy and cost issues this was not feasible for this study.

Implications for Practice, Education, and Research

Practice.

Identifying and addressing stressors. Although this study found that Canadian critical care nurses and members of CACCN generally have a supportive attitude towards family, the results indicate there are areas in which nurses' attitudes could improve. It was noted, for example, that some of the lowest scores on the items on the FINC-NA instrument related to the items addressing family as stressor or burden. As noted previously, a supportive attitude is required for nurses to invite and engage with families in nursing care; if nurses have a supportive attitude they will be more likely to collaborate with families to provide nursing care (Benzein et al, 2008). Families are important in nursing care for many reasons and establishing collaborative relationships with families can lead to desirable outcomes. Families are often knowledgeable and can provide information to the health care team about their loved ones (Astedt-Kurki et al., 2001a; Astedt-Kurki et al., 2001b; Benner et al., 1996). Positive outcomes may result for

patients when nurses know their patients (Radwin, 1996), including the development of an individualized plan of care for patients (Crocker & Scholes, 2009) or improvement in nurses' clinical judgment (Tanner, 2006). Family members also act as surrogate decision-makers for vulnerable and compromised patients who are not capable of making decisions in the ICU. In order to make good decisions on behalf of patients in ICU families need to: share the role of decision making with the physician, communicate with health care providers, and receive adequate information about patients (Heyland et al., 2003).

The findings of this study indicate that there is a need for better policies related to FCC in ICUs. Support for FCC is required from the multi-disciplinary health care team. Nurses' comments in this study suggested that they needed more support in providing care to families from physicians, social workers, and spiritual care providers while they provided care for unstable patients. The American College of Critical Care Medicine's clinical practice guidelines for supporting families address issues related to stress associated with interactions with families in ICU (Davidson et al., 2007). Poor communication with physicians in particular has been found to be very stressful to staff. Staff are encouraged to minimize stress by keeping clear lines of communication with families open in the following ways: identify a family spokesperson; educate the family on how the ICU operates, for example, visiting hours and when rounds occur; include all members of the health care team and support staff in discussions with the family; plan routine family conferences; ensure staff members have time to debrief about their feelings regarding outcomes of patient care (Davidson et al., 2007, p. 609).

It is important for nurses to recognize the stressors that they experience and be aware of action they can take in order to minimize the effects of stress. Stress is an adverse reaction the individual has to excessive pressure or demands that are placed on them (Royal College of

Nursing, 2005). Stress impacts nurses and it is important to understand that: stress can cause psychological and mental harm that affects patient care in a negative way and stress may cause tremendous distress to nurses, affecting nurses' health and attendance at work (Royal College of Nursing, 2005). Signs and symptoms of stress manifest in: physical symptoms, thoughts, behaviours, and feelings. It is important that nurses are aware that workplace stress may affect staff attitude and behaviours, increase absence related to sickness, affect relationships at work and work performance. It is important for nurses to take action and inform their employers if they are experiencing stress in the workplace. Employers may be able to do a risk assessment in order to develop practical ways to reduce stress, ensure that staff support systems are made available, or introduce nurses to their stress policy which provides guidelines for stress management in the work place and provide stress management training (Royal College of Nursing, 2005). As noted previously, administrators and managers have a role to play in creating policies that support FCC and in providing nurses with the resources needed to work effectively with families.

Bazuin and Cardon (2011) provide interesting suggestions on ways to create healing ICU environments that may decrease the physical and psychological impact of the loud and often chaotic ICU environment. Creating a healing environment is important to meet the needs of staff, patients, and families in the ICU. The design of ICUs should focus on healing the body, mind, and senses. Policies were recommended in order to create a healing and less stressful ICU environment and included open visitation and use of technology in the ICU, such as Skype or smart phones, that may allow nurses to connect with families and physicians. Music therapy has also been recommended in stress policies as a way to decrease stress (Bazuin & Cardon, 2011, p. 262). Ways to reduce stress of staff members who work in ICU and enhance staff performance

included: larger patient care working areas; charting areas close to patient rooms; training for staff that focuses on policies that encourage the treatment of employees with dignity and respect in order to promote self-care; an integrative healing arts training program for nurses; alternative therapies that provide helpful ways to provide calming and healing for patients; development of policies that promote meeting the needs of patients; and pain management approaches in ICU that include massage and acupuncture for patients (Bazuin & Cardon, 2011, p. 262).

Environmental changes that may minimize stress in the ICU include good lighting that can be adjusted by nurses, the presence of window shades and coverings, adjustable workstations, access to supplies and equipment in multiple places throughout the unit and within patient rooms, and ICUs designed with patios, atriums, and courtyards (Bazuin & Cardon, 2011, p. 266).

Improving family-centered care. The findings of this study highlight some of the challenges associated with implementing FCC. Providing a general approach to families requires a shift to focus on the forming collaborative relationships with families who must be perceived as experts of the illness of the family member (Benzein et al., 2008, p. 177). The pediatric literature has clearly identified the fact that family-centered care in pediatrics is more advanced than adult care. Research done in pediatrics provided ways to bridge the divide between families and direct care providers on the issue of FCC. MacKean, Thurston, and Scott (2005) have identified that coordination within and between systems, more resources (i.e., staff and time), and services that meet the needs of family members are necessary to promote FCC. A significant priority for change was in the coordination of services both within the health care and related systems so it is easier to navigate, as many direct care providers felt the system was not friendly to families (MacKean et al., 2005).

Digioia, Fann, Lou, and Greenhouse (2013) provided four ways to change policy and implement patient- and family-centered care. They describe a method of implementation, the Patient- and Family-Centered Care Methodology and Practice (PFCC MP), which has been developed to meet the needs of all the stakeholders including patient, families, providers, payers, and governments in regards to improving patients' experiences, safety, and clinical outcomes and decreasing cost and waste. The methodology is a new operating system which has three keys to success: "1. viewing all care as an experience through the eyes of patients and families; 2. engaging patients, families, and caregivers in co-designing ideal care delivery platforms; and 3. implementing simple solutions in a complex system" (Digioia et al., 2013, p. 138). Leaders in health care spend a considerable amount of time interpreting data from patient satisfaction surveys and measure their results in comparison with others. Patient satisfaction data is representative of what patients and their families can recall after the fact. Although it is important to take action that is effective based on the data received in patient satisfaction surveys it is more important to understand the experience of the patient and family, "which is best understood in real time to identify root causes and to eliminate the time lag of surveys" (Digioia et al., 2013, p. 138).

The PFCC M/P consists of the following six steps: 1. Selecting a care experience to improve and defining beginning and end points this experience will focus on; 2. Establishing a council to guide PFCC; 3. Evaluating the current state by shadowing, care flow mapping, tools in the PFCC; 4. Establishment of a PFCC working group; 5. Creating a vision that is shared by writing an ideal care story from the perspectives of the patients and their families; 6. Establishing a PFCC Project Improvement Teams to address the gaps between the current state care experiences and the ideal (Digioia et al., 2013, p. 138). This methodology draws attention to

resources around the patient and family instead of fitting patients and families around the health care provider and the system. Teams of caregivers can implement projects in order to improve the care experienced. The experiences of both the caregiver and the patient and families are used to improve the care experiences. The authors do not mention if this program PFCC M/P has been evaluated, but they do claim the it “provides the mechanism to develop, implement, test and provide operationally accountable care” (Digioia et al., 2013, p. 144).

In relation to the research question about policies and processes in place that support FCC, this study finds that there is a lack of implementation of policies promoting FCC. The results of this study suggest that there is a need for policies in relation to family presence during patient care and invasive procedures, resuscitations, and attendance at rounds and/or support to follow those policies. In terms of policy, Digioia et al. (2013) recommend that education to governing boards about PFCC/MP, in the Canadian health care context, could translate to education for hospital administrators about ways to implement FCC.

Education.

The findings in the Sveinbjarnardottir et al. (2011) study indicate that there is a need for more education in undergraduate nursing programs related to the care of families. Given that more junior nurses had less positive attitudes towards families than their more senior colleagues, education within ICU educational programs could also be implemented. The education program implemented in the psychiatric nursing study carried out by Sveinbjarnardottir et al. (2011) proved successful in improving nurses’ attitudes towards families, with a result that “nurses felt the families to be less of a burden after the family nursing education and training had taken place than before” (Sveinbjarnardottir et al., 2011, p. 900). These finding suggest that an education program like the one used in the Icelandic study may help nurses working in Canadian adult

intensive care units feel families are less of a burden. The findings in relation to policies and practices in place in the nurses' units also highlight the need for education in a variety of areas. Tailoring education sessions to assist critical care nurses to meet individual family members' needs upon admission of their family member to the ICU have been found to result in the following positive outcomes for family members: a significant decrease in family members' anxiety and an increase in family members' satisfaction (Chien et al., 2006). The findings of this study related to family presence, specifically family members who are being asked to leave during patient care, invasive procedures, resuscitations, and rounds, indicated that tailored education sessions that would assist critical care nurses to meet patients' and family members' needs would be beneficial as well.

The comments of the nurses regarding the challenges of FCC suggest that families, too, would benefit from education. The American College of Critical Care Medicine Task Force 2004-2005 recommended that families of ICU patients receive education about "visiting hours, when rounds occur, and when and how the physician can be reached" (Davidson et al., 2007, p.608). It may be helpful to identify a family spokesperson as the family member who will be responsible for decision making on behalf of the patient shortly after the patient is admitted to the ICU (Davidson et al., 2007). Finally, the concerns expressed by the nurses in this study related to their need for support from inter-professional colleagues to effectively implement FCC highlight the need for education for all health care team members regarding the benefits of FCC and how best to implement it.

Research.

While research has been carried out in the area of critical care nurses' attitudes in relation to families and FCC in the ICU, additional work is needed. The open-ended responses regarding

FCC obtained through this survey were interesting, but it would have been useful to interview the nurses in order to better understand their comments. A qualitative study on critical care nurses' perceptions of FCC, using interviews for data collection, is needed to better understand the opportunities and challenges in this area. It is also recommended that future research examine the perceptions of other members of the health care team (e.g., physicians, spiritual care providers, social workers) and administrators within hospitals with regards to FCC and meeting the needs of the families of patients in ICUs. Unmet needs of family members impact negatively on family satisfaction with care and decision-making. Regardless of the positive outcomes found, meeting these needs of families is not routine practice in ICU (Khalaila, 2013) and research could prove instrumental in improving family-centered care. In addition, a national study such as the one carried out in Belgium (Vandijck et al., 2010) should be considered in Canada.

Another area of future research would involve using the FINC-NA instrument with a larger sample of critical care nurses. For example, the attitudes of a broader sample of ICU nurses in Canada, including those that may not belong to a professional organization such as CACCN, would be interesting to examine. We also need to have a better understanding, using research, about the needs of new ICU nurses in relation to providing quality FCC. This study found that experienced nurses have a more supportive attitude towards families. Understanding the needs of new ICU nurses in relation to FCC may provide knowledge on the ways in which these new nurses could be supported in order to provide quality FCC in ICUs. Future research could include a method to evaluate FCC interventions that would help determine if these interventions are being implemented successfully. Regular evaluation of FCC outcomes may be a way to promote the implementation of FCC.

Ajzen's Theory of Planned Behavior

Ajzen's theory was used as a guiding framework for this study and provided some justification for exploring nurses' attitudes towards involving families in nursing care. It was noted in the first chapter of this thesis that Ajzen's Theory of Planned Behavior identifies that if an individual has a positive attitude about a behavior, there is an increased chance he/she will perform that behavior. The theory proposes that human behavior is intentional and that three variables predict an individual's intention to perform a behavior. These variables include: the individual's attitude towards the behavior (i.e., positive or negative), subjective norms, and how much control the individual perceives he/she has over performing the behavior (Zhou et al., 2010, p. E401). The results of my study indicate that nurses in this sample generally have supportive attitudes about the importance of families in nursing care, with concerns raised in relation to the attitudes of direct care providers and younger, less experienced nurses. These findings can be linked to Ajzen's Theory of Planned Behavior and the argument can be made that if nurses have a positive attitude towards the importance of families in nursing care they will be more likely to involve families in care (Ajzen, 1991).

My study finds that nurses' distance from the bedside, increasing age (greater than or equal to 50 years), and experience as nurses are related to more positive attitudes towards families. If Ajzen's theory holds true, it can be argued that these nurses are more likely to engage with and involve families in nursing care. Nurses who are direct care providers had significantly less supportive attitudes towards families than nurses in other roles (e.g., advanced practice nurses, educators, managers) and, therefore, may be less likely to engage with and involve families in nursing care. Education has been found by Sveinbjarnardottir et al. (2011) to improve nurses' attitudes towards families. Ajzen (1991) claimed that "the extent that a person

has the required opportunities and resources, and intends to perform the behavior, he or she should succeed in doing so” (p.182). An education program may be considered a resource and opportunity for nurses, specifically in relation to the role of the direct care provider (p.182).

Ajzen (1991) described perceived behavioral control as “perception of the ease or difficulty of performing the behavior of interest” (p.183). Some nurses indicated in the open-ended comments post FINC-NA and the open-ended question about perceptions that there was a lack of support to implement FCC. Providing nurses with support such as an interdisciplinary approach to FCC, support from administration by implementation of policies, and education programs may improve their perceived behavioral control towards involving families in nursing care (Ajzen, 1991).

Subjective norm “refers to the perceived social pressure to perform or not to perform the behavior” (Ajzen, 1991, p.188). This concept may be applied to this study by making the assumption that creating a supportive environment for nurses to implement FCC and acceptance of this philosophy throughout the ICU by nurses, members of the health care team, administration, and family members of critically ill patients may result in a feeling of social pressure for nurses to perform the behavior of involving families in nursing care (Ajzen, 1991).

According to Ajzen’s theory, if a nurse has a supportive attitude this will have a significant impact on his/her intentions to involve families in nursing care. Considering that the direct care providers in this study had significantly less supportive attitudes towards families than advanced practice nurses, educators, and managers and that direct care providers have the most contact with families, they could benefit by receiving support from administration and the inter-professional team and education to improve their attitudes towards families (Ajzen, 1991). Considering these results, Ajzen’s theory could inform an intervention study that included

examining critical care nurses attitudes towards families before and after an education program similar to the program used in the psychiatric nursing study carried out by Sveinbjarnardottir et al. (2011). Research is also needed to assess the links between nurses' attitudes, as measured using the FINC-NA instrument, and their actual behaviors in relation to involving families in the care of their loved ones in ICUs.

Conclusion

In this study, critical care nurses' attitudes about the importance of families in nursing care in adult ICUs were examined and perceptions of FCC in adult critical care were explored. In addition, nurses were asked about the policies and practices in place in their units to promote FCC. Analysis of the data collected from the FINC-NA instrument determined that in general, nurses in this study had positive attitudes towards the importance of families in nursing care, with more positive attitudes found in more experienced and older nurses. The responses to the open-ended question about critical care nurses' perceptions of FCC in adult ICUs provided some understanding as to why policies and practices that promote FCC in adult ICU may not be consistently implemented. These reasons include the challenges experienced by nurses caring for both family members and patients, especially when families were stressed and the acuity level of the patient was very high. Nurses identified that providing support for nurses to care for patients and family members and encouraging an inter-professional approach may promote the implementation of FCC in adult critical care units. Results of the analysis of the responses to the questions related to policies and practices that promote FCC in adult ICUs illustrate a positive relationship between the number of FCC policies and practices in place in nurses' units and their perceptions of their units' ability to provide FCC. The limitations of this study include potential selection bias, given that a sample of nurses who were members of the CACCN, a professional

organization, was surveyed. The results of this study have implications for practice, education, and research.

The practice of FCC is encouraged by the World Health Organization. As Digioia et al. (2013) identified, FCC “matters” for the following reasons: “it is the right thing to do...; families are a vital part of the care experience...; it improves value...; it improves clinical outcomes and decreases waste and costs...; it provides for shared decision making” (p. 140). The results of this study indicate that there is work to be done to promote FCC in adult ICUs, but they also point to the potential leadership in implementing FCC to be found in experienced critical care nurses in Canada.

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Appendix A: Research Ethics Board Approval



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APPROVAL CERTIFICATE

October 3, 2012

TO: **Sandy Alguire** (Advisor M. Edwards)
Principal Investigator [REDACTED]

FROM: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2012:081**
"Nurses' Attitudes about the Importance of Families in Nursing Care: A Survey of Canadian Critical Care Nurses Working in Adult ICUs"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- If you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix B: Request Access to CACCN Membership for Survey

From: Sandy Alguire
Sent: 05 October 2012 16:02
To: CACCN
Cc: 'Marie Edwards'
Subject: Request for Access to CACCN Membership: MN Thesis Survey

Dear [REDACTED] and Board Members of CACCN,
Attached please find a request for assistance with the research study I am carrying out as part of my Master of Nursing Program at the University of Manitoba. Please let me know if you have any questions about this.

Sincerely,
Sandy Alguire RN BN
Graduate Student, Faculty of Nursing
University of Manitoba

From: CACCN
Sent: 17 October 2012 14:54
To: 'Sandy Alguire'
Cc: [REDACTED]
Subject: RE: Request for Access to CACCN Membership: MN Thesis Survey

Dear Sandy

I am pleased to advise the Board of Directors of the CACCN has approved the distribution of your survey Nurses' Attitudes about the Importance of Families in Nursing Care: A Survey of Canadian Critical Care Nurses Working in Adult ICUs.

When you are ready to proceed with the survey, please provide the following information:

1. Payment for the survey (this does not have to be paid prior to the survey distribution)
2. Date the survey will open
3. Date the survey will close
4. Three notifications for our members (word documents):
 - a. First notification introducing the survey with the link and contact information
 - b. Second notification of the survey with the link and contact information
 - c. Third/final notification of the survey with the link and contact information

Marie will be a good source for the information required, as she has completed a number of surveys through CACCN.

Please let me know if you have any additional questions or require any additional information.

Thank you and we look forward to distributing your survey to the members of CACCN.

Sincerely,

[REDACTED]
Chief Operating Officer
Canadian Association of Critical Care Nurses
Website: www.caccn.ca

Appendix C: CACCN Email Notification of Survey

Survey Request

October 31, 2012

YOUR chance to Speak with Conviction!

Dear CACCN Member

I am writing to you as a member of CACCN and a student in the Master of Nursing Program at the University of Manitoba. My thesis project for my program is entitled *Nurses' Attitudes about the Importance of Families in Nursing Care: A Survey of Canadian Critical Care Nurses Working in Adult ICUs*.

The purpose of my study is to identify Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs and perceptions of family-centered care in adult critical care. The knowledge gained from this study may serve as a beginning point to help us understand possible barriers and facilitators to implementing family-centered care in adult ICUs. **This study has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba.**

The following is a link to the survey found on the FluidSurveys site, a Canadian company:

<http://fluidsurveys.com/surveys/...>

If you work in an adult ICU and choose to participate in this study, you will be asked to complete some demographic questions (e.g., age, sex, years of experience, type of hospital) and the *Families' Importance in Nursing Care – Nurses' Attitudes* questionnaire, developed by Dr. E. Benzein. There is also one open-ended question regarding your perceptions of family-centered care in adult ICUs. It is anticipated that this survey will take you approximately 20 minutes to complete.

Participation in this study is voluntary. Your identity as a study participant will not be known to the researcher as e-mail addresses will not be collected. The privacy policy of FluidSurveys ensures data collected will not be shared. Only I, my thesis committee, and a statistician and research associate or assistant from the Manitoba Centre for Nursing and Health Research at the University of Manitoba will have access to the data. Data will be stored on a password-protected computer and hard copies of data will be stored in locked drawers (in my home or in my thesis committee members' offices) and will be accessible only to me or members of my thesis committee. All data will be destroyed 5 years after the study results are published. Findings will be presented in aggregate form. Excerpts from responses to the open-ended question may also be used in presentations or publications, but any identifying information will be removed first. A summary of the findings of the study will be posted on the CACCN website. The plan is to submit a manuscript of the study results to Dynamics for possible publication and to present study findings at relevant conferences.

If you have any **questions** about this study, please feel free to contact me at:
You may also contact my supervisor, Dr. Marie Edwards

Sincerely,
Sandy Alguire RN BN
Graduate Student, Faculty of Nursing
University of Manitoba

Canadian Association of Critical Care Nurses
www.caccn.ca

October 31, 2012

Appendix D: Email Notification of Survey

Dear CACCN Member

I am writing to you as a member of CACCN and a student in the Master of Nursing Program at the University of Manitoba. My thesis project for my program is entitled Nurses' Attitudes about the Importance of Families in Nursing Care: A Survey of Canadian Critical Care Nurses Working in Adult ICUs.

The purpose of my study is to identify Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs and perceptions of family-centered care in adult critical care. The knowledge gained from this study may serve as a beginning point to help us understand possible barriers and facilitators to implementing family-centered care in adult ICUs. This study has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba.

The following is a link to the survey found on the FluidSurveys site, a Canadian company:

<http://fluidsurveys.com/surveys/...>

If you work in an adult ICU and choose to participate in this study, you will be asked to complete some demographic questions (e.g., age, sex, years of experience, type of hospital) and the Families' Importance in Nursing Care – Nurses' Attitudes questionnaire, developed by Dr. E. Benzein. There is also one open-ended question regarding your perceptions of family-centered care in adult ICUs. It is anticipated that this survey will take you approximately 20 minutes to complete.

Participation in this study is voluntary. Your identity as a study participant will not be known to the researcher as e-mail addresses will not be collected. The privacy policy of FluidSurveys ensures data collected will not be shared. Only I, my thesis committee, and a statistician and research associate or assistant from the Manitoba Centre for Nursing and Health Research at the University of Manitoba will have access to the data. Data will be stored on a password-protected computer and hard copies of data will be stored in locked drawers (in my home or in my thesis committee members' offices) and will be accessible only to me or members of my thesis committee. All data will be destroyed 5 years after the study results are published. Findings will be presented in aggregate form. Excerpts from responses to the open-ended question may also be used in presentations or publications, but any identifying information will be removed first. A summary of the findings of the study will be posted on the CACCN website. The plan is to submit a manuscript of the study results to Dynamics for possible publication and to present study findings at relevant conferences.

If you have any questions about the survey, please contact:

Sandy Alguire

Marie Edwards, Thesis supervisor

Sincerely,

Sandy Alguire RN BN
Graduate Student, Faculty of Nursing
University of Manitoba

Appendix E: Email Notification of Survey

Email Reminder Notice #1

Dear CACCN Member

I am a student in the Master of Nursing Program at the University of Manitoba. Two weeks ago I contacted you to invite you to participate in a web-based survey on the topic of Nurses' Attitudes about the Importance of Families in Nursing Care: A Survey of Canadian Critical Care Nurses Working in Adult ICUs. If you have already completed the survey, thank you. If you have not yet participated in the survey, you still have the opportunity to respond.

The purpose of my study is to identify Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs and explore nurses' perceptions of FCC in adult critical care. This research has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba. Below I have inserted a link to the survey found on the FluidSurveys site, a Canadian company. If you work in an adult ICU and decide to participate, you will be asked to respond to some demographic questions (e.g., age, sex, years of experience, type of hospital) and the Families' Importance in Nursing Care – Nurses' Attitudes questionnaire, developed by Dr. E. Benzein. There is also one open-ended question regarding your perceptions of family-centered care in adult ICUs.

This survey will take approximately 20 minutes to complete. Your email address is not tracked and your participation is anonymous and voluntary. I will not receive any identifying information about you. Only I, my thesis committee, and a statistician and research associate or assistant from the Manitoba Centre for Nursing and Health Research will have access to the data and data will be stored on a password-protected computer or in a locked drawer. A summary of the study results will be posted on the CACCN website. The plan is to submit a manuscript of the study results to Dynamics for possible publication and to present study findings at relevant conferences.

To complete the survey now, please follow the link to the survey found on the FluidSurveys site, a Canadian company:

<http://fluidsurveys.com/...>

If you have any questions about the survey, please contact:

Sandy Alguire

Marie Edwards, Thesis supervisor

Sincerely,

Sandy Alguire RN BN
Graduate Student, Faculty of Nursing
University of Manitoba

Appendix F: Email Reminder Notice #2 of Survey

E-mail Reminder Message #2

Dear CACCN Member,

I am a student in the Master of Nursing Program at the University of Manitoba. I initially contacted you 3 weeks ago to invite you to participate in a web-based survey on the topic of Nurses' Attitudes about the Importance of Families in Nursing Care: A Survey of Canadian Critical Care Nurses Working in Adult ICUs. If you have already completed the survey, thank you.

If you have not yet participated in the survey, you still have one last opportunity to respond. The survey will close on Friday November 23, 2012.

The purpose of my study is to identify Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs and explore nurses' perceptions of FCC in adult critical care. This research has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba. Below I have inserted a link to a survey found on the FluidSurveys site, a Canadian company. If you work in an adult ICU and decide to participate, you will be asked to respond to some demographic questions (e.g., age, sex, years of experience, type of hospital) and the Families' Importance in Nursing Care – Nurses' Attitudes questionnaire, developed by Dr. E. Benzein. There is also one open-ended question regarding your perceptions of family-centered care in adult ICUs. It is anticipated that this survey will take you approximately 20 minutes to complete. Your email address is not tracked and your participation is anonymous and voluntary. I will not receive any identifying information about you. Only I, my thesis committee, and a statistician and research associate or assistant from the Manitoba Centre for Nursing and Health Research at the University of Manitoba will have access to the data and data will be stored on a password-protected computer or in locked drawers.

A summary of the study results will be posted on the CACCN website. The plan is to submit a manuscript of the study results to Dynamics for possible publication and to present study findings at relevant conferences.

To complete the survey now, please visit the following web-site address:

<http://fluidsurveys.com/...>

If you have any questions about the survey, please contact:

Sandy Alguire

Marie Edwards

Thank you in advance for your participation.

Sincerely,

Sandy Alguire RN BN

Graduate Student, Faculty of Nursing, University of Manitoba

Appendix G: Email Reminder Notice #3 of Survey

Survey

Nurses' Attitudes about the Importance of Families in Nursing Care:

A Survey of Canadian Critical Care Nurses Working in Adult ICUs

Dear CACCN Member:

I am a student in the Master of Nursing Program at the University of Manitoba. I initially contacted you 4 weeks ago to invite you to participate in a web-based survey on the topic of Nurses' Attitudes about the Importance of Families in Nursing Care: A Survey of Canadian Critical Care Nurses Working in Adult ICUs.

If you have already completed the survey, thank you.

If you have not yet participated in the survey, you still have one last opportunity to respond. The survey will close on Friday November 23, 2012.

The purpose of my study is to identify Canadian critical care nurses' attitudes about the importance of families in nursing care in adult ICUs and explore nurses' perceptions of FCC in adult critical care.

This research has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba.

If you work in an adult ICU and decide to participate, you will be asked to respond to some demographic questions (e.g., age, sex, years of experience, type of hospital) and the Families' Importance in Nursing Care – Nurses' Attitudes questionnaire, developed by Dr. E. Benzein. There is also one open-ended question regarding your perceptions of family-centered care in adult ICUs. It is anticipated that this survey will take you approximately 20 minutes to complete. Your email address is not tracked and your participation is anonymous and voluntary. I will not receive any identifying information about you. Only I, my thesis committee, and a statistician and research associate or assistant from the Manitoba Centre for Nursing and Health Research at the University of Manitoba will have access to the data and data will be stored on a password-protected computer or in locked drawers.

A summary of the study results will be posted on the CACCN website. The plan is to submit a manuscript of the study results to Dynamics for possible publication and to present study findings at relevant conferences.

To complete the survey now, please visit the following web-site address for Fluid Surveys, a Canadian Company:

<http://fluidsurveys.com/...>

If you have any questions about the survey, please contact:

Sandy Alguire

Marie Edwards, Thesis supervisor

Thank you in advance for your participation.

Sincerely,

Sandy Alguire RN BN
Graduate Student
Faculty of Nursing
University of Manitoba

Canadian Association of Critical Care Nurses
www.caccn.ca

November 19, 2012

Appendix H: Survey Demographic Questions

Faculty of Nursing

Demographic Questions

Age Gender

- Female
- Male

How many years have you been working as a Registered Nurse?

Is there a general approach to the care of families at your place of work?

Yes

No

Has a member of your family ever been seriously ill and in need of professional care?

Yes

No

How many years have you been working in ICU?

What is your current role in the unit?

Clinical Nurse Specialist

Nurse Practitioner

Educator

Manager

Direct Care Provider

Other, please specify...

What type of hospital are you working in?

Quaternary Care Centre
Tertiary Care Hospital
Community Hospital
Rural Hospital
Other, please specify...

What type of Intensive Care Unit (ICU) do you work in?
Surgical ICU
Medical ICU
Mixed Medical/Surgical ICU
Other, please specify...

Appendix I: Survey Policy and Process Questions (modified from questions used by Vandijck et al., 2010)

Bed capacity of your ICU

<6 beds

6-8 beds

9-12 beds

13-15 beds

16 or more beds

Are family members given an information package on admission to your unit?

Yes

No

Do not know

Is a family conference mandated soon after admission to your unit?

Yes

No

Do not know

Does your unit have?

Open visits (no restrictions)

Restricted visits

Do not know

If restricted visits, what types of restrictions are in place?

Are the doors to your unit locked so that families need permission to gain access to visit a patient?

Yes

No

Do not know

Does your unit have a quiet time where no visitors are allowed?

Yes

No

Do not know

Are family members asked to leave during nursing care and patient procedures?

Always

Usually

Sometimes

Rarely

Never

Are family members permitted to be present during resuscitation?

Always

Usually
Sometimes
Rarely
Never

Are families included in rounds in your unit?

Always
Usually
Sometimes
Rarely
Never

Do families have access to a social worker in your unit?

Yes
No
Do not know
Bottom of Form

Appendix J: Families Importance in Nursing Care-Nurses' Attitudes (FINC-NA) instrument (Benzein and colleagues)



Faculty of Nursing

FINC-NA Questionnaire

The questionnaire consists of a number of general statements about the importance of the family in nursing care. The statements are similar but they are not identical. They are not listed in any particular order. Please, respond to these statements quickly, giving the first reaction that comes into your head when you read them. Select the response that best describes your thoughts for each statement. [5-point Likert scale] The term family refers to the patient/client and family members, friends, neighbors or significant others. You are welcome to make comments in the space provided at the end of this questionnaire.

	Totally Agree	Agree	Neither Agree or Disagree	Disagree	Totally Disagree
It is important to find out what family members a patient has.					
The presence of family members holds me back in my work.					
A good relationship with family members gives me job satisfaction.					
Family members should be invited to actively take part in the patient's nursing care.					
The presence of family members is important to me					

	Totally Agree	Agree	Neither Agree or Disagree	Disagree	Totally Disagree
as a nurse.					
I ask family members to take part in discussions from the very first contact, when a patient comes into my care.					
The presence of family members gives me a feeling of security.					
I do not have time to take care of families.					
Discussion with family members during first care contact saves time in my future work.					
The presence of family members eases my workload.					
Family members should be invited to actively take part in planning patient care.					
I always find out what family members a patient has.					
The presence of family members is important for the family members themselves.					
I invite family members to have a conversation at the end of the care period.					
I invite family members to actively take part in the patient's care.					
I ask families how I can support them.					

	Totally Agree	Agree	Neither Agree or Disagree	Disagree	Totally Disagree
I encourage families to use their own resources so that they have the optimal possibilities to cope with situations by themselves.					
I consider family members as co-operating partners.					
I invite family members to speak about changes in the patient's condition.					
Getting involved with families gives me a feeling of being useful.					
I gain a lot of worthwhile knowledge from families which I can use in my work.					
It is important to spend time with families.					
The presence of family members makes me feel that they are checking up on me.					
I invite family members to speak when planning care.					
I see myself as a resource for families so that they can cope as well as possible with their situation.					
The presence of family members makes me feel stressed.					

Comments

Appendix K: Open-Ended Question Regarding FCC

Faculty of Nursing

Open-ended Question

In a report created for the Institute for Family-Centered Care in Bethesda, Maryland and the Institute for Healthcare Improvement, Conway et al. (2006) described patient- and family-centered care as placing an emphasis on: "Collaborating with patients and families of all ages, at all levels of care, and in all health care settings. Further, it acknowledges that families, however they are defined, are essential to patients' health and well-being and are allies for quality and safety within the health care system.... Family members are more than surrogates to be called on when the patient is unable to make decisions on their behalf; they are essential members of the care continuum and care-giving team." (p. 6)

What are your perceptions of family-centered care (FCC) in adult ICUs?

On a scale of 1 to 10, how would you rate your unit's ability to provide FCC?