Situating the Family in the Care of the Adult Patient:

A Qualitative Study of Nurses' Perspectives

by

Belinda Mayer

A Thesis submitted to the Faculty of Graduate Studies of

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Of

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Dedication

To Dave

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Chapter 1

Statement of the Problem

Everyone comes from a family. There is recognition among healthcare personnel that family has an impact on a person's well-being, whether as a positive or negative influence (Astedt-Kurki, Paavilainen, Tammentie, & Paunonen-Ilmonen, 2001; Benzein, Johansson, & Saveman, 2004; Craft & Willadsen, 1992; Laitinen, Merilainen, & Sinkkonen, 1996; Rantanen, Kaunonen, Astedt-Kurki, & Tarkka, 2004). Differences exist on what family means to different people, including those of various cultures and societies, and therefore, variations also exist on how the family will have an impact on the individual.

As global mobility increases, new traditions are introduced into various different societies, which lead to cultural diversity in ways of life. Healthcare workers, who have been raised in their own belief systems, are providing care to groups of individuals who may practice traditions and have family role expectations different than their own. This, in conjunction with a patient-centred approach to adult care common in today's healthcare, leaves in question whether our healthcare system is cognizant of the role of the family with adult patients and fosters their role in the trend to holistic healthcare.

Literature on the term "family-centred" care is plentiful, although it is used primarily in context of the pediatric nursing domain, and only minimally touches on adult provision of care in psychiatry and palliative care. Meanwhile, patient-centred care, or client-centred care which it is interchangeably known as, is promoted within adult care and is especially studied in the literature within the occupational therapy context (Law, Baptiste, & Mills, 1995; Restall, Ripat, & Stern, 2003; Sumsion & Law, 2006; Wilkens,

Pollock, Rochon, & Law, 2001). Family is studied in other contexts as well, such as in literature that investigates the experiences of family in adult intensive care units (Barr & Bush, 1998; Eggenberger, 2004; Goodell & Hanson, 1999; Hallgrimsdottir, 2000; Johnson, Craft, Titler, Halm, Kleiber, Montgomery, et al., 1995; Lam & Beaulieu, 2004). It is also studied in literature describing cultural care (Barker & Giles, 2003; Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000; Mazanec & Tyler, 2004; McLaughlin & Braun, 1998; Pelusi & Krebs, 2005; Wong & Pang, 2000) and in cancer care (Lobchuk & Stymeist, 1999). Despite these discussions, it is not clearly indicated whether the family becomes part of the healthcare providers' care approach. Suggestions are made by some authors that the family should be studied as a collective unit and family nursing be encouraged (Astedt-Kurki, Paunonen, & Lehti, 1997). Shortcomings are evident in empirical literature regarding understanding of where the family fits into the specified models of adult care.

Traditionally, healthcare providers in the paternalistic, medical model made the decision on what was best for the patient without the patient and family involvement. For example, fear of the spread of infection was one of the major determinants that prohibited parents from being at the bedside of their children. Unfortunately, it was not until the mid 20th century, that researchers began to study the negative emotional and physical effects caused by the separation of children from their families during times of illness (Rennick, 1994). Consequently, over the next 50 years, the evolution and institution of family-centred healthcare for pediatric patients took place.

In the 1950's, adult patient care also began moving away from the medical model towards partnership. Medicare in Canada in the 1960's ensured equitable healthcare for

all, and the ensuing drive for public health in the community gave the patient shared responsibilities for their health. Self-determination and choice became part of the concept of patient-centred care that followed.

Interestingly, how patient-centred care is practiced in the healthcare system today is not universally conclusive. Astedt-Kurki et al. (1997) suggested that societal pressures for individualism and extensive social support networks have reduced the need for and importance of family bonds. These authors became interested in investigating if and how nurses were reacting to this change in social climate. According to Saveman, Mahlen, and Benzein (2005) in a Finnish study exploring university nursing students' beliefs about families, students reported that they were frequently exposed to nurses who approached patient-centred care as individualistic. Although the nurses commented to students on the importance of family, they nonetheless often considered only one family member, if any, in the patient-centred care approach. Ironically, students themselves shared the importance of family in the healing process, despite being taught that the care of patients should be focused on the "individual" and family should be viewed as part of the patient's context.

A case study by McCarthy (2006), investigated how preceptors in nursing education programs instilled patient-centred care on their students. Although preceptors were informed on patient perceptions of ideal patient-centred care, including involvement of family and friends, limited focus on the patient's social network took place in the teaching. The findings reinforced that patient-centred care remains unclear in concept, and that nurses do not follow a particular model of care. Ultimately, literature on student nurses' perceptions of the family is limited. Also, despite evidence that addresses nurses'

perceived needs of families, the author was unable to locate any literature describing what nurses feel the role of family is in the patient-centred care of adult patients. The lack of literature in this area indicates a clear need for study. A greater understanding of how nurses situate the concept of family in their practice of adult patients is warranted in order to help promote sensitive and comprehensive care for adult patients. Nurses should be successful at articulating how they practice in order to meet the needs of their clients, as well as educating future nurses on their roles in the healthcare system.

Research Purpose and Research Questions

The overall purpose of this qualitative research study was to arrive at an increased understanding of how nurses situate the concept of family in their care of adult patients. Special attention was given to identifying if the meanings nurses assign to the concept of family in the context of adult care varied between different care settings.

In addressing the research purpose, the following research questions were asked:

1. What meanings do nurses assign to the concept of family in their care of adult patients?
2. What meanings do nurses assign to the concept of care in the context of adult-care settings?
3. What roles do nurses feel families should have in the care of adult patients?
4. What influences do nurses feel families have on their practice of care of adult patients?
5. How do nurses' perceptions of the concept of family in their practice of adult care vary between different care settings?
6. What recommendations do nurses have about how to best situate the family in their care of adult patients?

Definition of Key Terms

The following key terms were used in this study. The definitions supplied were compiled from various sources, and indicated the diversity in meaning attributed to each term.

Family

McMahon (1992, p. 212) defined the family as "...a small social system made up of people held together by strong reciprocal affections and loyalties and living in a permanent household that persists over time. ...The family has been described as a system through which and by which family heritage and social, cultural, and ethnic values and beliefs are perpetuated." Furthermore, McMahon stressed that a family can be defined by its structure, such as: a nuclear family, made up of parents and children; an extended family, made up of a variety of people such as people from different generations, cohabitating couples of same sex, single-parent households, or members of communes; and blended families, made up of a couple who marries, each bringing with them their own children. Craft and Willadsen (1992) presented a more fluid definition of the family. They concluded that "the family is a social context of two or more people characterized by mutual attachment, caring, long-term commitment, and responsibility to provide individual growth, supportive relationships, health of members and of the unit, and maintenance of the organization and system during constant individual, family, and societal change" (p.519). Lastly, a simplified meaning to the concept of family from Benzein et al.'s (2004) descriptive study concluded that the family is "...persons who show an interest in each other" (p. 870). The traditional meaning of family living under

the same roof, with legal affiliation or kinship to each other is no longer the assumed social order of the family unit (Paavilainen, Seppanen, & Astedt-Kurki, 2001).

From a culturally sensitive aspect, family takes on various meanings. Kaslow, Celano, and Dreelin (1995) made note of this cultural variance, and give examples of what family can mean, depending on tradition. Compared to the traditional white, Anglo Saxon Protestant meaning, which portrays the family as a single nuclear unit, African Americans might view family as an extended network of community and relatives. Italian Americans may have a concept of family which may include three or four generations in a network including friends and godparents. Finally, the Chinese culture's definition of family includes distant ancestors and descendants as the family unit.

For the purposes of this study, the term *family* followed the definition provided by Brown (1993). Brown's definition of family is very broad with an intent to include various meanings. In other words, family includes those individuals in non-traditional relationships, and families of personal choice. Family members may be those of biological relation, legal union, non-legal union (e.g. "partner" or significant other), or a friend who is a caregiver to the individual. This definition afforded nurse participants the opportunity to define "family" according to their beliefs, values, and respective cultures.

Care

Patient-centred care is a social, holistic model of care. It has various interpretations, and although promoted in contemporary medicine, remains largely understood simply by what it does not represent, that is, physician or hospital dominated, or disease focused care (Stewart, 2001). In this model, the patient is completely involved in their plan of care and service (Gillespie, Florin, & Gillam, 2004), and the focus of care

hinges on particular elements: communication and partnerships between patients and healthcare professionals, and moving beyond the illness concept to health promotion (Bauman, Fardy & Harris, 2003). Despite the obligation of health professionals to provide expertise in discussion with patients, patients experiencing patient-centred care maintain shared responsibility in medical decision-making (Weston, 2001). Interestingly, patient-centred care is sometimes referred to as a philosophy of care (Archibong, 1999; Headwaters Health Care Centre, retrieved July 27, 2007), or as a methodology and approach (Bauman et al.; Mead & Bower, 2000). Family-centred care on the other hand, is recognized as a philosophy of care pertaining traditionally to pediatrics (Ahmann, 1994; Burns, 2002; Hammer, 1998). However, recognizing that patient-centred care has various interpretations, it was anticipated and most wanted that nurse participants would bring to this study their own assigned meanings to patient-centred care.

Nurse

In the context of this study, a nurse is a registered member of a regulatory body, hence known as a registered nurse (RN). RNs are academically prepared for practice in two ways: diploma preparation, which involves a three-year course of study, or degree preparation, which entails four years of studies and entitles the nurse to bear the academic credential of Baccalaureate of Nursing (BN). Regardless of educational preparation, an RN is required to become registered in order to practice in the nursing profession. Therefore, references to nurses in this study are inclusive of any registered professional nurse of the College of Registered Nurses of Manitoba who has obtained either diploma or BN training, regardless of years of training or specialty area.

Adult Patient and Adult Care Setting

For the purposes of this research study, an adult patient was defined as any individual of legal age or older who was an inpatient in an adult hospital unit. This hospital unit provided the adult patient with physician and nursing care, and offered services both on a consultative basis and on personal request in order to meet care plan requirements of the adult patient, and provided an environment conducive to healing and health promotion.

Assumptions

The following are the investigator's assumptions about where nurses situate the concept of family in the care of their adult patients:

1. The concept of family is not clearly defined within the nursing profession.
2. A clearly defined model of patient-centred or family-centred care of adult patients is not universally taught or practiced in the nursing profession.
3. Lack of a clearly articulated model of care for adult patients may compromise the care afforded the adult population by the healthcare system.

It was anticipated that the findings of this study would either contradict or verify these assumptions. Findings are discussed in following chapters.

Significance

The significance of this study lies in its contribution to furthering an understanding of the nursing culture in four ways. First and foremost, this study gave nurses a forum to voice their personal perspectives on their profession and the work they do with families. Second, professionals engaged in nurse education and administration, as well as front line nursing staff may use the findings to improve nursing practice. Third,

this study may lay the ground work for future research that directly explores the nursing profession, and indirectly studies the role of social networks as a support for patients. Finally, this study may affect public policy regarding funding and resource allocation within the healthcare system in order to meet the need of the population it serves.

Conclusion

This study on where nurses situate the concept of family in the care of their adult patients is an important contribution to the profession of nursing. Not only may the findings enable nurses to possess a greater understanding of how their perceptions of family roles may differ from other nurses and give insight on how patient ideas may also differ from their own, but this research may prompt inquiry on how our nursing education may either be addressing or failing both nurses and those under the care of nurses, which ultimately impacts the health of our adult population.

In the following chapter, an in-depth overview of literature speaking to family in adult patient care is presented, which will provide the reader with insight into the variable practices in adult care.

Chapter 2

Literature Review

This chapter discusses the literature that addresses the role of family in patient care. Specific areas included are where families interact with the pediatric patient; the critically ill adult patient; the adult patient in the Emergency room; the elderly patient; the palliative patient; the adult psychiatric patient; the adult surgical patient, and the adult medical patient. Furthermore, literature is reviewed that addresses culturally sensitive patient care, client-centred practice, and family perspectives on what they see their role to be. Comparisons will then be made from the literature concerning patient-centred care versus family-centred care, and family-centred care versus family nursing.

The Family Role in Patient Care

The family and the pediatric patient.

Family-centred care is the popular term and philosophy for the care of pediatric patients (Ahmann, 1994; Astedt-Kurki et al., 1997; Clayton, 2000; Luciano, 1972; Ochieng, 2003; Porter, 1979). A hallmark element of this philosophy is the involvement of parents in caregiving and their shared partnership with service providers (Law, Teplicky, King, King, Kertoy, Moning, et al., 2005). In this care model the nurse's role is sometimes viewed as the consultant or advisor rather than the actual caregiver (Hutchfield, 1999), and implementation of care is flexible and creative (Porter).

The expected degree of caregiving performed by parents varies depending on the attitude of the health professional. Research shows that a contributing factor to the degree of caregiving may be the general lack of guidance on the nurses' part surrounding the family's/parents' need for psychological care, and uncertainty of what the parents' role

should be in the care of their hospitalized child (Brown & Ritchie, 1990; Peden-McAlpine, Tomlinson, Forneris, Genck, & Meiers, 2005). Research revealed that it is common for nurses to perceive parental care to encompass non-medical duties only, whereas family may expect to take on more technical responsibility (Gill, 1993). On the other hand, in a theoretical paper by Lee (2004), some parents restricted their involvement because they had no desire to do the job of nurses.

In Gill's survey (1993) nurse leaders such as instructors, supervisors and administrators were more likely than other nursing staff to invite the involvement of family in care. The nurse leaders may use their position to mentor staff nurses, and the leaders' attitudes may begin to reflect in the staff nurses' practice. Gill hypothesized that baccalaureate prepared nurses were more encouraging of family participation than diploma trained nurses, and healthcare professionals who were married and parents themselves were more inclined to support parental caregiving. Ultimately, research suggested that academic preparation of nurses provided insights into the benefits of family involvement, and encouraged nurses to invite interaction with families (Brown & Ritchie, 1990; Gill).

In Brumfield and Lansbury's (2004) interviews with young adults, a major difference between pediatric and adult delivery of care rested on the self-responsibility of the patient. In pediatric care, family-centred care is practiced when the physician communicates largely with the parents and family members and the focus of care rests on the growth and development of the child. Meanwhile in adult care, because the physician deals directly with the patient and gives the patient self-responsibility and control, the model of care is patient-centred (Brumfield & Lansbury).

Regardless of how family-centred care is defined within the context of the pediatric patient, it is well recognized that childhood illness affects the whole family unit. From a longitudinal study exploring the symptom experiences across the cancer trajectory, Woodgate (2006a) described cancer narratives as lived by children and their families as "life is never the same" (p. 11). Upon receiving a childhood cancer diagnosis, family lives were torn apart; their lives would never be the same again. Some participants in Woodgate's study described the experience as a nightmare; the cancer going "right to the core of your being" (p. 11). The family unit's overall sense of self as well as the sense of self of individual family members changed drastically with the cancer diagnosis. Woodgate described a merging of the ill child and parents' sense of self, particularly during times when symptoms worsened.

The family and the critically ill adult patient.

It is recognized that critical illness can have dramatic and detrimental effects on the functioning of the family unit, and it has also been recognized in findings from interviews and questionnaires of nurses that critically ill patients benefit from emotional support from their family (Barr & Bush, 1998; Johnson et al., 1995 ; Sapountzi-Krepia, Tsirintani, Binioris, Psychoyiou, & Peterson, 2001). In addition, research with nurses shows that the health of the family can itself affect the health of the patient (O'Malley, Favaloro, Anderson, Anderson, Siewe, Benson-Landau, et al., 1991). Literature speaks of the family as an irreducible unit and therefore, both the family and patient need to be cared for in times of critical illness or emergency, as is discussed in the descriptive study with nurses by Hallgrimsdottir (2000). But most nurse participants in Hallgrimsdottir's study shared that they were not educated to deal with family psychosocial needs, and that

they themselves (78%) were distressed at having to do so. Interestingly, the way the family responds to the patient's illness can in itself affect how the patient recovers. Family visits may actually elicit calming effects on a patient's cardiovascular system; on the other hand, family visits may create detrimental effects such as arrhythmias or high blood pressure, as was found by Lazure (1997) in an experimental repeated measure study of 60 ICU patients.

The need for family to make spontaneous decisions for the critically ill patient is not uncommon, and in a theoretical paper by Neabel, Fothergill-Bourbonnais and Dunning (2000), healthcare professionals should have an awareness of the family stresses throughout this process and provide the needed support. Much attention has been placed on the need for family-centred care in the adult critical care nursing area, and research findings from questionnaires to both families and nurses acknowledgd that the health and support of the family is an important component in the patient's well-being (Astedt-Kurki et al., 1997; Craft & Willadsen, 1992; Rantanen et al., 2004). Eggenberger's (2004) phenomenological study of 11 families of critically ill patients identified the same circumstance.

Informal caregiving, a service provided by friends, family, and others who care about an individual, does not require payment on the behalf of the organization; however, as Thalanany, Mugford, and Mitchell-Inwang (2005) pointed out in their prospective, longitudinal survey of 54 visitors to an ICU, this service has huge economic value. Despite this, family-centred care is not always supported because of barriers that exist in the healthcare system today: fiscal restraints such as organizational budgets and nursing shortages that create limitations on the availability of nursing staff to provide support and

guidance for family members of patients, leave family-centred care as an ideal situation rather than the norm. It is suggested in Neabel et al.'s (2000) discussion paper that with the move towards shorter lengths of hospital stay and a decrease in professional community healthcare personnel, that the family takes on a greater caregiving role. As a result, involvement of the family becomes an absolute necessity in the care of the adult patient (Neabel et al.).

The family and the adult patient in the emergency room.

Although research from interviews and questionnaires to nurses and families has found that emotional support from family benefits critically ill patients (Barr & Bush, 1998; Johnson et al., 1995; Sapountzi-Krepia et al., 2001), there is much debate about the family presence during resuscitation of the critically ill patient in the emergency department. In surveys of patients and families, emotional benefits for family were identified when allowed to be present during the resuscitation of a loved one (Benjamin, Holger, & Carr, 2004; Duran, Oman, Abel, Koziel, & Szymanski, 2007). Literature does not exist on other issues of family in the emergency room.

According to survey findings, patients generally wanted family members present if they were being resuscitated, and family believed they were helping their loved one by being present (Benjamin et al., 2004; Duran et al., 2007). Benjamin et al. surveyed 200 patients and families in an emergency department waiting room, and found that the presence of family in the emergency department decreased their post-traumatic stress and increased family coping with grief if the event of death. They found that the patient's desire for family presence during resuscitation was more prevalent with younger adult patients, although did not specify what constituted 'younger'. This variation from older to

younger adult age may align with the healthcare workers' expection of parental presence during pediatric resuscitation. Benjamin et al. also found that ethical dilemmas arise when healthcare professionals suggest death is merely a clinical event. If death should occur during resuscitation attempts, family presence provides the element of dignity which a clinical event simply does not afford.

Timmermans' (1997) interviews with 57 health care providers found that the family's presence is an attempt to humanize institutional dying. Timmermans' findings acknowledged the need for healthcare personnel to take on a holistic perspective, which would include the involvement of family members. Furthermore, if the holistic approach to healthcare is taken, the family members are partaking in caring *with* the staff and are not being cared for by them, since the likelihood is that the family has already initiated patient care by providing cardiopulmonary resuscitation prior to hospital arrival.

Duran et al. (2007), in their descriptive survey of 336 clinicians, families, and patients, found that only 54% of staff participants supported family presence during resuscitation. It was learned in this study that nurses were more favorable of family presence than physicians.

The family and the elderly patient.

Involving the family in the care of elderly patients may result in various outcomes. Research shows that involvement of the family can increase communication with healthcare personnel, thus generating greater support for the family, and involvement of family can provide for an environment where there is psychological and emotional patient support (Bauer, 2006). On the contrary, qualitative research showed that involvement of family in the care of the elderly can also lead to patient

dissatisfaction. Interviews and questionnaires with elderly patients and informal caregivers found that if participants expected the care was to be provided by staff, then having family take on that care may lead to dissatisfaction of the elderly patient (Crist, 2005; Laitinen et al., 1996). Despite this, greater involvement of family in the care of elderly patients is recognized as a holistic approach, giving family and the patient greater control over plan of care. In Laitinen et al.'s descriptive qualitative study that employed questionnaires to 369 informal caregivers of elderly patients, findings indicated that families felt they were prevented from providing care to their family member due to barriers such as lack of communication with the healthcare providers and factors such as ward policies, lack of privacy, and lack of time. Factors reported to improve family participation in caregiving included communication with healthcare providers, close proximity for the family to commute to the centre, and nurses that provided support for the family through empathy and flexibility. In Haesler, Bauer and Nay's (2007) systematic review of 32 articles, additional factors impeding family-staff collaboration in care of the patient were decreased staffing levels, high staff turnover, and lack of staff commitment to the family to support them to take part in the patient's care.

Ward-Griffin, Bol, Hay and Dashnay (2003) conducted an ethnographic study of 17 family-nurse dyads, and found that two different types of nurse-family relationships existed that focus on family-centred care: collaborative family-centred care, in which the family is very much involved; and carative family-centred care, in which the family is only involved to a small degree. The relationships differ in that in collaborative caring, the healthcare staff and family are seen as equal partners in the care of the client, whereas

with the carative approach, the family becomes a co-client with the elderly patient and no demands are placed on the family to provide care for the elderly person.

In an ethnography by Pickard and Glendinning (2002) involving interviews and observation of care activities with 24 carers and 24 nurse professionals, findings showed that family carers as well as nurses looking after the elderly in the community performed a variety of tasks ranging from less complex activities (washing and dressing) to technical skills (colostomy and fistula care). Themes that emerged were the roles of family caregivers and nurses in caregiving, how family and nurses worked together, and the similarities and differences between how the professional and informal caregiver provided care in the home. The major difference between the two types of caregivers was that family caregivers were with the patient around the clock, whereas nurses were only there during daytime hours. A narrative provided by a nurse in the study spoke of the family caregiver: "Obviously [family caregivers] can give [patients] much more individualized and continuing care. But they're with them 24 h, they know that if they moan in such a way it means something hurts..." (p. 149).

Davies and Nolan (2004) used an exploratory descriptive design to interview 37 family members, and sought to understand what family experienced when their loved one was moved into a care home. Findings suggested that families progressed through stages when transitioning a loved one into a care home, and "making the move" was considered quite stressful for the family members. Key themes included pressure versus no pressure, working together versus apart, feeling supported versus unsupported, being informed versus in the dark, and being in control versus losing control (p. 521). Because the family knew the patient the best, family usually had concern about whether the staff would learn

about the patient's likes and dislikes, since there was often no indication that an initial patient assessment had been completed. The family would take it upon themselves to ensure the patient and staff familiarized themselves with each other. It was also found that when family wished to continue caregiving in the care home, staff would sometimes discourage them from doing so. Findings from this study suggested that staff perceived family as having no further role in the physical care of the patient. In order to create a positive environment for both patient and family, Davies and Nolan advised that organizations ensure their policies reflect a family-friendly philosophy.

The family and the palliative patient.

Benzein et al. (2004) used focus group interviews with five nurses in a qualitative descriptive design to explore the perspectives of nurses on families of palliative care patients. Interestingly, and similar to literature on families of psychiatric patients, nurses in this study perceived families to be both resources and burdens to their patient's care. If the families were comfortable having open discussion about issues, the nurses described them as being resources to the patient, which encouraged the nurses to invite the family to take part in caregiving. If the family members were not communicating with the staff, but rather were demanding in decision-making and ignored the nurses' advice, they were perceived as a burden. These latter families were discouraged from taking part in the caregiving and were perceived as being controlling and difficult to handle.

In Lobchuk and Stymeist's (1999) discussion paper, the family was viewed as one with the palliative patient in illness, disease, and symptoms, and thus the family played an integral part in interpreting the patient's symptom experience. Patient symptoms were described as being subjective in that they were not easily detected by other people.

Lobchuk and Stymeist elaborated that the understanding of symptom management may prove to be different between the family, biomedical, and nursing cultures. These authors discussed the necessity of good communication between the three cultures, since effective management of symptoms is at risk when the understanding of the symptom experience conflicts between patient, their caregivers, and healthcare providers. Ultimately, family distress can result when families perceive the uncontrolled suffering of their loved one. Lobchuk and Stymeist stressed the importance of shared meaning of symptoms between biomedical, nursing, and family cultures in a "patient-focused, family-centred environment" (p. 24). The philosophy of palliative care outlines a collaborative approach to develop interventions which may ease the patient and family suffering. In doing so, Lobchuk and Stymeist indicated that the healthcare team continues to be challenged in finding a common ground in which they may effectively support the patient and family in the end of life.

The family and the adult psychiatric patient.

Psychiatric nursing places significant emphasis on the importance of family in the care of the adult patient. In McMahon's (1992) discussion paper, families may choose to take on various roles with the mentally ill patient, whether it be as a direct caregiver, monitoring the patient's well-being from a distance, acting as a patient advocate, or perhaps not becoming involved at all. Nurse focus groups in Sjoblom, Pejlert, and Asplund's (2005) study, and a grounded theory study by Piippo and Aaltonen (2004) in which 22 patients were interviewed, identified that family of the adult psychiatric patient can be an important resource for information on the patient. However, they may simultaneously contribute to the patient's problems if the family itself suffers from

pathological problems (Sjoblom et al.). Therefore, the patient and family needs can conflict, resulting in the nurse experiencing difficulties with demands on providing support to both. Sjoblom et al.'s findings determined that there is an ongoing need to find ways to improve family health and patient outcome by finding whether and how to incorporate family into caregiving.

Topor, Borg, Mezzina, Sells, Marin, and Davidson (2006) interviewed 12 patients in their explorative qualitative study to understand the role of family, friends, and professionals in the patient's recovery from schizophrenia. They found that the mental health patient's social support system in addition to the healthcare provider enhanced the lives of these patients by ensuring the psychiatric disorder did not limit the individual. Social functioning becomes more difficult for the mentally ill patient, and human interactions may become less frequent as the individual spends more time alone. In their findings, Topor et al. suggested that the psychiatric adult patient benefits from having relationships with family and friends who act as catalysts in the recovery process. Because family and long-term friends often have a recollection of the individual prior to their becoming ill, Topor et al. shared narratives by patients regarding family as "standing alongside the person" (p. 22) and "being there for the person in recovery" (p. 23). The family provided continuity from life before the illness. Consequently, the family may take on additional burdens of the patient, and when others reject the patient, the whole family may become ostracized. Topor et al. found that this determination and commitment to the psychiatric patient may be perceived by outsiders as the family becoming overly involved in the patient's care. The family may be perceived as subconsciously harming the patient which ultimately can be damaging to the family unit.

Research has shown that mental illness within the family can threaten the health of the entire family unit (Kuisma, Murtonen, Paunonen, Lehti, Koivula & White, 1997).

As Jacobsen and Severinsson (2006) found in their explorative qualitative study interviewing six parents of adult psychiatric patients, the social network of family and friends cannot be replaced by anything offered by public healthcare. Findings from this study showed that parents often felt information and decision-making was withheld from them, which was not perceived as beneficial to the patient.

Winefield and Burnett (1996) surveyed and interviewed a combined total of 134 informal carers and found that difficulty for parents existed when they felt the patient made poor decisions as a result of their illness. Comments by participants encompassed what Winefield and Burnett suggested are barriers to professional-relative relationships. These barriers included that healthcare professionals felt uncertain of the relatives' place in the patient's care, healthcare professionals blamed parents for the patient's illness, power struggles existed between parents and professionals, parents were unappreciative of the care given to their adult child by the healthcare system, there was a lack of professional training amongst healthcare staff in dealing with families, and lack of time and resources afforded by healthcare personnel to invest in relatives.

Thurston, Rimmer, Flynn, and Swidells (2003) provided perspectives on caregiver support in mental health in their theoretical paper. Inadequate involvement of "carers" in communication sharing, extreme rigidity due to confidentiality which can result in no communication at all, and lack of continuity of care were seen as contributors to decreased amount of carer contact with services. Lack of available hospital staff for information-giving was noted in this paper. Thurston et al. indicated the imperative need

for improved support for and involvement of family caregivers, who save the healthcare system enormous expense every year. Caregivers who feel marginalized and excluded from the care of their loved one is a recurrent theme in the literature that Thurston et al. sought to address with professional training geared at inclusive care of both psychiatric patients and their caregivers.

The family and the adult surgical patient.

Family-centred care has been studied within pediatric perioperative cases, and literature indicates this style of care may also be useful in the care of adult patients. Paavilainen et al.(2001), in a survey of 112 emergency surgical patients, found that the need for healthcare personnel to attend to distraught families in the preoperative, intraoperative and postoperative phases of an acute surgical case was paramount. Paavilainen et al. found that family care should be addressed simultaneously with care of the surgical patient: patient care in the preoperative phase hinged on the information that could be gathered from the family at the bedside as well as through observation. Furthermore, Paavilainen et al. found that an incorrect assumption existed that all surgical patients desired their family be present perioperatively. Likewise, some families preferred to be absent. Paavilainen et al. recommended that nurses develop their decision-making skills to enhance their awareness of family-centred care and further develop an understanding of family-centredness in the perioperative nursing area.

In a survey of 222 informal caregivers and their patients who had undergone knee replacement surgery, Weinberg, Lusenhop, Gittell, and Kautz (2007) found that there was a need for high quality communication between formal and informal caregivers in order to ensure good patient outcome and facilitate good management of the patient at home.

As healthcare shifts into the community and informal caregivers take on expanded roles, healthcare providers are encouraged to attend to both physical and interpersonal aspects of support for the family as caregiver to the surgical client (Weinberg et al.).

The importance of family and patient opinion on what is desired healthcare is apparent in a descriptive study of 225 medical-surgical patients by Ahmad and Alasad (2004). Ahmad and Alasad sought to explore predictors of positive adult patient experiences in medical-surgical inpatient wards and found that it was not enough to simply have health professionals be the judges of good patient care; feedback from patients and families regarding nursing care provided direction on how to improve care practice. Findings from Ahmad and Alasad's questionnaire indicated that patient satisfaction in the medical-surgical hospital unit increased when nurses provided support and respect for families. Furthermore, Ahmad and Alasad shared findings that 83% of their participants who were tested using a 26 item likert type Nursing Care Scale were satisfied with the amount of assistance they received from family while in hospital.

The family and the adult medical patient.

Research shows that family members are receptive to and desire to be involved in the care of their adult cystic fibrosis (CF) family members, as indicated in a study by Lowton (2002). In Lowton's phenomenological study, interviews with 31 family members of patients with CF took place. Lowton described the care of adult CF patients who were being cared for at home, in a model known as "hospital at home" (p. 175). Hospital at home (HaH) provided healthcare services to patients in their home, rather than requiring the patient be cared for in hospital, with the intent to have lay carers provide assistance to patients between services provided by professional personnel

(Lowton). Lay carers in this study consisted of significant others and parents of patients. Findings indicated that carer perceptions of their role in care and treatment of these patients in the home environment were unclear. Despite this, findings from Lowton's study indicated there was general consensus from patients that being cared for in the home by a combination of professional and lay carers was preferable than being cared for in hospital.

Montalto's (1996) retrospective descriptive survey study found that carers have different perceptions of their role: some felt they are used to replace professionals when there was minimal staff available, such as with a physiotherapist shortage, while others felt they needed minimal or no special training in order to assist by cooking meals, doing household chores, or simply just being present in the household. In Montalto's survey, 62 of the 67 spouses and mothers who comprised the carer sample felt confident in their undefined roles as carers, and would do it again, despite concerns from some that they were required to stay home and be available all day.

Research also shows that communication and information sharing is an important component to relative and patient satisfaction in the adult inpatient medical unit. Attree (2001), in a grounded theory study where 34 medical patients and seven relatives were interviewed, sought to understand how patients and their relatives perceived quality of care. "Good quality care' was described by both patients and relatives as patient-focused, with special attention to care being "....provided humanistically through the presence of a caring relationship" (p. 459). Attree's study found that not only patients, but relatives as well, expressed dissatisfaction when they were not well-informed. Attree shared suggestions made from patient and relative narratives alike, requesting staff should "...let

you know what's going on" (p. 462). A sense of entitlement to information was found to be present with families in Atree's study.

Schumacher, Stewart, Archbold, Dodd, and Dibble (2000) interviewed 30 patients and 29 caregivers in their grounded theory study involving patients receiving chemotherapy and their primary family caregivers. Findings showed that due to increasing family caregiving, nurses must keep current in their skills in order to teach and provide support for families in the caregiving role. It was found that caregiving in the community did not reflect merely tasks or procedures, but rather, caregiving by family included complex skills involving critical thinking and reasoning. Schumacher et al. learned that the teaching of family by nurses extended into homecare, care of outpatients, and in discharge planning within hospitals.

In Ward-Griffin's (2001) critical ethnography of 23 nurse-family caregiver dyads, family members' services were identified as a method to reduce homecare costs. Several nurses in Ward-Griffin's study described family caregiving as unskilled, and therefore they placed less emphasis on the work family did as compared to the nurses. Ironically, the study found that there was a certain amount of overlap between duties of nurses and families, and it was not unusual that families took on highly technical, skilled work. Ward-Griffin's study resulted in an important finding critical to this present study on where nurses situate the role of family in the care of their adult patient: "...the degree to which family members "should" care for their elders [is] shaped by personal values and assumptions based on traditional gender roles, family relations, and the caregiver's age..." (p. 74).

May, Ellis-Hill, and Payne (2001) observed 19 informal caregivers and 25 trained healthcare providers in an ethnomethodological research study to explore the relationship between family caregivers and healthcare workers. In this study interesting results revealed that both nurses and patients and their families sought to control the hospital environment in which they worked and lived. May et al. found that the family had expert knowledge on the patient, but the nurse had the technical knowledge associated with care. Similar finding are evident in Haesler et al.'s (2007) systematic review which noted competitive interpersonal relationships between staff and family, leading to disagreement on who would take on what task, and ultimately resulting in gaps in the care provided to the patient.

Culturally Sensitive Patient Care

In a theoretical paper by Kaslow et al. (1995), culture is defined as "...a collective organization of tacit behaviors, ideas, attitudes, values, beliefs, and customs shared by a group of people, and transmitted by families across generations" (p. 621). Minority ethnic groups in the majority culture often hold cultural values that organize the family structure differently than the popular norm. This may become particularly noticeable in times of illness, when family members from collectivist societies rally around the bedside of their loved one. Extended families become part of the illness experience, as indicated in Ochieng's (2003) theoretical paper, suggesting that healthcare professionals incorporate not only care of the patient, but the family as well. Kaslow et al. identified that what is considered the familial norm for one culture should not be considered the norm for another, and therefore, deviations from the majority culture should not be thought of as dysfunctional. It is important to note that not only is culture a part of

ethnicity, but culture is not limited to beliefs associated with ethnicity alone. Rather, as stated in Lobchuk and Stymeist's (1999) discussion paper, biomedicine and the nursing profession are also cultures, which have their own representations of illness.

Increasing awareness of cultural diversity is an educational need for healthcare providers, since unique relationships exist between ethnicity and family structure (Friedemann, 1991). Not only has some aspect of patient care moved into the community, but patients are being increasingly cared for by non-professional healthcare providers, and this is especially so in cultures where caring for their sick is expected: responsibility for caregiving increases and is expected by family members. Nurses are required to provide support and educate the caregivers in the community on how to provide care, which suggests the importance of family involvement from the start of the illness experience. Lack of knowledge of available social services and resources may prevent caregivers from seeking medical assistance. Unfortunately, families may not always seek the guidance of a healthcare professional in the community until they have reached the stage of health crisis which may result if negative consequence to the ill patient. For instance, immigrant families from societies living under dictatorship may find that being assertive and asking for assistance is unfamiliar to them (Kaslow et al., 1995).

Likewise, large family groups might expect to be present at a patient's bedside, although an organization might have the policy and capability of accommodating no more than two 'immediate' family members at any one time. Research from Blackford (2003) involving narratives of 26 nurses, found that conflict can arise between the family and the healthcare organization when the family's definition of "immediate" family deviated from the organizational expectation of parents, children, and spouses and now

included extended relatives or close friends. In Blackford's study, this broad definition of family was found to create strain with the family and hospital because rules of visitation were not commonly understood. Although this practice may be perceived by some healthcare providers as the family being obstructive to health interventions, it instead requires staff gain knowledge of differences in cultural expression (Friedmann, 1991), and flexibility in how the patient is cared for.

Pelusi and Krebs (2005) interviewed 125 patients, supporters, and healthcare professionals on their views on family responsibility in the Aboriginal culture. Representative findings provide an example of these interviews: "This is the way we live... I had to educate the doctors – about who could make the decisions – the oldest female, my mother, she will decide for me...but the doctors – they see me as a man and felt I should make the decisions" (p. 16). In a survey of 126 nurses by Narayanasamy (2003), nurses felt the culture of patients and families were to be acknowledged and respected, which created a safe environment to establish trusting, therapeutic relationships with healthcare providers.

Issues in culturally sensitive care do not only affect the value system of the family and patient. Nurses too, may struggle with internal conflict when their value system clashes with what is expected from a culture different than theirs. Migration of people from different countries and cultures will inevitably lead to nurses that care for patients and families with customs and social norms different than there own. In Cioffi's (2005) qualitative study involving interviews with 10 nurses, conflict was found to exist in reference to privacy legislation. Healthcare professionals were taught to maintain patient confidentiality by discussing patient information with only the patient, but, as was found

in Cioffi's study, in particular cultures where the family must act as a filter for the patient, the nurse was required to speak to the patient through the family. Filial piety, which is practiced by many cultures, requires that the family takes care of their members, especially in illness, and the failure to fulfill this obligation is considered to fail in role responsibility, as identified in discussion papers by McLaughlin and Braun (1998) and Wong and Pang (2000). In theoretical papers by Barker and Giles (2003), Ellerby et al. (2000), Mazanec and Tyler (2004), and McLaughlin and Braun (1998), discussions identify the case of collectivist groups, where family members might expect to participate in dialogue about the patient's illness and partake in decision-making. Often, staff is required by family to speak indirectly to the patient through the family, which may impinge on patient autonomy. In collectivist societies, family always takes precedence over the individual.

Furthermore, gender biases in some cultures might create difficulties within the female dominated nursing profession. Cioffi's (2005) interview with 10 nurses found that males from some cultures where males are dominant may intimidate or refuse to interact with female nurses. This study also found that nurses identified the importance of family in transcultural nursing but felt there was lack of guidance in knowing where the family members should be placed in the context of patient care.

Client-Centred Practice

Similar to patient-centred care, Wilkins et al. (2001, p. 71) defined client-centred practice as "...collaborative and partnership approaches used in enabling occupation with clients who may be individual, groups, agencies, governments, corporations or others...". It also "...reflects changes wanted by consumers who desire more control in defining

health issues as well as changes in how health is viewed" (Law et al., 1995, p. 251). Used primarily in occupational therapy, this practice of being client-centred redirects power in the therapist-client relationship to one of partnership and mutual interdependence (Law et al., 1995; Sumsion & Law, 2006). Client-centred practice takes on a patient-centred care approach, with key concepts being the developing of partnerships and providing clients with information and the expectation that clients will make choices based on this knowledge (Restall et al., 2003).

In partnership, the client is the keeper of expert knowledge in their life situation while the therapist provides current knowledge in the technical aspect of the condition. This gives the client control and allows them to set and achieve their own goals and outcomes (Sumsion & Law, 2006). Having said this, it is important to note that one of the key aspects of client-centred practice involves the family, since the client in conjunction with the client's family maintain responsibility for decisions (Wilkins et al., 2001). However time constraints as a result of increased family demands and organizational limitations may limit practice from becoming fully client-centred, which was noted in Wilkins et al.'s review of three qualitative studies.

Traditional approaches in occupational therapy had not followed the client-centred model in the past. Instead, therapists made the decisions for their clients, and clients were expected to follow the therapist's instruction and plan of care (Wilkins et al., 2001). As shared in the theoretical paper by Wilkins et al., therapists must be aware of the client's individual needs in a shift to a client-centred approach, such as if the client cannot make decisions solely on their own. This situation would require the therapist guide the decision-making, all-the-while maintaining client-centred practice by

continuing to meet the needs described by the client (Wilkins et al.). In certain situations, the therapist may not agree with choices made by the client, requiring a greater understanding on the therapist's part to ensure the therapist can support the client to the best of their ability even though their decisions might morally conflict (Restall et al., 2003).

Patient-Centred Care Versus Family-Centred Care

Bauman et al. (2003) list three important elements in patient-centred care: physician and patient communication, patient partnerships with health professionals, and health promotion via healthy lifestyles. In a discussion paper by Stewart (2001), good communication between healthcare provider and patient may result in greater patient satisfaction, and therefore better patient outcome. With effective communication and information sharing, patients may develop expertise in their health. At times, this empowerment will steer patients to take risks in their health decisions that conflict with their health providers' beliefs, but underlying these choices is the right of self-responsibility.

Important to this topic is the move of healthcare from the hospital into the community, where community support services of all types are more readily available. In Bauman et al.'s (2003) discussion paper, the issue is presented that there is a strong move towards individualism since adults are empowered to make medical decisions for themselves, which may weaken the importance of the family role in healthcare. Money saved from reductions in hospital spending when client care moves to the community is now available for reinvestment in the community where patients can be managed. This

move to the community benefits especially those with chronic illnesses that can now be managed without a hospital admission (Bauman et al.).

Research pertinent to the area of education can be examined to understand where the family role is taught. McCarthy (2006) undertook participant observation of six preceptors, and found that the involvement of family was one of the key aspects of patient-centred care, along with emotional support, respect for patient perspective, providing of information, and coordinating of plan of care. In a descriptive study by Saveman et al. (2005) in which nine nursing students were interviewed, student nurses shared opinions on what they had learned about the importance of family on the patient's well-being. The study found that aspects of patient-centred care highlighted by the students included the support given by family to the patient; the comfort for the family knowing they could take part in the patient's care at home; and the benefits of being cared for by one's family, which left the patient's identity intact. Ultimately, the students in Saveman et al.'s study felt strongly that family was an important component in the healthcare process for all members involved, including the patient, the family themselves, and for the nurses. Saveman et al. recommended that nursing educational programs teach the presence of family in patient care, since the traditional role of nursing had stressed highly individualistic patient-focused care, and had largely pushed the family out of patient care.

Transition of patients from being cared for in the hospital to being cared for in the community by their families has acted as a catalyst in projecting the patient-centred model of care into the family-centred model, as found by Benzein et al., (2004) in their focus groups with five nurses. Family-centred care in the community is "...an open,

multidimensional system of health management which acknowledges the inseparability of the individual from his family and environment and which effectively and efficiently utilizes the complementary skills of all members of the health team, including the client and his family" (Porter, 1979, p. 330). Gill (1993) simplifies this definition by stating family-centred care is a philosophy that "...supports families in the caregiving role"(p. 257). The support suggested here is support given by healthcare professionals to the family, and is further described in Lee's (2004) definition of family-centred care: "...the professional support of the child and family through a process of involvement, participation, and partnership underpinned by empowerment and negotiation" (p.38). Family-centred care maintains the patient as the central focus, yet supports the family in order to create an environment where partnerships between family and healthcare professionals are possible for the best interest of the patient (Porter). Ultimately, the collaboration between health professionals and the family may lead to effective healthcare (Burns, 2002). Kinsala's (1999) discussion paper identifies that having the family at the bedside can reduce anxiety, fear, and isolation in the patient.

In addition to family-centred care being encouraged in pediatric areas, nursing staff who participated in the exploratory study by Astedt-Kurki et al. (2001) perceived families of adult neurological patients as needing information from staff, but the staff failed to fully understand the support family needed from staff in order to relieve distress for the family members. Staff communicated with family more readily if the family initiated the interaction, indicating a need for nursing to pay closer attention to the patient's family members in order to provide enhanced quality of care for both the patient and well-being of the family. Without taking into account family needs, patient care

cannot be seen as holistic and complete, as declared in Anderson's (2000) discussion paper. The patient becomes the centre in the family system, which is comprised of people who provide support and structure; the individual life takes place within the context of the family life (Newby, 1996).

Research conducted by Astedt-Kurki et al. (1997) administering a questionnaire to 70 family members, suggested that there is no right way of providing family-centred care; professional nurses should provide different options to support the family of the patient, depending on what the family needs, which would then allow the family to support their loved one more fully. Astedt-Kurki et al. found that despite families ultimately needing support from nurses, they did not always succeed in obtaining it for various reasons, including the family not wanting to, not having the confidence to approach nurses, or not knowing how to. Family-centred care is important not only for pediatric care, but for all age groups of patients, since the family is undeniably intertwined with the patient and therefore important for maintaining the health of all its members, as found in Craft and Willadsen's (1992) questionnaire of 54 nurses. Research finds that a good nurse-patient relationship needs to go beyond the patient and include the whole family in order to provide the optimum nursing care, as discovered in Archibong's (1999) qualitative interviews with eight families. As Robinson (1995) learned from interviews with five families, the patient should be considered both an individual as well as a family member.

It appears that patient-centred care makes use of components of the family-centred care philosophy when dealing with adult patients, and vice versa: both advocate

for the importance of the family in the well-being of the patient. This suggests there is necessity to combine both models when providing care for a single adult patient.

Family-Centred Care Versus Family Nursing

There is minimal literature that describes the phenomenon of family nursing. It is "...an evolving specialty area encompassing other areas in nursing that includes the family as client within the nursing paradigm" (Burns, 2002, p. 19). This hinges on the idea that although the individual patient has traditionally received all the focus of attention, the fact remains that the patient is part of a larger unit, the family, and the patient's health is affected by the well-being of the whole family and vice versa as found in discussion papers by Anderson (2000), and Friedemann (1989). The meaning of family nursing should be differentiated from the concept of family-centred care.

By looking at patient and family needs, the context of the family changes. According to a discussion paper by Claveirole, Mitchell, and Whyte (2001), family-centred care can mean care of either the family or the patient, depending on what context is used. When one studies how the family is involved in the patient's care, as in the case of family-centred care, the patient is observed within the context of the family. On the other hand, as found by Craft and Willadsen (1992) in their questionnaire of 54 nurses, when looking at the needs of the family, the family was observed as the unit of interest which called for family nursing. In a theoretical paper by Friedemann (1989), family is described as being the environment for the patient, and also as a group of interacting subgroups which interacts with the environment as a single unit. Since the environment and the family influence the patient's health, the family needs should be studied as a whole (Friedemann). Discrepancies lie in how healthcare providers determine what the

needs of the family are. According to Rennick's (1995) discussion paper, nurses' perceptions of family needs often differ from family-perceived needs, which can indicate a lack of knowledge and understanding of what family nursing really is. In Vehvilainen-Julkunen and Sohlberg's (1995) questionnaires of 134 nursing educators, disagreement among educators was found to exist on whether family should be taught as an environmental concept or related to the individual instead.

The key difference between nursing the patient in the family-centred care model and family nursing, then, is who the focus is on. There is a significant interconnection between the two, that is, the patient and the family, which suggests one is inextricably linked to the other.

Family Perspectives

Literature on the experiences of families in healthcare examines their personally perceived roles and responsibilities. In Astedt-Kurki et al.'s (1997) questionnaire to family members, it was found that less than half of the 50 participants felt nursing staff was interested in their well-being. More than half felt they were expected to take part in the care of their family member, and did. Likewise, in Lam and Beaulieu's (2004) interviews with 13 family members, family felt it was their responsibility to be an advocate, and ensured the patient was getting the best care possible. According to the results of the descriptive explorative study by Lam and Beaulieu, families also perceived that their duty was to gather information, and provided companionship for the patient to prevent feelings of loneliness, anxiety, and isolation. Lam and Beaulieu found that families considered it helpful to develop relationships with healthcare professionals.

Schoot, Proot, ter Meulen and de Witte (2005) conducted focus groups with eight patients and caregivers in a grounded theory study, and found that the client (which in this study is referred to as the family and patient collectively) desired communication with healthcare professionals. However, this study stressed that the client had the final decision about their body, health and treatment. These relationships between family and healthcare professionals are not the focus of care, but rather they are an indication of caring itself (Robinson, 1996).

Summary

To sum up the literature, the family is seen from different perspectives. The family is a resource for staff in providing information regarding the patient (Crist, 2005; Laitinen et al., 1996; Lobchuk and Stymeist, 1999; McCarthy, 2006; Neabel et al., 2000; Piipo & Aaltonen, 2005; Sjoblom et al., 2005). In addition, the family provides emotional support and shows interest in the patient's well-being (Barr & Bush, 1998; Benzein et al., 2004; Gill, 1993; Jacobsen & Severinsson, 2006; Johnson et al., 1995; Lam & Beaulieu, 2004; Sapountzi-Krepia et al., 2001; Saveman et al., 2005; Topor et al., 2006; Ward-Griffin et al., 2003). This interest in the patient can portray the family as an extension of health services which provides cost-savings for the healthcare system (Lowton, 2002; Montalto, 1996; Neabel et al., 2000; Pickard & Glendinning, 2002; Schumacher et al., 2000; Thalanany et al., 2005; Thurston et al., 2003; Weinberg et al., 2007).

Conversely, family is also seen by some as having no part in patient care (Davies & Nolan, 2004; Duran et al., 2007; Haesler et al., 2007; May et al., 2001; Thurston et al., 2003), and is sometimes even viewed as a burden by healthcare workers (Benzein et al., 2004; Blackford, 2003; Freidmann, 1991; Pelusi & Krebs, 2005; Winefield & Burnett,

1996). In the majority of literature, however, the family is considered a co-client and requires the support and guidance of healthcare personnel in order to manage the illness episode with the patient (Anderson, 2000; Astedt-Kurki et al., 1997; Benjamin et al., 2004; Craft & Willadsen, 1992; Duran et al., 2007; Eggenberger, 2004; Hallgrimsdottir, 2000; Kinsala, 1999; Law et al., 1995; Neabel et al., 2000; Ochieng, 2003; Paavilainen et al., 2001; Porter, 1979; Rantanen et al., 2004; Restall et al., 2003; Schoot et al., 2005; Sumsion & Law, 2006; Timmermans, 1997; Ward-Griffin et al., 2003; Wilkins et al., 2001).

Conclusion

The literature review indicates that a lack of consistency and clarity exists determining how nurses situate the concept of family in the care of their adult patients. Although literature that makes use of family-centred care in pediatric, palliative, or psychiatric models of care is abundant, how the family should be situated in the care of adult patients that are not palliative or receiving psychiatric care is unclear. It therefore becomes paramount that further research into where nurses situate the family in caregiving would add to the understanding of how the concept of family affects the adult patient healthcare experience.

Chapter 3

Introduction

The following chapter describes the research design and methodology that was chosen to guide this qualitative study. Sections describing the design and methodology, guiding framework, sampling and sample criteria, recruitment of participants, data collection approach and data analysis, as well as a discussion on ethical consideration outline how this study proceeded. Special attention was paid to the discussion of establishing rigor in order to ensure validity of this research study.

Research Design

A qualitative research design eliciting a focused ethnography approach was applied to this study of where nurses situate the family in the care of their adult patients. Ethnography is aimed at describing a particular group of individuals who share specific values, norms, roles, and origins (a culture) in order to understand those people (Byrne, 2001). Ethnography was the chosen method for this study for several reasons. Ethnography makes explicit what is implicit in a culture (Speziale & Carpenter, 2007). It is holistic in nature, as it aims to study not only the overt dimensions of a culture, but also those aspects that the culture can not articulate, otherwise known as *tacit* behavior (Higginbottom, 2004). Because individuals largely base their understanding of different cultures on knowledge they have of their own, full comprehension of another culture can be limiting when there is only one interpretation made. Ethnographers break free from this way of thinking by seeking to understand different truths and realities of different cultures (Speziale & Carpenter). By applying ethnography to this particular study, the

complexity and behaviors of the nursing culture was studied to develop a greater understanding of where nurses situate the family in the care of adult patients.

In focused ethnography the topic of study is determined prior to data collection, compared to other ethnographies where the topic becomes apparent from the data and its analysis (Morse & Field, 1995; Wright, 2001). "Focused ethnographies have as their focal point a distinct problem that is studied within a single context with a limited number of individuals" (Speziale & Carpenter, 2007, p. 204). When performing a focused ethnography, members of a culture or subculture can be studied based on their shared experience in a common location and in an environment in which the experiences are occurring (Morse & Field; Roper & Shapira, 2000; Savage, 2000; Wright). This type of ethnography is not limited to understanding a culture that only shares a place of residence and can be extended in the case of this study to a particular hospital unit (Morse & Field; Wright) where the nurses become a subculture within the healthcare system (Roper & Shapira). Leininger (1985) indicates that focused ethnographies (also known as mini-ethnographies) have increased in popularity with nurses simply because they are expedient in nature. Focused ethnography, then, is conducive for application in the health sciences and makes this methodology ideal for improving nursing practice by studying a specific issue in a short time frame, usually with a small group of key informants (Morse & Field).

In keeping with the qualitative approach of ethnography, key characteristics were maintained by the student including the researcher as research instrument, being fully immersed in the culture, the cyclical pattern of collecting and analyzing data, and reflexivity (Speziale & Carpenter, 2007). In this ethnographic study, the student became

the research instrument through interviewing, observing, and recording field notes. By these actions, the culture under study was analyzed and interpreted through the eyes of the student, with attempts at understanding the insider's perspective through the outsider's interpretation. Data collection occurred off-site, thus behaviors as they occur in the work environment were not recorded. Instead, the cyclical nature of data collection and analysis occurred during interviewing and taking field notes. This process provided for immersion into the culture under study, but inevitably leaned towards the need for reflexivity as the student became part of the culture and all the while maintained an objective role as the researcher. Reflexivity is the awareness required by the researcher that reminds them of their role as the researcher despite realistically and additionally being a member of the culture under study (Speziale & Carpenter). Reflexivity becomes necessary as a means of ensuring trustworthiness, which is described under the heading of *Data Analysis*.

Guiding Framework

Qualitative research is inductive in nature, that is, it does not test existing hypotheses but rather aims at developing theory (Morse & Field, 1995). As Morse and Field stress, this does not suggest qualitative research is without theory, it simply means the research is not driven by it. In this research study, the student made use of a nursing theory as a guiding framework. Leininger's Transcultural Nursing Theory (1978) was first developed in the 1950s and is based on nursing care practices. This is an exciting theory to use particularly in this study, as participants were asked to reflect on their perceptions of where family fit within their adult care practice. The student used this theory as a tool for comparison when findings emerged from this study, which assisted

the student to critically think about the developing theory and its fit to existing literature. A discussion on how the findings reflect on this theory takes place in following sections.

Leininger (1978, p. 33) defines Transcultural Nursing Theory as "...a set of interrelated cross-cultural nursing concepts and hypotheses which take into account individual and group caring behaviors, values, beliefs based upon their cultural needs, in order to provide effective and satisfying nursing care to people; and if such nursing practices fail to recognize culturological aspects of human needs, there will be signs of less efficacious , nursing care practices and some unfavorable consequences to those served". The theorist developed this theory further over the next decade into the Theory of Culture Care Diversity and Universality, defining its purpose as a means to provide care to clients which is satisfying to their cultural needs (Leininger, 1988), while acknowledging that there are similarities and differences between every culture (Leininger, 1995). Leininger (1995) identified two types of caring practices, one being generic (including lay, folk, or indigenous practices) and the other being professional (practice taught in an educational institution), both which are essential and should be incorporated into effective nursing care practices. One should not be practiced without the other in the healthcare system.

Cultural care, as defined by Leininger (1988; 1995) is the cognitively understood belief system that enables a person or group to act in support to maintain or improve another's well-being. In order for nurses to provide cultural care that is congruent with client needs, Leininger (1985; 1988) developed three factors which must be pursued and understood by nurses in order to meet this goal:

1. The preservation and maintenance of the cultural care in which enabling or supportive actions/decisions are made by the nurse to assist clients in maintaining health or finding recovery;
2. Accommodation and/or negotiation of the cultural care in which enabling or supportive actions/decisions are made by the nurse to assist clients in either adapting or negotiating what they view as an acceptable health status, or death;
3. The repatterning of the cultural care in which enabling or supportive actions/decisions are made by the nurse to assist clients to adjust their life choices in culturally meaningful ways to support a healthy lifestyle.

Nurses, as part of the nursing culture, and personally part of their own culture as individuals, must be educated to identify cultural care needs, differences, and similarities, and work together with their clients to provide practice which will meet the needs of the client and their family. An important statement in Leininger's (1988, p. 155) work is that "caring is essential to curing: however, there can be no curing without caring, but there can be caring without curing". Leininger (1995) expressed an urgency to expand nurses' thinking and knowledge on the missing aspects of culture care in nursing practice, and to learn more fully about the human being in order to provide meaningful holistic care. The research questions in this study sought to understand how nurses as part of the nursing culture situate the concept of family in the care of their adult patients, and as the analysis of data from this research study began to formulate theory, Leininger's (1978; 1985) work was compared in order to facilitate further questioning and analysis.

Sampling and Sample Criteria

Random sampling was not required in the current study since the desired outcome of this qualitative method was not to generalize, manipulate, or control the findings (Speziale & Carpenter, 2007). The aim of qualitative research is to discover meaning within a population; the aim is not to measure the distribution of a characteristic (Morse & Field, 1995). Accordingly, participants were selected using purposive sampling. This technique involves selecting participants who will help to provide the richest data. RNs and Registered Psychiatric Nurses (RPNs) working with adult patients were recruited from four units (emergency department, adult medicine, adult surgery, and adult psychiatry) in a large tertiary teaching hospital in Winnipeg, Manitoba. This sample provided for a variety of different nursing care scenarios for study. The intent was to recruit five nurses from each area. However, the final sample size was determined by the completeness of the data and the ability to achieve data saturation.

There were two inclusion criteria for this study; firstly, participants were RNs or RPNs who had practiced in the nursing profession for a minimum of three years, and secondly, participants had to have practiced on the particular units for a minimum of six months. Having a minimum of three years of professional practice experience ensured the participants established a practice from experience outside of classroom teaching.

Sample Recruitment

Under the direction of the Chief Nursing Officer at the tertiary care centre, names of receptive hospital units and permission for access from the respective unit managers was obtained. The unit managers served as intermediaries for the study and sent out the study's invitation letters to eligible nurses who met the inclusion criteria (see Appendix A

for the recruitment letter). Included in the letter was the student's phone number for nurses interested in the study to contact. As well, the phone number of Dr.Woodgate (student's supervisor) was noted on the invitation letter.

Two months after the unit managers distributed the letters to eligible participants, the student provided an electronic copy of the invitation letter for the managers to distribute as a reminder to the same eligible nurses. Due to poor response rate (approximately one participant nurse per month), the student attended a meeting with managers from different units within the chosen programs to describe the study. From this meeting, the student was then invited to distribute electronic copies of the letter to six additional medical and two additional mental health unit managers, who subsequently agreed to distribute letters to eligible nurses in their areas. An inservice was also held on one of the surgical units, and additional electronic copies were then distributed to five managers of different surgical units. After five months of attempts at recruiting a sample and continued poor response rate (despite 195 letters having been distributed), the student was required to rethink her recruitment approach. After further discussion with the student's thesis chairperson, and in consultation with the Chief Nursing Officer and Nursing Research Projects Manager of the facility, the student received permission to place posters advertising the study in a location near the hospital elevators and elevators in the nearby research building. Authorization was also received to put up a poster in the nursing office of the facility. This final approach to recruiting by placing posters in high traffic areas yielded a dramatic increase in nurse interest in the study. The recruitment phase of the study ended up taking place over a total of eight months.

The student explained the study to those interested in the study via the telephone. Nurses who agreed to participate were informed that they may withdraw at any time (see Appendix B for consent). A time and location for an interview was determined. Nurses who agreed to participate were requested to consent by means of a written consent form at the time of the interview.

Data Collection Methods

Semi-Structured, Open-Ended Interviews

The main method of data collection was a semi-structured, open-ended interview. The aim of semi-structured, open-ended interviews is to elicit storytelling and provide an in-depth examination of the topic. It can elicit unexpected information from the participant, and thus provides the participant the opportunity to relate their ideas in their own way (Leininger, 1985). Storytelling provides rich, descriptive context of a phenomenon that makes qualitative research desirable (Morse & Field, 1995). In the current study, because of the personal nature of asking participants about their belief system, one-on-one interviews were felt to be the preferable choice over focus groups.

An interview guide developed by the student and supervisor was used to guide the interviews (see Appendix C for the guide). At least one interview was invited from each participant, although it was open to participants to engage in a second interview in order to feel they had adequately shared their experiences (Morse & Field, 1995). All interviews were conducted by the student. Interviews took place at a time and in a location chosen by the participant. Attempts were made to ensure an environment of privacy and one free of interruptions and distractions. Interviews were approximately 60 minutes in duration, and were audio-taped with the consent of the participants. Audio-

recording equipment was checked prior to, and during the interview to ensure proper functioning. Audio-tapes were then transcribed verbatim. Only the student and the student's supervisor read the interviews.

Field Notes

The second source of data collection was field notes that the student dated and recorded at the end of each interview and then later transcribed verbatim. As Spradley (1980) indicates, the researcher's journal and field notes provide insight into biases and feelings which the researcher, while acting as research instrument, will use to understand his or her own personal influences on the study. The field notes included a description of the interview setting, nonverbal behaviors, interruptions in the flow of conversations, reminders or critique on the methodology, and patterns discerned from the work in progress. The student also wrote down personal assumptions regarding the nurses' stories and experiences. The student consciously strove to be aware of her own perceptions while she conducted the interviews and interpreted the data, so as not to create biases. Preparation by reading extensive literature pertaining to family made the student receptive to differences which helped alleviate any biases. Regular meetings were held with the student's thesis supervisor to discuss entries and address methodological, theoretical, and personal issues pertinent to the study.

Demographic Form

Socio-demographic information was collected during the interview session by using a demographic questionnaire (see Appendix D for the questionnaire). Variables of interest to this study included age of participant (in years), number of years worked as a

nurse, nursing education level (baccalaureate or diploma), and gender. The expected length of time for completion of the form was 5-10 minutes.

Data Analysis

Thorough data analysis in ethnography comes about as a result of "...astute questioning, a relentless search for answers, active observation, and accurate recall" (Morse & Field, 1995, p. 125). Ethnographic research is inductive in nature, and the data collection methods used allowed for *thick description* of the culture (Speziale & Carpenter 2007). Data analysis lead to the uncovering of *cultural domains*, which Spradley (1980) defines as categories of meaning specific to the culture. As Spradley shares, discovering cultural domains is both a science and an art. This is exemplified in the analogy of a child who grows to understand the way their culture operates without consciously being aware of it. So too, must the researcher understand completely the culture at hand in order to study it (Spradley).

To further the understanding of cultural domains, the student applied the basic steps in ethnographic analysis and immersed herself in the data. These steps were performing a domain analysis (discovering patterns of a culture within a particular social situation), taxonomic analysis (understanding how cultural domains are arranged), componential analysis (identifying the attributes associated with the terms in each domain), and thematic analysis (seeking the relationships between domains and how they interrelate with the culture) (Spradley, 1980). These steps were applied to all qualitative data (i.e., interviews and field notes). Emerging cultural domains and themes were co-created by the student and student's supervisor.

Various techniques and procedures were used by the student when analyzing the data. Comparing and contrasting cultural domains were used to clarify meaning, on the premise that "...cultural meaning is determined, in part, by how categories inside a domain contrast with one another" (Spradley, 1980, p. 125). As well, coding of field notes and interviews were used to identify repetitive words, themes, or concepts by descriptive labels which highlighted underlying patterns in the culture (Morse & Field, 1995).

Once coded, the student sorted descriptive labels into smaller sets as the codes became more general and as patterns emerged (Roper & Shapira, 2000). The student then generalized the data findings by identifying relationships between the participants' insider (emic) perspective as compared to the outsider's (etic) perspective of the data, aiming to construct theoretical interpretations that validated both views (Roper & Shapira).

All data was carefully reviewed. Careful attention was placed on cases that did not fit with other findings. These *outliers* were kept separate to validate and test the remainder of the findings (Roper & Shapira, 2000). Since questions evolve from the data as it is gathered and analyzed, it is expected in ethnography that data analysis will be cyclical in nature rather than linear, causing the student to flex between various techniques throughout the data analysis process (Roper & Shapira; Spradley, 1980). That having been said, the student documented memos (insights and ideas about the data findings) in the margins of the transcribed interviews which acted as prompts to question and further explore the data for a deeper understanding of the findings (Roper & Shapira).

Ultimately, and in order to facilitate clarity in processing the data, a matrix was developed to display how the codes, patterns, and inductive theory interrelated with one another (Roper & Shapira, 2000). Regular bi-weekly meetings were held with the student's supervisor to discuss the emerging domains, cultural themes, and matrix.

Basic descriptive statistics, including means, medians, percentages, and ranges were used to analyze the socio-demographic data (demographic form). This provided an overall profile of those participating in the study.

Trustworthiness

The interpretation by some is that qualitative research consists of *soft* data, that is, data that cannot be converted into numerical format for statistical processing. This leads some to believe that qualitative study is lacking in science and credibility (Morse & Field, 1995). On the contrary, qualitative research is a sound approach to scientific inquiry, and therefore, it is the researcher's responsibility to ensure a qualitative study has rigor (Speziale & Carpenter, 2007). "The goal of rigor in qualitative research is to accurately represent study participants' experiences" (Speziale & Carpenter, p. 49). This study accomplished this by addressing the four techniques in establishing trustworthiness as outlined in Speziale and Carpenter: credibility, dependability, confirmability, and transferability.

Credibility.

As the word implies, credibility refers to precautions taken to ensure results will be reliable. Prolonged engagement with subjects is an effective and useful approach to ensure integrity in the data (Speziale & Carpenter, 2007). By giving participants the option of having more than one interview, participants are given the opportunity to

contemplate and share information as they think of it, which increases the chance of gathering a full perspective of the culture. In this study, the student provided opportunity for at least one interview with each participant. By giving the participants opportunities for more than one interview at their discretion, the researcher enabled each participant to fully disclose their perspectives.

Dependability.

Once credibility is established in a study, dependability should be addressed. This means the researcher should ask how the results can be verified to be true. By using field notes and reflecting on interviews, the student was able to verify assumptions and themes that emerged from the interviews. Again, with the cyclical nature of data collection and data analysis, dependability of the findings became evident.

Confirmability.

The process of confirming data involves documenting clear activities and processes that led to a researcher's conclusions (Speziale & Carpenter, 2007). This is normally accomplished by leaving an audit trail which can be followed by other individuals. In this study, the student made use of the study supervisor who validated data gathered. Because interpretation is a subjective process, it is believed that an audit trail may not be effective in ensuring confirmability (Speziale & Carpenter). Since the student conducting this study was a novice in performing research, the supervisor's advice in confirming findings was valued. The student and thesis supervisor jointly developed an interpretation of the nurses' experiences.

Transferability.

The ability to use the findings from one study in other situations is what defines transferability (Speziale & Carpenter, 2007). It is the intent that the findings from this study will inform others in the healthcare administration arena who wish to improve applied practice and education planning. As indicated in Speziale and Carpenter, however, transferability is determined by those using the findings, and is not predetermined by the researcher of the study itself.

Ethical Considerations

This study was conducted after permission was granted from the researcher's thesis committee, the University of Manitoba Education/Nursing Research Ethics Board (ENREB), the Health Sciences Centre Research Impact Committee, and the consenting participants. Special attention was paid to ensure this study was conducted in accordance with three basic ethical principles used for study with human subjects: autonomy, beneficence, and justice (Speziale & Carpenter, 2007).

Autonomy

The first ethical principle is based on the understanding that research participants are self-governed individuals with decision-making abilities (Speziale & Carpenter, 2007). This implies participants are fully informed and aware of benefits and risks to themselves when voluntarily agreeing to participate in a study. Informed consent is crucial to upholding the principle of autonomy in any research study.

In this study, the student had invitation letters distributed to all nurses on the selected wards who met the inclusion criteria. In this letter, the purpose and goal of the research study was explained. The nurses who responded to the student's invitation were

further informed of the methodology and data collection strategies. Participants were made aware that the study was to fulfill the student's Masters Thesis requirement, and also that direct quotes may be used in the final written report. Participants were informed of the student's intent to publish the study in a professional peer-reviewed journal once the study was completed.

Importantly, the participants were reassured that they could drop out of the study at any time. Once the student was comfortable in knowing the participants were fully informed, the participants were asked to sign a form of consent. Only participants who gave written consent to participate were further approached.

Considering the unpredictability of qualitative interviews, concerns regarding potential breaches of informed consent arise (Roper & Shapira, 2000; Speziale & Carpenter, 2007). Issues emerging from interviews may lead to the vulnerability of participants when the participant feels they have divulged too much information. *Process informed consent* has therefore evolved to counteract this dilemma faced in a qualitative research study. *Process informed consent* is the re-evaluating of informed consent at various points throughout the study, which allows opportunity to change the original consent when necessary (Roper & Shapira; Speziale & Carpenter). On this premise, the student reiterated the participants' right to bow out of the study at any time and ensured the participant's authorization by reaffirming their consent prior to and during the interviews.

Confidentiality

In order to ensure confidentiality and anonymity in this study, no identifying characteristics of the participants were placed on any data collected. No one other than

the student had the names or contact information of the participants, required solely on initial contact in order to arrange for informed consent and arranging for interviews. Code numbers were used on all data collected, including demographic questionnaires, audiotapes, transcribed interviews, and field notes. Two separate lists recorded participant names and code numbers assigned and were kept in a locked cabinet as well as in password-accessed computer in the student's home. Only the student and the student's supervisor read the interviews. Special care was taken to ensure anonymity was maintained when the final report was written and will be ensured with future publications or presentations based on this study. All forms of data (e.g. audiotapes, demographic questionnaires, field notes, transcribed interviews) are locked in a cabinet in the student's home. After a period of seven years, and when the study is complete, the data will be destroyed.

Beneficence

The second ethical principle advocates for "...doing good and preventing harm..." (Speziale & Carpenter, 2007, p. 65). *Beneficence* speaks to the pledges of confidentiality and anonymity necessary to pursue an ethically sound research study. Although complete anonymity could not be ensured at all stages simply because the student knew the names of the participants when they were interviewed, no names were used once the data was collected (audio-tapes, transcripts, field notes, or socio-demographic questionnaires) or in the written report of the study. Instead, the participants were assigned a code number which was used to identify data. These code numbers were kept on a roster of participant names in a cabinet locked in the researcher's home, along with all sources of data. After a

period of seven years, and after the study has been written and completed, the data will be destroyed to maintain confidentiality.

Justice

The third basic ethical principle pertains to the fair treatment of all participants, and concerns confidentiality and anonymity. Since the latter two principles have been addressed in the previous paragraph, at this time only the principle of fair treatment will be addressed.

The characteristic nature of the ethnographic research study involves the lengthy and often deeply personal relationship between participant and researcher. In order to develop a relationship with good rapport and trust which will ultimately result in rich data, the boundaries of participant and researcher may sometimes become blurred. Nurses, who "nurture" and "protect" others, may find this relationship challenging as the researcher may be expected to, or unexpectedly take on a therapist, counselor, or caregiver role (Speziale & Carpenter, 2007, p. 67). This can present as an ethical dilemma that questions the integrity of the investigation and the researcher (Roper & Shapira, 2000).

Keeping in mind that research is not a therapeutic intervention, the student of this study paid special attention to the focus of the interviews, and made a conscious effort not to ask questions which compromised participants because they felt obliged to say things they had originally not consented to. The participants of a study must primarily and foremost have their welfare protected, which upholds the principle of preventing harm (Speziale & Carpenter, 2007).

Conclusion

Research design and methodology are the foundation of any research study. Planning and rationale behind process are imperative to ensure a study adequately fits the research purpose and questions and ultimately results in a trustworthy study that will contribute to the knowledge base in the field of study. The design and procedures behind the implementation of this study were clearly articulated to ensure rigorous insight into where nurses situate the family in the care of their adult patients.

Chapter 4

Findings

The following chapter is a presentation of the findings that emerged from this research study. A description of the sample is provided, followed by a table containing the demographic data. The chapter is then broken down into sections which provide a description of how the themes answer the research questions. A table is included which provides the research questions and corresponding themes. In addition, a diagram to provide a visual link on how the themes relate to each other can be found at the end of the chapter.

Description of Sample

In total 14 nurses participated: 12 nurses held RN status, 1 held RPN status, and 1 held both RN and RPN status. Ages ranged from 24-61 years of age, with a mean of 40.2 years. All participants were female. Number of years working as a nurse ranged from 3-40 years, with a mean of 16.2. Number of years working in their present practice area ranged from 1.5-25 years, with a mean of 7.9 years. Diplomas in nursing were held by 6 (42%) of the participants, 11 (85.7%) held Baccalaureate degrees, and 3 (21.4%) were either studying to complete a Graduate degree or had already obtained one. Other training had been obtained by 4 (28.5%) participants, of which 2 (50%) held Canadian Nurses Association certification, and 2 (50%) indicated having completed training sessions, courses, certificates, or workshops. Six (42.9%) of the participants worked full time, working between 38.75 and 50 hours a week. Eight (57.1%) worked part time, between 23 and 40 hours a week with a mean of 29 hours. Nine participants had experience

working in 1-3 different areas of practice, and 5 participants had worked in 4-7 areas throughout their nursing career, with 3 being the average number of areas worked.

Table 1. Demographic Data

		Medicine (N=4)		Surgery (N=6)		Mental Health (N=2)		Emergency (N=2)	
Characteristic		Mean	Range	Mean	Range	Mean	Range	Mean	Range
Years worked as a nurse		28	14-39	4	3-6	32	24-40	14	10-18
Areas worked as a nurse		4	2-6	1	1-2	4	4	4	3-5
Years worked on present unit/area		14	2-25	4	2-5	11	6-15	7	6-8
Age		55	52-61	27	24-35	53	48-58	39	38-40
Hours worked a week		32	25-39	35	28-40	31	24-39	41	32-50
Characteristic		N	%	N	%	N	%	N	%
Employment status	F/T	2	50	2	33	1	50	1	50
	P/T	2	50	4	67	1	50	1	50
Gender	M								
	F	4	100	6	100	2	100	2	100
Education:	Diploma	3	75			2	100	1	50
	Bachelor's Degree	2	50	6	100	1	50	2	100
	Master's Degree	1	25					1	50
	Family Education Sessions/ Workshops/Training/ Courses/Certificates	2	50						
	CNA Certification			1	17			1	50

Note: CNA= Canadian Nurses Association.

Introduction to Themes and their Relationships to the Research Questions

In the analysis of the data, several themes emerged which address the questions posed by this study (see Appendix E for definitions of the themes). Participants linked questions 1 and 3 closely, regarding what meanings nurses assign to the concepts of family and their roles in the context of adult care settings. The concept of family in the care of adult patients is described by nurses as *being there*, which is an abstract term used by many participants and portrays the family role as one of constant support for the patient. Participants clearly conveyed that the patient maintains *control* over the right to decide who constitutes their family, and although the ideal role of the family *depends* to a certain degree on practice area, a presence of the family was described as expected in all care areas. In the case that there was minimal family involvement in the care of the adult patient, this was explained to be the family's *choice* on whether the family wanted to, or could ultimately participate.

The second question regarding concept of care in adult patient care was described by the participants as *depending* on different care areas and taking into account the availability of time. Programs like Mental Health invited family involvement more so than Emergency, suggesting that the longer the relationship between patient and healthcare personnel, the greater the involvement of family in the care. Question 4, inquiring about the influence of family on nurses' care practice, was addressed by the participants with the theme of *time gets in the way*. Time was seen as a constraint on what care could be provided to the patient by the nurse due to the consistently busy work assignments and large ratio of patients to nurses. Sharing of information was seen as a necessary component of healthcare, and this was suggested to enable good quality care

when families, patients, and healthcare providers shared information and communicated easily. Participants also felt that families and healthcare personnel alike needed to *feel valued* in their role with the patient and not be discounted for whatever level of participation they had in the patient's care. Nurses wanted families to acknowledge what the nurses did for the patient, but nurses also noted the importance of whatever the family could contribute. This mutual respect was seen by the participants as an absolute necessity in order to maximize patient care and positive outcome.

Participants conveyed their feelings of how families affected nursing practice of the adult patient in different care areas as a response to question 5, in that families who demanded a lot of time from the nurse actually lessened the amount of time the nurse could spend with the patient. Thus, in this situation nurses felt that care of the patient was compromised. The family's ability and choice to be part of the patient's experience was seen as one of several factors affecting family involvement. When boundaries became blurred in what role individuals had in the care of the patient, a sense of struggle ensued between the triad of patient, family, and healthcare provider over who had the most influence over the care of the patient. This *gate keeping* was sensed by the student, although not overtly described by the participants, and was more pronounced in different care areas depending on patient acuity. The more acute the patient, the less likely nurses felt the need to involve families. Examples of this phenomenon were described in working with outpatients in the emergency room, where an obvious trauma patient does not require a lot of patient history to be taken from the family, or the emergent surgical patient who is en route to surgery and there is little time to spend engaging the family.

Therefore, nurses in different care areas identified different levels of involvement needed by the family.

In response to question 6, participants had some definite ideas and suggestions on where the family is ideally situated in the adult patient's care. The patient's existence extends beyond the snapshot taken in hospital, and therefore this *life outside of illness* cannot be overlooked. The family was a part of the patient's life before the illness, and therefore *being there* provides this constant support, steady, and sure. The family also has a *choice* on whether they can or want to become involved. Ultimately, reciprocal respect for all players is necessary in the ideal world of adult patient care. It isn't possible to discredit the patient, family, or the nurse in the patient's path to healing.

Nine themes emerged from the analysis of the participant interviews. In the following sections, each of these themes will be discussed in detail so that their full meaning can be understood.

Life outside of illness.

The importance of placing the patient in the context of what their life is like outside of the hospital was echoed by all the participants in the study. Nurse participants identified that prior to hospitalization, a person may hold multiple and simultaneous roles as a spouse, parent, or bread-winner, and even though the patient becomes hospitalized does not mean that these responsibilities will go away. Therefore, the stresses of the patient illness will affect the entire family network in some way: children will still need a parent and a household will still require an income. Nurses said that healthcare providers should seek out family in order to get a "...better picture of the person..." as one participant who works in an acute area stressed:

> It's hugely life altering, life shattering, so, you know, so these are people that are up doing their thing, they're at the lake, and then *boom* [italics added], permanently altered, and that has a huge impact on the people that are around them, and you can't, you just *can't* [italics added] ignore that. These are men and women who have teenage children, and...husbands and wives who have occupations and bills to be paid...and you just can't ignore the whole picture. Yeah, you just can't!

Keeping this in perspective is what the nurses found sets the stage for better care while in hospital, as well as better planning for what goes on when life comes to a halt in the outside world for these people. Participants stated that families are the experts on who their loved one is before the hospitalization, and this awareness from the nurse makes the transition from community to hospital, and hospital to community, that much easier. The community is where the patient's life is lived, and a full understanding of that life creates the context in which to view the patient.

> I mean, you're caring for that individual on a rudimentary level, but you really need to address that family, because they're the ones facing huge decisions, and probably financial burden, like they have huge issues to deal with...there is still a huge impact on their lives.

Although the family is impacted upon by the patient illness, participants acknowledged the need for "getting on with [their] own life". They acknowledged that the rest of the family needs to continue functioning, and the nurse can take the opportunity to teach family members to take care of their own needs in a balance with

sharing the illness experience with their loved one. As one participant noted, "...you can still have a healthy life even though you have a sick member of your family".

Need for information.

Communication is the key to care of the adult patient, and it works to the advantage of the patient when the patient, family, and nurse communicate openly with each other. Positive interactions are considered to take place when there is open and considerate dialogue between the nurse and patient or family. Participants noted that when families felt they were not getting enough information and the communication was breaking down that the nurse/patient/family relationship became negative. This becomes a stressor for all involved, and a participant described how healthcare professionals would defensively cope with families when the families were "badgering" staff for information:

> You might not be as inclined to start a conversation, that's the only way I can think of explaining it...because if the family is always there, and always in your face, then you are kinda in a defensive mode..."why are you doing this, why are you doing that"...you might not be able to develop quite as good a rapport with the patient, but I...think what needs to be done, would still be done. The care that needs to be given would still be given.

Lack of accurate information can result in the negative portrayal of nurses by the media, a concern that nurses in the study shared. Despite the defensive approach caused by feeling challenged by the family, nurses in the study understood that there is an element of fear associated with a patient's illness, and that families are afraid they will

not know what to do should something bad happen. Nurses indicated that the public has been scared into questioning everything that nurses do as a result of this fear and distrust.

> I think that sometimes when people come into the hospital, especially people who don't come in very often, I think the media has set health care professionals up.... They come in already thinking that there's going to be a problem, maybe none exists, every little thing they watch. Every little thing, because someone is going to make a mistake...and probably there is really good reason, but I think it's going overboard. Like people are terrified of the care they are receiving, and...I'm not sure how the roles come about, they just really do think that something is going to go wrong, and meanwhile, I'm not sure they really know what's supposed to happen.

Findings indicated that the nurse often takes on the role of informant, relaying information between patient, family, and the remaining health care team, often because the family perceives the nurse to be most accessible. In the same token, nurse participants felt that information imparted by the patient, family, or physician to the nurse was perceived as useful to develop care plans that most closely reflected what the desired goals were in the patient's care. It was shared by the participants that not only is information on the patient important to the care planning by the nurse, but communicating with the patient and the family provides for educational opportunities, and feedback and support that can be used to aid in decision-making and reduce stress.

Information is imperative when issues such as privacy and the Personal Health Information Act (PHIA) are addressed. Many participants shared the frustrations with having to guess who visitors of patients were, or the uncertainties associated with having

individuals telephone the patient units requesting information on the patient status and the nurse not being able to confirm their identity. PHIA was described as creating a barrier for trust between the family and nurse, and this complicated family interaction between the nurse and family when the nurse was unable to share information with visitors or inquiring individuals.

> Trying to stick with PHIA, and our Code of Ethics, well...I mean we do all the time, but in return what we get are that people are upset and frustrated. Not upset with us, but frustrated, because we can't give them information at the time that they want it.

Uncertainties about the rules of PHIA were echoed by the participants, who were often struggling with who they could or could not speak with regarding the patient. This was seen as an extreme misinterpretation which prevented communication and was damaging to establishing rapport.

Time gets in the way.

Time constraint was identified by the nurses as a factor limiting family engagement and direct nursing care of the patient. Although nurses recognized the importance of family involvement in patient care, things like increased nurse workloads were seen to impact on the quality of time spent with patients and their families and the ultimate satisfaction that nurses gained from doing their jobs at the end of the day. One participant indicated she would only engage certain family members of one patient because she did not have the time to engage any other visitor. Another participant from a critical care area indicated that patient-centred care was not practiced because the patients rotated too quickly through the area, thus not giving enough time for the nurse to focus

on the patient, but rather the focus became solely on the illness. In addition, care was prioritized by determining urgencies so that the nurses' time could be managed more efficiently. Family involvement was seen as an additional workload that could potentially strain the nurses' already taxing assignment:

> I think sometimes people can see family as being extra work. It's extra work. It *is* [italics added] extra work to include the other person, when you have to answer questions, to take the time to reassure them. It is a lot of extra work. But the benefits are so great. Like, from my experience, it was worth the work.

Some participants felt confident that what they knew to be "patient-centred" care took up a great deal of their time, and therefore they did not feel they were providing care to the level they desired. Some nurses were disappointed that basic care practices such as "pillow-fluffing" and backrubs could not be provided out of sheer lack of time, while others were concerned that they were not finding the time to hear the family, being too rushed to even listen to the family so questions that the family had were not actually being answered. Others felt that concentrating on the family demanded too much of their time, and therefore they could not focus enough time on their patients. One participant expressed that this time constraint upset her work:

> You're not responsible for [the family's] care, but you are really, because they need your time. Before they can leave at night they need to know their mom is safe, you know. That takes a lot of extra work. But it's still patient-centred focus. Even though you have the family, you still need to say "please don't interrupt me when I'm working". It was always upsetting, because you are trying to do your job, and they're interrupting.

The participants suggested that it would be a challenge to develop a model of care that would universally be acceptable to all areas of nursing practice, because there is little time in the nurses' schedule to focus exclusively on the patient or the family. In one work area, a nurse participant identified the ideal model of care to be physician led in order to reduce the time factor, with the family becoming involved only if they chose. This participant indicated that the importance of providing patient-centred care was reduced correlating with the patient's increased acuity. This is contrary to the generally accepted wisdom as noted by other participants who suggested the patient should be the central focus of care at all times, and is a case in point where the concept of patient-centred care means completely different things to different people.

An ideal model of adult care was suggested and given a name by one participant, who referred to this ideal as the *Collaborative Patient Family Community Model.* In this model, the family and community would have input into the patient care in a collaborative way. The nurse was quick to add however, that healthcare today is not capable of supporting this type of patient focused model because of lack of resources and time. Several other participants repeated this same concern.

Being there.

Being there for their loved one was unanimously agreed upon by the nurses as a way in which families could provide positive support for the patient. Sometimes difficult for participants to articulate, words to describe "being there" included unconditional support, being nurturers and watchdogs, being a constant in the patient's life, policemen, informants, patient advocates, supporting the patient to make wise choices, and providing the patient with someone who they could bounce ideas off of, as well as "...being

physically in the room, physically doing something for [the patient] every minute of the day". The sense of being there had positive connotations and nurses clearly indicated this need for of a type of social network required by all people, especially while experiencing the healthcare system.

In cases where family could not be identified by a patient, participants noted that hospital staff became like surrogate family and filled in the role of "being there" for the patient. This need for a social network was described by one nurse who spoke of patients being admitting repeatedly: "...it's much better to get sick and go back with your family [staff in a healthcare facility], than it is to be well enough in the community where you don't have anything". People need to connect with other people as part of being healthy and achieving a healthy life:

> For someone who comes in who clearly says they have no-one, they have been orphaned, or maybe live halfway across the world from their next relations...or who have really isolated themselves...a big piece of the work is finding supports, finding family in a sense, finding them some way of connecting with people outside of here....Families do a piece of that, whether they want it or not. That's really another purpose of family it seems, to keep someone engaged whether they want to be or not.

Therefore, nurses found that to deny this social support from the patient would be perceived as counterproductive to the patient's well-being. Ironically, this is contradicted to a certain degree with respect to how nurses associated theory with their practice. One participant shared frustrations at the family's presence while at the same time

acknowledging that family presence was beneficial, especially in situations where cultural practice played a part:

> We try to adopt a culture. Like with [certain] culture[s], they have their own thing. Like they usually have big groups....They can come and visit and that's fine, but I don't think we should necessarily have to change the way that the hospital works because of their culture. Like I get frustrated...we try to put them in a private room if we know they are going to have big groups of people coming, but...I find it insulting to a patient who is sharing that room with them who isn't of the same culture. Like why should they have to go through that?...You have a patient who is really sick and needs their rest, and then you have one who has visitors...and they are fine if they can go into the lounge...but if they can't, then I believe they should wait [to have large groups of visitors] until they can. I think that is only considerate of the other patient. But then we're told that we have to let it happen, because that's their culture.

A participant in an inpatient area shared how experiences with the family presence are positive, until concerns develop with the patient's health status which prompt inquiry by the family. This nurse viewed the family's concerns as something negative and bothersome:

> You can have a really good relationship with the family and then their family member usually helps, like they'll come in and help, and everything is going fine, but if they're not recovering properly, like if there are complications, or whatever, or they are really old people and they don't want to take their meds, or they are difficult, then the family is always coming and saying something is wrong.

Families were welcomed and invited to participate in the patient care by the nurse if they were agreeable with the nurse and made an effort to "help" by taking on tasks otherwise assumed by the nurse. This alleviates some workload from the nurse, and is seen as positive participation in the patient's care:

> Every little bit helps. Most people are really good about it. Like they want to help. ...Sometimes family call and say "how is so and so", and you feel like saying "well, you never come and visit, so why don't you make the effort to see them and then you'd know". It's not like everyone lives outside of the city, I'm sure.

But, if families ask questions or raise concerns which increase the nurse's workload, they are viewed as a nuisance and are seen as being critical of the nursing profession. This is a double-edged sword. Ultimately, nurses felt the patient's family should "be there" for the patient, but it must support the nurses' agenda.

Patient control.

The nurses recognized patients' desire and need for control over their lives, but the participants found that patients were at times unwilling or unable to gain control, and healthcare providers were at times unwilling or unable to cede control. Participants easily relayed that it was considered patient-centred to have patients participate in their own care, although there were mixed feelings on whether this patient involvement was routinely practiced. One participant explained the inconsistencies, attributing the patients' inability to make their own decisions to lack of knowledge and time constraints. Nurses found that whether the patient was actually unable to make these decisions could be a perception of various individuals, including the nurse, patient, or the family. A nurse on a busy inpatient unit with high patient turnover elaborated:

> I guess maybe some decisions are made and involve the patient, but I don't think they are asked what they choose to do. But then again, I don't know how many patients are actually able to make those decisions. I don't know, I mean some people now look on the internet because they think they know what's wrong with them, but I don't think they really know...people are more kinda just accepting of what goes on. They're not there long enough to have much say in decisions.

In addition, there was a discrepancy in what nurse participants considered patient participation. Many participants described patient-centred care as "meeting the needs of the patient", but there was no consensus on whether these needs were defined by the patient or decided on by the healthcare professionals. The patient's control over their participation in care was not clear for the nurse participants, despite an unequivocal statement that patient's should "make the choices that are good for them". Nurse participants found that a disconnect between the patient's right to control over their care plan and actual nursing practice existed. One nurse explained: "patient rights are great, but sometimes they don't know what's good for them, and you do land up with issues". This nurse's experience was with trauma patients who had sustained life-altering injuries, and these patients routinely challenged medical advice in what was perceived as attempting to regain some control. This being said, nurses understand that adults have the right to take risks with decision-making if they choose to do so, and nurse participants felt that they as nurses should not feel they are doing the patient a disservice by allowing them to make what they perceived as poor choices. "Ultimately, it is the patient that makes the decision, and even if you may advise them that it's not in their best interest,

that it is not healthy for [them], ultimately, it's their choice and their decision. You can give them the pros and cons, but they have to make that decision for themselves."

The nurse participants unanimously indicated that a nurse relies on the patient to identify who their family is and determine what role they are to play in the patient's care. Participants shared that in the case of patients who are incapacitated in some way or are unable to speak for themselves, the healthcare professionals or the family may assume control over their care plan. Findings showed that this is especially the case with elderly patients nearing the end of their life trajectory, who often acquired a caregiver and support person, very similar to a child at the opposite end of the life cycle. Nurses described the care of the elderly or individuals who were incapacitated as being family focused, which aligns closely with pediatric care models. However, this was not the experience of all participants. In some cases, nurses identified that families were excluded from the patient's care at the patient's request, in order to avoid placing additional burdens on the family. In these situations, the patient was unable to assume direct control over their care, but rather orchestrated who they would task with taking their care on.

It depends.

Nurses stated that a variety of variables influenced the care of an adult patient, but on a situational basis. Personal style of the nurse, generational differences, culture, and personal experience were some of the factors which the nurse participants indicated were determinants of how they practiced care. Therefore, "it depends" was what nurses used in various contexts to represent an action or a response to a situation which could not be clearly defined or predicted.

From the interviews, nurse participants shared their opinions that many of the parameters of their work could not be delineated, which contribute to inconsistencies in patient care practices. Nurses felt that the culture of the nurse as well as the culture of the patient and family played a role in how care was provided. For instance, a participant who is of a particular culture indicated the expectations placed upon her to look after her elderly relatives. Her exposure to the role of family affected her nursing practice by increasing her sensitivity to include family in the patient care. She felt that an individual's upbringing determined how they form an opinion on things, inclusive of the role of family.

> Our culture is very family oriented. I do notice a lot...like family members that try to push their children out of the house...try to get them to experience things on their own, and growing up that way. The Filipino culture...we like keeping the generations together and taking care, and...my grandma even told me, that if we ever treated her, or sent her to a nursing home, she'll kill herself, like joking...but I think she is serious that she expects us to care for her because she gave her whole life caring for us, and bringing us up. Something like that.

On the contrary, participants also shared experiences with patient families where cultural stigmas to certain illnesses prevented the nurse from involving the family in the patient's care. A nurse shared the frustration of not being able to find support for individuals who were suffering with Human Immunodeficiency Virus, because the patients could not disclose their illness to their families:

> My experience with family is unconditional support around all issues. I am very lucky. That is my experience with family, grandparents, parents...I accept it, but I

> feel badly for people who don't have unconditional support, or people who have such disenfranchised lives, like such serious injection drug users who can't help themselves, the alcoholics who can't help themselves...it's very sad. I understand it's an addiction for a lot of them, and that's what creates this disenfranchised life for a lot of them, but you can only do so much. And over time, I've accepted this.

Although culture was identified as an important factor affecting patient care, some participant approaches to cultural identification were less accommodating. This discussion stirred reflection by some participants, who did not feel the need to have to change their care plan to suit the patient or family. The value of cultural needs varied depending on the participant.

Aside from culture, participants noted that the care they provided was dependent to a certain degree on whether they viewed the family as part of the patient. If the nurse viewed the family as part of the patient, the nurses felt they might be more inclined to invite family participation. This was the case especially when nurses indicated that patient acuity was high. Some of this involvement was contributed to the nurse's experience, and chalked up to intuition on how to approach families, while some impressions were made that the hiring of young staff can change the mindset of fellow colleagues into "well, I don't mind if [family] come".

Educational preparation, ironically, was not seen by nurse participants as a determinant of good patient care. Nurses shared that what is taught in schools is completely different than the real world, and participants in this study reflected on how nurses "learn on the fly". This is seen as a detriment, because as one nurse working in an inpatient unit identified, nurses are ill prepared and then are forced to learn as they go, by

not the best resources. Some participants noted that nurses who are fatigued and burned out are sometimes the only role models available. A nurse with over 25 years experience shared:

> They have people who don't want to work anymore, they're just coasting along. You want my personal opinion? I mean if I were a supervisor...they would be working much harder and doing things a lot different. It's just appalling. It's lack of experience, its lack of motivation.

With several different factors outlining nurse, patient, and family expectations, nurses felt that there was need for flexibility in addressing various patient care situations. It became obvious from the participants that different care areas, different consumer populations, and different healthcare providers contribute to the challenge in providing a system where situations and responses can be predicted.

Choice.

The patient maintains the right to either invite their family into their care, or exclude them. But ultimately the family has a say in the extent of their roles in the patient's care. Involving the family is not as simple as it seems, and participants in this study shared experiences that both hallmarked families desire to take part in care, but also, their disengagement with the patient. Feeling powerless in the patient's illness, and making a choice not to participate because of lack of confidence in their role, was seen by nurses as contributors to family disconnect in care:

> I would like to see them have more participation....I think many think they don't have a say. You know, there is still that "doctor is God" kind of attitude. So it would be nice if [the family] knew that they could...have a say.

Aside from family wanting to participate in care, findings showed that there are also those individuals who choose to abdicate their responsibilities. One participant reflected on family members who arrive with the patient as escorts, and are provided airfare, accommodations, and meals to accompany patients to the city from rural communities. Nurse participants shared that insoluble frustrations for the nurse become evident when these escort duties are seen as free rides to the city centre, and the escort instead decides to use the trip as a vacation, completely shirking off any responsibility to support or assist the patient.

Nurses also felt that family avoidance in caring for their loved one was sometimes attributed to coping abilities, and they avoided participating in care not because they did not want to, but rather because they could not deal with the situation for whatever reason. Nurses indicated that consideration needs to be made of the family's social situation: a spouse may not be available to be at the patient's side if there are childcare issues, or perhaps transportation barriers prevent them from commuting to be with their loved one. Nurses felt that tolerance must be provided for those families who need encouragement to become involved. Nurses also noted that considerations of the family's well-being should be taken into account, especially in cases where behavioral issues are at the stem of hospitalization:

> Sometimes depending on the [patient's] age, the family has had to withdraw in order to be safe. The patient is too destructive to the family, so to maintain contact with the patient, and for their own health they need to separate....That's their personal choice. You know, you can't make them become involved.

Nurses felt that ultimately, family could only become involved if they were ready; otherwise they are not of any help to themselves or the patient. Participants felt that a nurse asking a family member to perform a care activity did not ensure it was done safely and correctly if the family had not made the decision to learn how to perform the task properly. When lack of commitment was evident on the family's part, nurses shared their frustrations with those who wanted simply to observe and not become actively involved. In cases where the family was disengaged for whatever reason, the patient was seen by the nurses to assume their entire burden on their own, because they did not have the family support, and this was viewed as a huge detriment for the patient.

Whether or not the nurse felt the patient had the right and ability to choose their care plan was an issue that was addressed by the nurse participants, and called them to evaluate their own ideas of what patient choice meant. A nurse who works in a post-acute inpatient area shared her thoughts:

> It makes you afraid of what's going to happen when they're out there. Or, you are teaching someone, and they're not interested, you teach them how to do things and you go back to evaluate, and they're sloppy at it, or they don't really care. It's a bad attitude. And you then worry what's going to happen in the community. And it's also the ones that go out on their passes, and come back drunk. Drinking or doing their drugs. Stuff like that happens, and they come back pretty wired, and this is what they're going to be like when they come out of hospital from rehab. You know, they're going to fall apart. O.K., maybe you're still coping with what's happened to them, or this is a pre-morbid behavior that got them into this situation that they're in now.

Nurse participants in general indicated they would like the family to be actively involved in the patient's care and see their role as one of support to improve the patient's health. The expected role of the family was seen by the nurses as support for the patient to make a positive choice, as one participant stated:

> Family is the key in support for patients. However, sometimes they're not always like that. It can be, family can be, not wanting the patient back, you know, trying real hard to place them in a personal care home, or having them stay in the hospital longer. So, they're not always a support. But I think the positive family environment is that they are there for support, to help the patient get better. I think they play a huge part in recovery.

A nurse participant stated very bluntly that "everyone has the right to a home, and to feel safe, and to have family", which was echoed by other participants in this study. This research found that part of the equation in making this become a reality was the nurses' choice to invite and allow families and patients to participate in the patient's care.

Gatekeepers.

Participants repeatedly spoke of the nurse taking on roles to mediate, monitor, and set limits with patients and families; in a sense, they were gate-keeping entry and control in the care of their adult patients. Nurses noted they were the "go-to" person when family or patients needed information, rather than individuals seeking out physicians or other healthcare providers. Nurses also said they were seen as those who could initiate family meetings and consults to healthcare services, encourage medical compliance with patients, and either allow or disallow visitors from accessing the patients. In short, nurses

felt they were required to assume a significant amount of power in the healthcare system, although in this study they did not admit to being powerful themselves.

Participants found that families and patients had the ability to exert control over the adult patient's care, but this was not always readily accepted by the nurses assuming care. Nurses shared that large family groups who would visit a patient were sometimes viewed as being a nuisance to other patients, who in the presence of strangers could not rest or relax, having a negative effect on their health. Nurses stated they took the responsibility to run interference in situations which they perceived was detrimental to the health of their patients – visitor numbers that exceeded organizational rules would be asked to leave. In the same token, nurses monitored family involvement in the patient's care, and would advise if the care exceeded expectations and was not considered helpful:

> Because there can be such a difficult time with boundaries, sometimes the family is here and they are doing more of the work than the patient. So, the family may be...demanding services, and wanting something, and yet they are not the identified patient. So sometimes, the involvement is in that way, and sometimes we have to talk to people about coming less, and less involvement.

In the same sense, nurses felt that families would sometimes ask many questions in order to understand the experience of their loved one, and prepare themselves for what the plan was and how it would play out. This questioning was described by some nurse participants as being interruptions, and often these interruptions were perceived as being unreasonable and demanding. Participants in general seemed to prefer families who were "friendly" and "nice" over families who asked questions:

> [The family] works the crowd....[The patient's wife] is very nice. She steps out of the room when things are happening. But, she's been around enough nurses...and if you're nice to the staff, things will work better....[The family is] not there for you to serve them. They just want to get better and then get home. That's the whole thing.

Another participant spoke of nurses whom she had experience with when she was a family member herself. The nurse stated she was exposed to nurses looking after her loved one who made her feel fearful of speaking up out of fear that the staff would harm her family member. This nurse described the patient as "being at [the staff's] mercy":

> I guess [the nurses] don't want to be questioned...so they disrespect families, and they're right...[nurses] shouldn't be at all questioned as to why they are doing something. I mean, to them, family is more of an interruption, and I can't say that's everybody. But, they don't necessarily want to work with people.

Families who asked questions and were not satisfied with answers they received could be perceived by the nurses as being interfering. One participant shared frustrations: "...if you did something a little bit different than another nurse, then either she was wrong, or you were wrong, or you know, they would play people against each other". This appeared to present a type of power struggle between the nurse and family, as reported by the nurses. Ultimately, nurses largely felt that the nurse and healthcare system ended up taking control, which then removed control from the patient and family altogether.

> Much of nursing is trying to find the balance between our real moral limitations, and what is best for the patient and the family. You know, you're always trying

> to find that balance, so that everybody agrees it's safe, everybody agrees it's... appropriate, but we're not totally listening to what the family wants. In the case of [a] guy who we tried to get back to the reserve...the team worked really really hard to make that happen because that is what the family wanted, and then...in the end the resources are not available, and it just couldn't happen....But, there is only so much that we can do too, I mean, it wouldn't have been safe to send him, and we have to draw the line, even though that's not what the family wanted....[Nurses are] always trying to find that common ground. But there are a lot of limitations put on nursing that sorta impairs our ability sometimes to help the family.

Nurses felt that different gatekeepers exist who want power, the family, the patient, and the nurse. The gatekeeper with the most power wins in each situation.

Feeling valued.

The importance of feeling mutually valued resonated in all of the nurses' interviews. Not only did nurses conclude that patients and families needed to be respected in their role, but nurses themselves needed to be valued for their work in caring for patients. "I try and treat everybody, like you know, as if they're significant. Because if they're here, that's a big commitment for family". Advice from participants was that nurses should place themselves in the shoes of the family and patient to understand the upset associated with an ill family member. Nurses stated they should "walk the talk" to role model how they themselves would like to be treated. Simply showing understanding and empathy could de-escalate an emotionally charged situation as indicated by the nurse participants, and showed a commonality between people. As one participant found insight in valuing whatever efforts the family placed in the patient's care:

> I think there is better outcome when you have supportive family who are... advocating for their loved one, and who are here, you know, like I'm not suggesting that people need to give up their lives, but who have a presence, those patients tend to do better...in the long run. They tend to achieve higher rehabilitation in my eyes. Some people are there, and other people just can't cope or whatever, you know, or they start coming less or more sporadic...you can't blame the families for their circumstances, I mean, because you don't know what's going on in their beyond.

Nurses also discussed their feelings of the family being an extension of the patient, and therefore, how the family experienced the healthcare system would reflect on how the patient responded. A nurse who worked in a critical care area suggested that if a family was feeling mistreated by a nurse they would maintain that opinion. The way a nurse communicated with families and patients would therefore have a significant impact on the experience for everyone:

> [There's the] feeling of being mistreated as soon as [the family] walk[s] in the door. There's a big difference when someone asks if their family member can get a bed, and you say "I'm sorry, but we don't have a bed right now, it's going be a wait. This is a chair, it's not a bed, but we're going to be checking on you". This is entirely different that saying "There's no bed, now just go sit in the waiting room". Huge difference. Because if it's a bad situation, right away the patient and the family are on the defensive, and that stays with them during their hospital stay.

Unfortunately, nurses found that it was difficult to maintain composure when nurses felt threatened or undervalued. The nurse participants shared personal experiences of "being attacked" verbally by families. This occurred in situations where nurses felt they were perceived as not devoting as much time to the patient as the family saw fit, or when things went wrong and the family felt the need to place blame on someone. Nurses said they had been targeted by name-calling and other statements of disrespect by families and patients alike. So much so, that nurses had on occasion refused to look after a patient, because of their perception of abuse. Gratitude was lacking from many patients, as some nurses noted, and thus their method of coping with this was to become hardened and unsympathetic towards patients and their families. In this way, nurses felt they collapsed under the pressures of the public who scrutinized their actions. A young nurse working in an inpatient unit shared: "We're also human beings, we can only do...we can only answer and do so much, and sometimes it's not enough for them. And it's frustrating as nurses to feel that way, like you didn't do your very best, but really you did". Another nurse explained her feelings of being devalued:

> In some situations the family member doesn't take you for being very important anyways, and they only want to talk to the doctor. I think that's really ignorant. I mean, when a family or patient is acting like that, like they want to talk to the doctor, well of course I'm going to get upset. I mean, I'm here all day, and I want to tell them that they should be happy that they have me here. But, I mean, whatever.

Some participants felt very passionately that the profession of nursing was responsible for not being respected. They felt that more nurses should promote the

profession as being a highly educated field, instead of allowing the public to interpret nurses as "unimportant' or "uneducated" and "not having a say". Some nurses who were in the nursing profession for only a few years found that they were feeling defeated and devalued. This begs inquiry into not only how this affects the care that is provided, but how nursing can sustain itself if its membership is taking the mindset of defeat.

Table 2. Research Questions and Corresponding Themes

Research Question	Corresponding Themes
1. What meanings do nurses assign to the concept of family in their care of adult patients?	• Being there – the primary role of the family • Patient control – patient decides who their family is and how much they can be involved • It depends – family role varies depending on the area of practice • Choice – the family owns the right to choose their role with the patient
2. What meanings do nurses assign to the concept of care in the context of adult care settings?	• Need for information – a reciprocal sharing of information leads to the best care for the patient • Time gets in the way – time limits what the nurse can do for the patient and this is complicated when there is a family present • It depends – description of "care" is different in the different areas of practice
3. What roles do nurses feel families should have in the care of adult patients?	• Need for information – sharing of information from all sides is necessary to provide the best care for the patient • Being there – the primary responsibility of family is to provide support for the patient (can be defined different way: e.g. emotional support; assisting with daily routines; assisting with therapies) • Patient control – patients own the right to invite family into their care, or exclude them • It depends – degree of family involvement varies depending on areas of practice
4. What influences do nurses feel families have on their practice of care of adult patients?	• Time gets in the way – family makes demands on nurses' time, which decreases the time the nurse has to spend on the patient • It depends – family influence on nursing practice is dependant on the are of practice (e.g. long term admission in psychiatry where the family and nurse become very close to each other vs. emergency room where relationship is short term) • Choice – families may be intrusive or cooperative in patient care, which could demand more or less time of the nurse, and therefore affect nursing practice • Gatekeepers – ongoing struggles exist to determine how much influence the nurse, family, and patient have on the patient's care, because somebody has to have the final say

- Feeling valued – nurses who do not feel appreciated by family tend to not want to involve them at all in patient care. As well, nurses who do not see the value of family in patient care, will prevent family participation

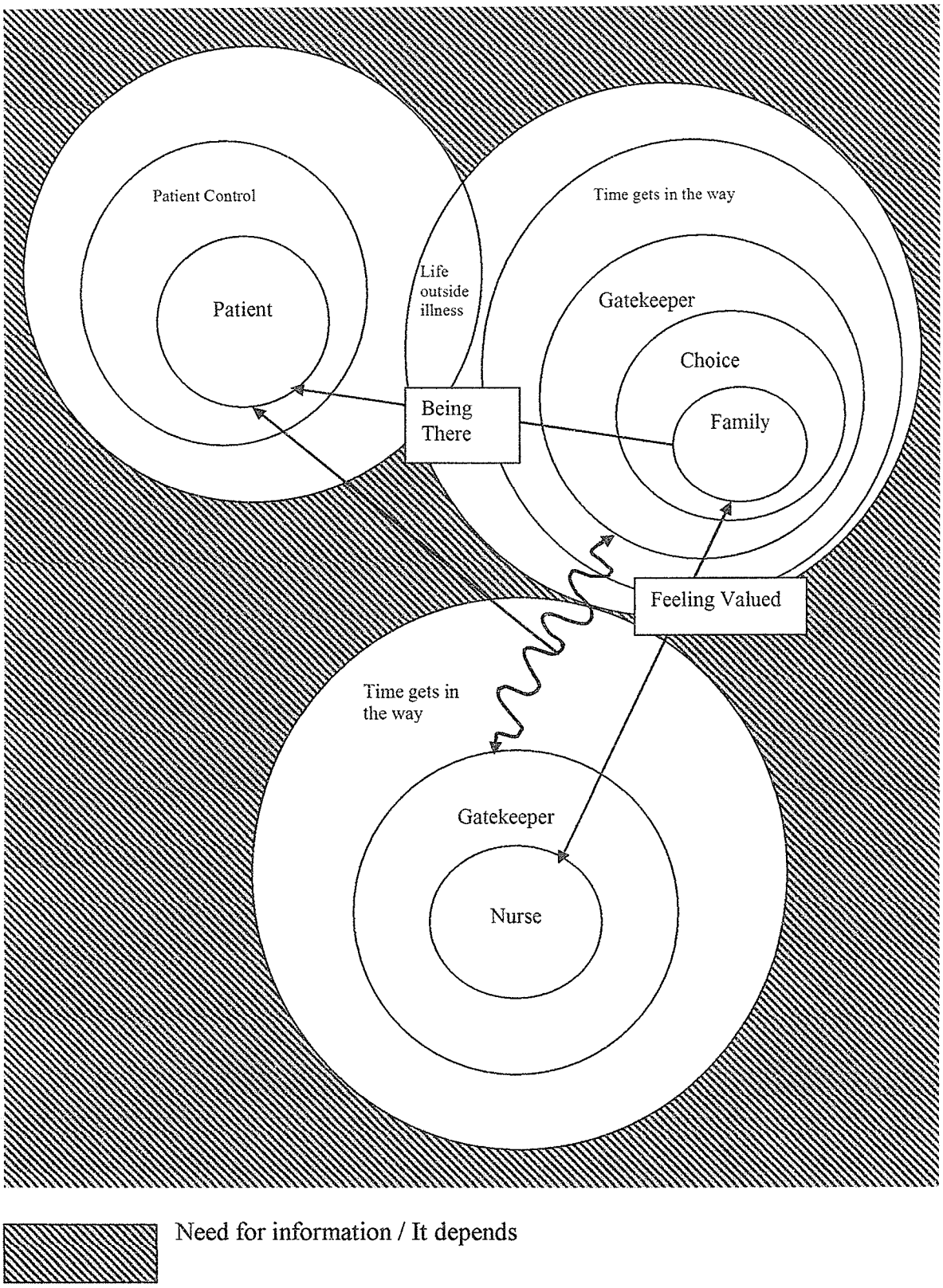
5. How does nurses' perception of the concept of family in their practice of adult care vary between different care settings?

- Life outside of illness – appreciation of who the person is outside of the illness is pronounced in care areas that deal with patients who may in some way be incapacitated (e.g. psychiatry, neurosurgery)
- Need for information – areas with a quick turn-around time like surgery, may expect less participation and dialogue with family in the hospital environment than areas where there is long-term treatment, such as medicine. Need for information sharing is lessened in some areas depending on acuity (e.g. patient presenting in emergency require only basic information in order to provide treatment, and some of the information is self evident, as in severe trauma cases)
- Time gets in the way – patient acuity and nurse to patient ratio can either hinder or promote time spent with the family
- Gatekeepers – need for control and power over the patient care detracts from the focus on the patient, and many hinder care (e.g. nurses may not see a need for the involvement of family in the treatment of the patient depending on level of acuity)
- Patient control – patients who are compromised or incapacitated may have less control over their care and the involvement of their families
- It depends – every patient case is different in the sense of different diagnosis, different patient, and different family
- Feeling valued – wherever the patient is in the care trajectory would influence the nurses' perception of the value of that family to the patient's care, and vice versa (e.g. long term treatment may result in a familiarity between nurse and family, enabling establishing a deeper relationship, whether it be good or bad)

6. What recommendations do nurses have about how to best situate the family in their care of adult patients?

- Life outside of illness – the illness experience in the hospital is merely a snapshot in a moment in time of the patient's life, and therefore the rest of the patient's existence cannot be neglected or excluded
- Being there – the family responsibility is to provide support for the patient (e.g. support can be defined in many ways: emotional support, assistance in drug administration, ensuring treatments are performed)
- Choice – families should be invited and encouraged to take on responsibilities to care for the patient when the patient desires
- Feeling valued – there should be emphasis on educating the public that family is an important part in patient care and also that the nursing profession is an important part in patient care; likewise, nurses need to understand the importance of family in the patient's life, no matter how family is defined for that individual

Figure 1. Relationships between themes.



Conclusion

The findings of this study of where nurses situate the family in the care of their adult patients, provided insightful information which could be applied in the context of the research questions. In addition to addressing those questions, further information was gleaned from the interviews. When participants were asked to articulate the kind of care they provide to their patients, most participants were lacking confidence in describing their practice. Terms such as patient-centred care and family-centred care were concepts that the nurses struggled to define, which suggests they had limited familiarity with the terms. Participants indicated that a philosophy was lacking which supported them in their work with families. This lack of support was attributed to lack of organizational philosophy, time constraints, and a damaged perception of the nursing profession made by the media which inhibits family from inviting nurse support. Nursing education was also noted by participants to be incongruent with nursing practice today, and experiences were shared by the participants indicating that what happens in school is different than what happens when nurses are exposed to the real working world. Participants felt that interactions with families cannot be taught in the school system, and therefore nurses may be struggling with the family role and its place in adult patient care.

The findings which emerged from this study can be compared to other research that saught to understand how nurses situate the concept of family in their care of adult patients. Therefore, the following chapter will discuss how the findings of this study relate to the literature which was reviewed.

Chapter 5

Discussion

Chapter five presents a discussion of the findings of this focused ethnography studying nurse perspectives on the role of family in adult patient care. This chapter discusses several topics. First, it examines the major themes which emerged in this study in relation to the literature. Next, a discussion on the chosen methodology and approach to exploring the research questions takes place. Finally, the significance of the study is presented, and recommendations for nursing practice, education, and research are offered.

Central Themes in Relation to Literature Reviewed

Life outside of illness.

Findings from this study revealed the importance nurses placed on the role of family in maintaining a connection to who the person was before the illness took hold. "Life outside of illness" was highlighted by participants in this study as being what the patient was all about. They identified that a patient's illness experience in hospital was only a snapshot in their life, and therefore there was so much more to the person than what the nurses saw. One participant shared:

> One of the biggest things that I'm always trying to remind myself is that we do not know these people, like [the family] knows them. And so, we can't ever benefit from telling family...from our limited perspective, about their loved one. I mean...we can't tell them what their situation should be....We tend to focus on the person in the bed....And we forget about the person that had a job, the person that had a family, the person that had a life, the person that had friends, and we're just focused on the illness and the acuity, and I guess for me my thoughts on family

> and the importance of that, makes me constantly remind myself that they know the rest, I don't know the person. And so I'm only the expert on what we do here and now, they're the experts on who the person really is...what their potential really is for recovery, like we don't know what their baseline was because we never saw it, and you forget that, and that they were an individual.

Literature supports this statement (Davies & Nolan, 2004; Topor et al., 2006) and stressed that obtaining information from the family is necessary in both understanding the patient as a person and understanding the role of the family in this person's existence, and vice versa. One participant stated:

> I mean there are times when [the family] were very helpful when they could explain something, for instance if their mom couldn't speak well, they could explain, you know, what she might be thinking, or what she might be feeling, because they knew their mother.

Participants in this current study conveyed that their practice was neither exclusively patient nor family-centred, but rather both. Nurses very much invited the family to participate in patient care, as long as the family was not the source of the patient's illness episode in the first place, and likewise the patient was not a risk to the safety of the family. Patients seemed to benefit from the involvement of family, and nurses shared opinions that families are the links to the world outside of the illness, which was echoed in the literature (Topor et al., 2006; Jacobsen & Severinsson, 2006). As found in the current study, families could readily access staff when needed, and families were invited to take part in family meetings, sometimes against patient wishes. If the patient was seen to be incapable of making sound judgment due to illness, the healthcare team

would make decisions in collaboration with the family regarding what was viewed as being in the best interest of the patient. Nurse participants in this current study felt that establishing rapport with patients and families in inpatient units enabled a type of "family" environment, largely made possible by the length of patient stay, which was said to be anywhere from a few weeks to a few years. Low turnover of staff and vacancy rate was also reported to play a factor in keeping the "family" atmosphere alive in inpatient units, where staff not only grew together professionally and personally, but staff also become like part of the patients' families. Participants in the current study proudly shared that the older generation of staff mentored the younger nurses in the specialty, and imparted values of respect and "family" on them, so that this not only changed the way they approached patients, but also how they approached co-workers.

Need for information.

Findings from this study reveal that communication is key among nurse, patient, and family in order to maximize patient care. Literature clearly outlines that the family is a necessary resource in providing patient information to the nurse (Crist, 2005; Laitinen et al., 1996; Lobchuk & Stymeist, 1999; McCarthy, 2006; Neabel et al., 2000; Piipo & Aaltonen, 2005; Sjoblom et al., 2005), and participants in this study shared this sentiment. Nurses must communicate with families and patients, since meaningful communication enhances good patient outcome when families have an understanding of the illness and are able to provide informed support for the patient (Weinberg et al., 2007). Not only is information necessary for the family to provide support for the patient, but in some areas of care, such as in surgery, patient care in the preoperative phase hinges

on the information nurses gather from the family at the bedside, consistent with what was found by Paavilainen et al. (2001) in their qualitative descriptive study of surgical patients.

Sharing of information has also been identified as an important determinant of patient and family satisfaction (Attree, 2001). Nurses in the current study spoke of positive experiences with patients and families when the nurse and family were able to establish rapport. This rapport led to increased participation from the family in the care of the patient, and this positive experience has been echoed in the literature (Laitinen & Isola, 1996). However, when things did not go as smoothly as planned, the family began asking questions which the nurse could not always provide the answers to; this is when the reported experience deteriorated. Thus, providing open lines of communication is required in order to reduce stress and increase family and patient satisfaction. One nurse participant shared:

> Different personalities can make or break the patient's hospital stay, you know, whether there is miscommunication between the patient and the nurse, or the family and the nurse, and it can really make or break...because if it's a bad situation, right away the patient and the family are on the defensive, and that stays with them during their hospital stay.

Bauer's (2006) qualitative study of nurses and health care attendants working in personal care homes found that involvement of the family increased the likelihood of communication with healthcare personnel which generated staff support for the family and in turn encouraged the family to provide psychological and emotional support for the patient. Participation by family was seen as a benefit for everyone all the way around,

and as Schoot et al. (2005) found in their qualitative study of patients and their caregivers, family and patients genuinely wanted to be involved in the adult patient's care. As was found in Benzein et al.'s (2004) qualitative descriptive study with nurses, nurses were receptive to family involvement if the family members were open to discussion with the staff. Benzein et al. also found if families were not interested in discussion, or rather became demanding in the patient's care, nurses perceived the family to be a burden. One participant of this thesis study described:

> There was one family, one family does come to mind, and she was a younger woman in her 30s, and she had cancer, and that was a positive experience. Her husband was with her every single day, he didn't interfere. He just had really good questions...[family] should be there to help, and to you know, I just don't think they should interfere.

It is documented in the literature that how family is perceived by the nurse may be impacted on by the nurses' personal experience (Ward-Griffin, 2001). This personal experience was also identified by nurse participants in the current study to influence the nurses' acceptance of cultural diversity. Personal exposure to cultural practices different from the nurses' individual experience requires flexibility with care, and literature indicates nurses are not always sure where to place the role of the family in transcultural care (Cioffi, 2005). Culture, which means more than just ethnicity, can be confusing to navigate, and nurses from the current study shared frustrations with not knowing boundaries and limitations on who was part of the patient's care. This was especially identified in cases affecting patient privacy, where nurses knew they could only share information where the patient's had granted consent for certain individuals, but were put

in compromising situations when the nurse could not confirm the identity of the visitor. This fear of breaching confidentiality often prevented information sharing, and as Thurston et al. (2003) discovered in their pre-test/post-test quantitative study, this may result in a total lack of communication exchange. Winefield and Burnett (1996) indicate this uncertainty of where the family's place is in the patient's care is a barrier to establishing a relationship between nurse and family.

Time gets in the way.

From the literature, it is found that family requires the support of the nurse and healthcare team in order to manage the illness with the patient (Anderson, 2000; Astedt-Kurki et al., 1997; Benjamin et al., 2004; Craft & Willadsen, 1992; Duran et al., 2007; Eggenberger, 2004; Hallgrimsdottir, 2000; Kinsala, 1999; Law et al., 1995; Neabel et al., 2000; Ochieng, 2003; Paavilainen et al., 2001; Porter, 1979; Rantanen et al., 2004; Restall et al., 2003; Schoot et al., 2005; Sumsion & Law, 2006; Timmermans, 1997; Ward-Griffin et al., 2003; Wilkins et al., 2001). This was confirmed by the nurses in this study, however, despite nurses identifying the ideal practice of providing support for families, their reported opinions were that there was limited time in the nurses' workday to do so at a level that satisfied the family or themselves. Family was often viewed as extra work, and even so far as being an interruption and nuisance in some of the nurses' workday, a concern the nurses felt might affect their nursing care of the patient. This confirms findings from the literature that family is sometimes viewed as being a burden on healthcare workers (Benzein et al., 2004; Blackford, 2003; Freidmann, 1991; Pelusi & Krebs, 2005; Winefield & Burnett, 1996).

Nurse participants who worked on medical units communicated that their practice was both patient-focused, but also very family-oriented. Because patients who are admitted to medical units may have a longer length of stay and may be older due to chronic illness, family presence or participation may be more pronounced than in a surgical area where length of stay is on average significantly shorter. Medical nurses in this particular study commented on time constraints which largely defined their interactions with family members. Staffing issues were noted by all participants, in that there never seemed to be enough people to provide enough care, and this supports the literature that barriers such as decreased staffing levels and high turnover affect collaboration between family and nurse (Haesler et al., 2007). Nurse participants reported welcoming family members, although this appeared as a contradiction, since the nurses stated they could not afford the time it took to engage family members and introduce them to patient care activities; nurses were simply too stretched by having to look after several patients. This supports Laitinen et al.'s (1996) study of families of elderly patients, who found they were prevented from participating in care of the patient because of lack of communication with healthcare staff and lack of time afforded by the nursing staff. In the literature, time constraints as a result of increased family demands and organizational limitations were identified factors which prevented practice from becoming fully client-centred (Wilkins et al., 2001). It was understood from the participants that participation of the family in the adult medical patient's care was important and welcomed; however, it was very evident with all participants that tension could exist between family and nurse. Nurses genuinely showed interest and desire to involve family in patient care and did engage families where possible. However, feelings

of being overworked and undervalued also existed and perhaps even created the sensitivity to the questions family posed to them regarding their practice.

In the emergency department, involving the family in patient care was described as difficult for various reasons. Nurse participants found that with acute presentations of illness, there was often limited time to involve anyone in the care planning aside from the physician and healthcare team. Of course, it was suggested that each case would be treated individually depending on urgency of intervention. Nurse participants alluded to welcoming the family into the department, but families were frequently only expected to *be there* for the patient. With the turnover of patients in the department, nurse participants felt that questions from the family required a time commitment which could not be easily afforded, and strict cooperation from the family was expected. Engaging the family was seen as a duty of the Clinical Resource Nurse so as not to take valuable time away from the bedside, but this engagement of the family was seen to be hit-and-miss depending on how the Clinical Resource Nurse viewed the family. Nurses at the triage desk were seen to set the stage for either a favorable or negative experience involving the family, as the interaction with the triage nurse either welcomed or excluded the family as part of the patient's care, and this first contact with the emergency department would provide the lasting impression.

Being there.

Patients in the healthcare system require a support network outside of what the healthcare system can offer them. As described by Woodgate (2006b) in her longitudinal qualitative study with adolescents experiencing cancer, "being there" described a phenomenon where an individual succeeded in developing a relationship with the

adolescent, making them feel part of the world. Similarly, this presence and act of *being there* for the adult patient is identified as being a positive force in the patient's experience (Jacobsen & Severinsson, 2006; Lowton, 2002; Montalto, 1996; Topor et al., 2006). Family was found to provide companionship for the patient in Lam and Beaulieu's (2004) qualitative study, aiding in relieving the burdens of loneliness, anxiety, and isolation which could be experienced while in hospital. It is described by the participants in this particular study as being a necessity for the patient's well-being, and although the concept of being there was difficult for the participants to define, it described an all-encompassing support for the adult patient, including mental, physical, and emotional support. In the case where the patient's family was not there for the patient, the staff providing the care would become a type of surrogate family; this was especially true in practice areas such as psychiatry, where a lengthy admission or repeat admissions of the patient enabled familiarity and rapport to be established with those who worked there. And in cases where the patient lacked a relationship with both family and staff, the patient was seen to shoulder the burden of their illness experience on their own. This was viewed by the nurse participants as detrimental to their progress.

Patient control.

A unique finding in this study was that patient-centred care, or family-centred care with the adult patient, did not have clear and universally known definitions. Although most participants in this study placed the patient at the centre of the care provided, this was interpreted differently in itself. Nurse participants could not identify having learned these models specific to adult care. Findings from this study indicated that

placing the patient at the centre of care was interpreted differently, and could be described by one of the following statements:

1. The nurse and healthcare team would develop the treatment plan for the patient, considering what they think would be in the best interest of the patient, with no input from the patient or family. Responsibility of the healthcare team rested solely with getting the patient medically well so as to get them home.
2. The healthcare professionals, patient, and family would collaborate to consider what they think would be in the best interest of the patient.
3. "This is what I need", with the patient having complete control in decision-making over what they need or want done to them.

Nurses in this study used the term "patient centred" to describe a holistic philosophy where the patient was treated as a whole unit: body, mind, and soul. Nurses found it challenging to articulate how to put this into action, and many were puzzled by who should be responsible to create the standard in which to measure whether this philosophy was being lived or not. Findings showed that healthcare personnel most often *treated the patient* as a whole within this philosophy; that is, the patient was a recipient of treatment, not a participant in it. With the different meanings assigned to the concept of patient-centred care, it became evident that a particular model of practice was lacking even within a single organization. Findings revealed that patients were either in control, lacked control, or were partners in their care planning.

The idea of partnerships is echoed in literature specific to occupational therapy, and in their discussion paper Restall et al. (2003) reveal that clients are expected to make personal decisions on their care based on information provided by the healthcare

provider. Sumsion and Law (2006) explain in their theory paper that the patient/client is the expert on their life situation, and the therapist is the expert in clinical knowledge; together, the patient and healthcare provider create the ideal partnership.

In the literature by Brumfield and Lansbury (2004), patient control is the hallmark difference between pediatric and adult care models, and thus the difference between family-centred and patient-centred care. Other literature indicates that the adult patient assumes responsibility for making choices in the patient-centred care model, and despite the possibility that these choices might conflict with the beliefs of their health care provider, the patient has the final say (Schoot et al., 2005; Stewart, 2001).

In the literature, the meaning of family is a subjective concept and is not exactly defined by any two sources; therefore, family can best be broadly defined as being of personal choice (Brown, 1993). From this particular study, nurses identified that family is a highly individualized concept, and therefore they were comfortable acknowledging that family is defined by the patients themselves. Participants were vague in identifying who the patient's family might be, and nurses in all areas of practice were accepting of whoever the patient identified to be their family. When asked to identify who the participants themselves viewed to be their family, some participants labeled family to be their next-of-kin, people who they trusted, or people who they could count on. The meaning of family for the participants themselves was not reserved for only blood relations, and participants openly shared that they had friends who they considered their family, and relatives who they were only tied to by blood-lines. The discussion with the participants clearly outlined that although family has been traditionally viewed as blood

relatives, all the nurses pointed out that present definitions of the family make-up no longer fit the traditionally accepted definition.

It depends.

By observing this difference in expected practice, findings showed that there exists an unclear set of boundaries where nursing role and family role intersect. A comment made by several of the nurse participants in this particular study was that the real world of nursing was quite different than what was taught in the nursing education system, and this does nurses a disservice when preparation is inadequate to meet workforce expectations. Many participants spoke of their dealings with families, saying that their practice was not taught to them by anyone; rather, nurses largely developed their own practice, or were mentored by other nurses in their work area, whether the role model was positive or negative. In the literature, nursing students identified that nurses frequently addressed only one family member in the care of their patients, despite boasting the involvement of the family network as the context in which to view the patient (Saveman et al., 2005). Nurse preceptors, who were reported to have been teaching students about the involvement of family and friends in patient-centred care, omitted teaching students how to address the patient's family (McCarthy, 2006). Likewise, another descriptive study identified that more than three quarters of the nurses sampled did not have instruction on how to deal with the psychosocial needs of the family, and were lacking confidence in how they dealt with the families of their patients (Hallgrimsdottir, 2000). Astedt-Kurki et al. (1997) found that there was no right way to provide support for the family and the patient. In their qualitative study with family members, it was revealed that support required by the family depended on their needs,

and if these needs were met the family would be more able to support their loved one as the patient.

Choice.

This study found that families maintain the right to choose whether they will participate in the patient's care. It became evident from the nurse participants that family choice may be based on various factors, including the ability to afford transportation to be present at the patient's bedside: "you're going to have family members who ...can't give that much". Nurses noted that although many families had good intentions to be involved in the patient's care, not all families had the confidence, or the emotional or physical ability to do so. A nurse participant spoke of what can happen when family choice conflicts with the patient's choice:

> You'll find a lot of patients that will say "oh, my husband will do that", or "my wife will do that for me, don't worry about it", and then if you take that [family member] aside and you tell them that their family member has said they would be doing something for the patient, and you ask them how they actually feel about it, you'll find that they really don't want to do it. And so this is where you have to get back to the patient, and you have to start having meetings, and realize who will be doing what. There is a lot of resentment...we have heard with younger couples that aren't married that there are a lot of separations, or divorces, because they just don't want to be committed to something like that for the rest of their lives if they have other options. That sort of thing. But yeah, a lot of times we have to ask what family think they can do to participate. And then we tell them what we think, and what our goals are.

Findings from the literature show that false assumptions exist regarding the preference of patients and families in the participation of patient care. For instance, in Paavilainen et al.'s (2001) survey of emergency surgery patients, patients were found to not always want their families present preoperatively, and likewise families did not always choose to be there. Patient preference of family involvement was also illuminated in Benjamin et al.'s (2004) survey of 200 patients and families in the emergency room, where it was shown that *younger* patients wanted their family present during resuscitation more so than *older* patients. It is difficult to make an assumption that families *should* be a visual presence at the bedside and participate in patient care. Some participants felt that despite the family being at the bedside, they chose not to contribute at all to the patient's care, which was difficult for some nurses to comprehend:

> Sometimes I get angry, and think "why isn't she doing more?" And a lot of times I think that I then encourage [the family] more. But somehow, we seem to get more families that just want to sit back. It's always like that. Most people don't want anything to do with it. I get really frustrated with that. Like people where there is just no happy medium.

Additional findings of this study pointed to families who chose to be irresponsible when it came to taking on duties within their family members' care, which caused a great deal of frustration for the nurse. One participant shared thoughts and fears about what could happen to patients when families made choices that negatively influenced their patient:

> You know, the escorts...they come down saying they're gonna learn their family member's care, and then they don't show up, and then you find out that they're at

> the casino. It's a trip to the city for them. And they don't show up, and they laugh it off. They may or may not learn. Or, you teach them, and then they never come back, and then you find out they went back to the community, and someone else shows up. There isn't any continuity. So it makes you afraid of what's going to happen when [the patient is] out there. Or, you are teaching someone, and they're not interested, you teach them how to do things and you go back to evaluate, and they're sloppy at it, or they don't really care. It's a bad attitude.

In McMahon's (1992) theoretical paper of the developmental stages of the family, the various roles which family may choose to take on in caring for a mentally ill family member are discussed. McMahon speaks of the role transformations which take place as family members attempt to accommodate necessary changes to ensure survival of the family unit in response to stressful life situations. Role transformations in response to a mentally ill patient included becoming a direct caregiver, observing and supporting the patient from a distance, advocating on behalf of the patient, or clearly choosing no involvement at all.

Findings from this study revealed that nurses focused on families who chose not to become involved in the patient's care. Participants tended not to discuss those families who chose to play an active part.

Gatekeepers.

Findings from this study revealed that although participants shared similar opinions that a family should be there for the patient, their involvement appeared to be on the nurses' schedule. Participants in every area of practice noted that family was welcomed, but on certain terms, and under certain conditions. Nurses reported needing to

limit who they spoke with from family, since there was often so little time to invest in family discussions and a family spokesperson was necessarily implemented. Some nurses shared that they were unsolicited intermediaries to protect a patient or family:

> I think you have to be careful with that....We've had numerous situations where a male comes in with a female who he says is his common-law wife, and something happens, and an hour later his wife shows up, so now he's got a married wife, and a common-law wife, now what? We can't have them both visiting at the same time...or the girlfriend comes in, and then the wife comes in. We've had situations where the person has passed away, and the son is asking for the valuables because he doesn't want the dad's girlfriend to get them, because he thinks she is going to clean out the bank account, but the wife is listed as the next-of-kin, but she lives in another province....Not to say that the next-of-kin can't be the significant other, but just that the significant other is not always the next-of-kin.

In Blackford's (2003) theoretical paper, culturally sensitive care involves the consideration of a patient's and family's culture, although conflict can arise within the healthcare setting when definitions of culturally acceptable practices clash. This is illuminated in this study's findings, as it was revealed that nurses struggled with cultural issues when philosophies contradicted what the nurse believed was right. Findings in this study showed that at times the nurse had no choice but to surrender control, as is the case with this nurse, who was required to defer to the family and her manager, the *gatekeepers,* when a large family began singing for their loved one as part of their cultural practice:

> We're told that we have to let [them stay in the same room while the other patient is there], because that's their culture. Whoever is in charge for the managers... [tells us]...that we don't really have a choice but to let them do that. I just don't think that's right. Like if I was in a bed next to that person, I'd be completely pissed off, right?...That makes me really really mad....[Nurses] really don't get to say anything....It really doesn't matter...because they'll do it anyway.

When families were unsettled, questioned the nurse, or perceived to want control over decision-making or care, the nurses perceived this as inappropriate and perhaps even threatening to their own role. A nurse participant shared the frustrations associated with power struggles between family and nurses: "...[if]you have a nurse who thinks she is supposed to be right all the time, then ...you can get rubbed the wrong way by a family who is very aggressive, so that doesn't work...".

Nurse participants in this study revealed the difficulties presented to them when there was no rapport with family, and a power struggle ensued between the family and healthcare providers. As this nurse shared, the nurse not only ended up having discord with the family, but the relationship with the patient was at risk:

> Like their 84 year old dad had surgery, and he was here for...two months, and he is just not recovering properly...now we're looking at a personal care home... because the family doesn't want to take him home....It's not so easy to get into a personal care home, so there's all this waiting, and the family gets so frustrated with everything, and then they take it out on us. I mean, and then we don't want to deal with them...and then nobody wants to deal with that patient because of their family.

This is also discussed in the literature. In the systematic review by Haesler and colleagues (2007), it was found that competition between family and staff and their roles in patient care can result in gaps in patient care. Issues of power can work for the patient, as in the case of protecting patients from harm, or against them.

Feeling valued.

Findings which emerged from this study revealed that the connection between family and nurse describes the need for mutual respect in order to maximize patient care. Nurse commitment to the family as part of the patient's care was described in the literature as promoting collaborative care of the adult patient, results of Haesler et al.'s (2007) systematic review of 32 articles. In order to take on this collaborative approach, families and nurses must appreciate the role each plays, but there appears to be a disconnect on what each feels their role should be. Past literature reports that family caregiving was viewed as unskilled, and therefore was less important than nursing work (Ward-Griffin, 2001). In some literature, family was even perceived to have no part in patient care (Davies & Nolan, 2004; Duran et al., 2007; Haesler et al., 2007; May et al., 2001; Thurston et al., 2003). In Davies and Nolan's exploratory descriptive study, nurses discouraged family from participating in physical care of the patient once the patient was admitted under their care. Likewise, families who did not communicate with staff or were not considered resources for the patient were perceived as being burdens to the nurse, and were often perceived to be demanding or challenging to the nurses' advice. In these instances, families were discouraged from taking part in the patient's care (Benzein et al., 2004). However, Astedt-Kurki et al.'s (1997) mixed method survey pointed out that more than half of families studied felt they were expected to take part in their family member's

care, and did, although less than half of the family participants actually felt that nursing staff was interested in their well-being.

Nurse participants with experience in the care of surgical patients shared different opinions on the care they provided and the family roles within these models, depending on their area of practice. Areas that dealt more specifically with post-acute surgical patients tended to operate with a more family-centred focus, while areas caring for acute surgical patients reported a more patient-centred approach. Nurse participants identified that sometimes there was frustration on the families part when patient outcome was not as planned, and this they note, could create tension in the nurse-family relationship. Similarly to the medical nurses, some participants shared challenges they experienced with families who required significant time investments, something that the nurse could not adequately provide. In surgical areas where surgeons spend most of their time in the operating theatre and less time on the inpatient units, some nurses felt they carried the bulk of the patient care on their own without the surgeons support, yet felt undervalued when families would only speak to the surgeons. With all surgical nurse participants, family involvement was welcomed both for the purpose of support for the patient and support for the nurse. When the family assumed tasks in patient care such as assisting a patient with physiotherapy, the nurse was always pleased. Time constraints were seen by some participants to somewhat limit their availability for each patient, and therefore, family interest and participation benefited both the patient and the nurse. This supports the literature which pointed out that family involvement in patient care was indirectly a cost-saving factor for the healthcare system, and could be perceived as a method of compensating for staffing difficulties experienced by healthcare organizations today

(Lowton, 2002; Montalto, 1996; Neabel et al., 2000; Pickard & Glendinning, 2002; Schumacher et al., 2000; Thalanany et al., 2005; Thurston et al., 2003; Weinberg et al., 2007).

Although many of the findings in this study support other literature, there are certain unique discoveries that were made. One finding which was not discussed in the literature but emerged from this study was the perception that nursing and the healthcare system are viewed negatively by the public. Nurses in this particular study shared perceptions that there are negative connotations associated with nursing, which negatively influenced the morale of members and their commitment to their work. Participants felt that the public perception of nurses was that of lacking empathy and being incompetent, and that families were distrustful of nursing staff, fearful that mistakes were being covered up. Lacking the confidence to diffuse situations was also reported, where nurses felt they needed to elicit the help of managers or physicians because families did not respect the nurses' judgment. Participants noted that when they themselves were family members of hospitalized individuals, they observed staffing issues in the organization which resulted in they themselves stepping in, for the purpose of getting their family member out of the hospital environment, the sooner the better, to spare the patient the risk of demise due to lack of care. Findings revealed that sometimes the lack of care was a result of not enough staff, inexperienced staff, or "...older nursing staff who were more interested in telling [you] how overworked they [were] than spending time with family". Several participants stated nurses are devalued and not treated as professionals, but were instead mistreated by members of the public who had little faith in the healthcare system, so much so that nurses felt they simply could not

"succeed" in the eyes of family "no matter how hard you try". Many nurses in this study shared feelings of defeat in the nursing profession.

The preceding discussion of findings outlines where nurses perceive the role of family to be in the care of the adult patient. The themes which have emerged in this study provide further insight into how these roles are played out, and enable a greater understanding of the care models practiced in healthcare today.

Findings and Leininger's Theory

Leininger's theory (1978; 1988), emphasizes the need for nurses to be sensitive to cultural practices of care, and to collaborate with clients and their families in order to provide the most effective care possible. The findings of this study clearly support the assumptions of the theory, in that nurses greatly appreciate the importance of family in the well-being of the adult patient and see the value in collaborating with them for everyone's benefit. What the findings also show are that family participation in adult care appears to be the desired framework for patients, families, and nurses alike, but family involvement and participation in adult patient care is subjective in meaning. Therefore, the role of family in adult care is also not universally understood, nor is a care model where family plays an active role universally practiced.

From the findings, a general description of nursing emerges: nurses tend to be task oriented, prioritizing and focusing primarily on the patient which then reduces the weight of family as a priority. This of course, may be the result of several factors already discussed, including but not limited to lack of time, lack of organizational philosophy to support family involvement, or lack of training to include family in care.

Culture, as defined by Leininger (1988, p. 156) "...refers to the learned, shared, and transmitted values, beliefs, norms, and life practices of a particular group that guides thinking, decisions, and actions in patterned ways". One might argue that the nursing culture has good intention to include the family, but that this becomes impossible when limiting factors are placed on practice, leaving the culture defeated and overwhelmed. Regardless of the cause, the bottom line is that nursing culture may not be what nurses want it to be, and this has serious implications for not only the profession, but for consumers of the healthcare system as well.

Discussion of Chosen Methodology

The use of ethnography in this study, and a focused ethnography in particular, was appropriately chosen to determine where nurses situate the family in the care of the adult patient. Since it was the values and beliefs of the nursing culture which were at the heart of the research questions, using a small number of key informants as a subculture of the larger organization allowed the study to be performed in a relatively short time.

The choice of this methodology prescribed the sampling technique, size and approach to data collection and analysis. The use of purposive sampling from selected care areas aimed at obtaining the richest data possible, and the use of one-on-one interviewing created an environment where the participants could share their beliefs freely without the added pressure of focus groups. Data analysis was performed in a cyclical nature, and cultural domains and underlying themes emerged as a result of the thick description of the nursing culture shared through storytelling.

Study Limitations

This study on how nurses situate the concept of family in their care of adult patients has limitations which should be addressed for future research in this area. Foremost, it was challenging to recruit participants to take part in this study. Posters were placed in strategic areas of the tertiary care centre, and an inservice was held on one of the units chosen to participate. In addition, reminder emails were sent to the managers of the units in order to ensure all staff who met the inclusion criteria had been accessed. Of the 195 invitations distributed, a response rate of only 7% was received. This alarmingly low rate of response from the nursing body raises concerns regarding the nursing profession's interest in research, and their desire to improve the way they provide their care. Further questions to investigate why this is so would merit another study to take place. Despite saturation having been reached as evidenced by the themes which emerged from the interviews, a larger sample size including corresponding practice areas from other organizations would have provided a broader assessment of nursing practice across the region.

A second limitation is that the units chosen to participate in the study were selected by the Chief Nursing Officer of the organization, and not the researcher. In purposive sampling, the researcher invites participants based on their knowledge of the topic which is being researched. In the case of this particular study, the units were chosen by the Chief Nursing Officer based on which units were felt would be most receptive to research taking place. The units selected may not have been chosen with the premise that they would provide for the richest data, and therefore, the sampling may not have been most appropriate.

Recommendations

Recommendations which have been developed as a result of this study include suggestions for education, practice, and research. In the following sections a discussion will address each of these areas.

Recommendations for Education

With respect to the findings of this study and implications for education, a careful evaluation of nursing curriculum may provide a better understanding of why nurses report a disconnect between what is taught to nursing students and what is practiced. Nursing students may not be prepared to advance into the workforce if concepts of care, including an understanding of their roles and the roles of others, have not been solidified.

It is essential that nurses and nursing students gain an understanding of the patient and family experience in healthcare, so that the popular concept of patient-centredness may be embraced and realized within the nursing culture. This can be done by applying research to improve practice, since it is through evidence-based learning that nursing will continue to move forward as a profession. Nursing students must understand the relevance of continued learning in order to maintain and develop competencies, and must be encouraged to constantly seek opportunities to expand their practice. It should be engrained in the nursing culture that the best patient care results from a combination of the art and science of nursing.

Recommendations for Practice

Findings from this study point to recommendations in practice. Ultimately, the nursing profession itself requires thoughtful contemplation. If the culture of nursing is to focus only on the patient for whatever reason, this defeats the holistic approach much

sought after today. If the nursing culture is only to be task-oriented, a challenge presents on how the nursing profession can advance.

Recommendations for practice include the following:

1. Governing bodies of healthcare professionals and healthcare organizations need to develop, implement and evaluate a philosophy of care for the adult patient which includes a role for the family.
2. Evaluation of nurse to patient ratios should be carried out by healthcare organizations to understand the reported effects of time constraints on patient care.
3. Evaluation of patient and family services should be routinely performed by healthcare organizations. Areas to measure include satisfaction with visiting hours and regulations, and patient and visitor access to information.
4. Evaluation of the participation of family in the care of the adult patient should be carried out by healthcare organizations, with the intent to determine whether increased involvement by family will improve the patient's health status, thereby reducing the patient's length of stay. As indicated by several authors, the well-being of the patient is impacted on by the family (Astedt-Kurki et al., 2001; Benzein et al., 2004; Craft & Willadsen, 1992; Laitinen et al., 1996; Rantanen et al., 2004).

Recommendations for Research

Several recommendations are made to further research in this area of interest. For one, professionals interested in nurses and nursing practice may benefit from the broadening of this study. A recommendation is to study nurses from work areas different

than those who took part in this study, or conversely focusing specifically on a particular area. Studying patients and families should be a next step, as it will benefit nurses to understand the experiences of patients and families. Studying individualistic versus collectivist cultures would additionally provide a necessary angle to understanding the role of family in adult care. Also, expanding this study outside of urban centres into rural communities may provide different findings altogether. And finally, understanding how other professions interpret the role of family, and whether their ideas have impact on nursing practice or vice versa, should also be considered.

Summary

To summarize, nurses situate the concept of family in their care of adult patients as "being there" for the patient, in the context that there is "life outside of illness". Although family has the "choice" on whether they wish to become involved in the patient's care, patients ultimately maintain "control" over who they wish to include as their family. Much of how the family participates in the patient care "depends" on different care areas, but generally, the patient, family, and nurse all require "information" in order to provide the best care possible. Unfortunately, when "time gets in the way", there is incongruence with what time affords, and how much collaboration can actually take place. Nurses who control or "gatekeep" how much involvement the family can have, negatively affect the family by signaling their lack of "value" in the patient's care. This is reciprocal, as the nurses too, share perceptions that families do not always value the nurses' role with the patient. Investing in further studies may confirm or deny these assumptions.

Conclusion

Further research is necessary to expand on this study's findings. Research should be furthered by questioning whether supporting and implementing an accepted philosophy of family involvement in adult care by governing bodies, educational institutions, and organizations will do the following: enhance patient and family outcomes and transitioning into the community; improve public perception of the nursing profession; and encourage nurses' morale to spur recruitment into and sustain the nursing workforce. The researcher hopes that this thesis project has provided the stepping stone for further inquiry, and has stimulated interest for others to develop a greater knowledge base on nursing practice which will have meaningful contributions to the science of nursing.

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APPENDIX A

INVITATION LETTER
(Printed on U of M letterhead)

November 23, 2007

Dear Registered Nurse,

My name is Belinda Mayer. I am a Masters student at the University of Manitoba in the Faculty of Nursing. I am extending an invitation to you to take part in a study I am conducting as part of my Masters thesis requirement. The study is supervised by Dr. Roberta Woodgate, Associate Professor in the Faculty of Nursing at the University of Manitoba. This letter has been distributed by your manager to all nurses on your unit who have worked as a registered nurse for a minimum of three years, and have worked on your unit for a minimum of six months. I do not know your name or anything else about you.

The overall purpose of this study is to arrive at an increased understanding of where nurses situate the concept of family in their care of adult patients. I am especially interested in learning if the meanings nurses assign to the concept of vary between different adult-care settings. Nurses from four areas in the Health Sciences Centre are being asked to participate: Emergency Department, Medicine, Surgery and Mental Health.

As a participant in this study, you will be asked to participate in an open-ended, audio-recorded interview and fill in a brief demographic questionnaire about yourself. In the interview, you will be asked to talk about what your views on patient-centred care are, and the role of family in the care of adult patients. You will control how much information you wish to share in this study. The interview should take about one hour of your time and will be audio-tape recorded. After each interview, I will write field notes that describe what took place during the interview. If you would like more than one interview in order to ensure you have said everything you want share, then a second interview would be arranged. All interview(s) will take place at a time and place that is convenient for you. The demographic questionnaire would take no more than 10 minutes to complete, and would be filled in at the time of the interview.

Once all the interviewing has been completed, I will summarize what you and other registered nurses have told me, and will write a paper as accurately as possible, based on what you have told me. This paper will ensure your anonymity by not making identifying statements on who you are, or who the other nurses are. I will present the findings from this study at a health conference or professional meeting or publish it in a professional journal. In all instances, your identity and name would not be revealed to anyone. Participating in this study is voluntary. If you are interested in taking part, I will ask you to sign a form indicating your informed consent. If at any time you wish to drop out of

the study, you may do so without further obligation. If you decide to take part, your identity and name would not be revealed to anyone else. I would be the only person who would know your name and contact information since I am required to meet with you to perform the interview. None of your supervisors or colleagues at Health Sciences Centre will be made aware of your participation in the study.

If you are interested in participating in this study, or have any questions or require additional information, I ask that you contact me by phone: 669-7004, or by my email address: bixbyand@shaw.ca. You may also contact my thesis chair, Dr. Roberta Woodgate by phone if you have further questions at 474-8338, or by email at Roberta_Woodgate@umanitoba.ca. A small honorarium will be provided at the end of the interview(s).

Thank you for considering participating in this study,

Sincerely,

Belinda Mayer
BN, Masters of Nursing Student
University of Manitoba

APPENDIX B

CONSENT
(Printed on U of M letterhead)

Research Project Title: Situating the Family in the Care of the Adult Patient: A Qualitative Study of Nurses' Perspectives

Researchers: Belinda Mayer, Masters Student in the Faculty of Nursing, University of Manitoba; Dr. Roberta Woodgate (thesis chairperson), Associate Professor in the Faculty of Nursing, University of Manitoba; Dr. Michelle Lobchuk (internal member), Assistant Professor in the Faculty of Nursing, University of Manitoba; Professor Jacquie Ripat (external member), Assistant Professor in the Department of Occupational Therapy, University of Manitoba

This consent form is only part of the informed consent process. A copy is for you to keep for your own records and reference. It explains what your participation will involve. If you require any further clarification, or if you have any additional questions, please ask. It is important that you take the time to read this carefully and that you fully understand the information it contains.

1. **A description of the purpose of the study.**
   The overall purpose of this qualitative research study is to arrive at an increased understanding of how nurses situate the concept of family in their care of adult patients. This study is being conducted by Belinda Mayer as part of the requirement of the Master of Nursing degree program at the University of Manitoba. Registered Nurses from four units at the Health Sciences Centre will be recruited for the study: Emergency Department, Medicine, Surgery, and Mental Health. Ethical approval has been granted from the Education/Nursing Research Ethics Board at the University of Manitoba, and from the Health Sciences Centre Research Impact Committee. Participant honorariums have been provided through the Health Sciences Centre Foundation.

2. **Description of the procedures.**
   A. Individual Interviews
   I understand that I am being asked to take part in an open-ended interview conducted by Belinda Mayer. I understand that during the interview I will be asked to talk about my views on patient-centred care, and the role of family in the care of adult patients. The interview should take about one hour to complete and will be audio-tape recorded. If I desire more than one interview, a second interview will be arranged. After each interview, I understand that Belinda will write field notes that describe what took place during the interview. I

understand that all interview(s) will take place at a time and place that is convenient for me.

B. Demographic Questionnaire
I understand that I am being asked to fill out a demographic questionnaire about myself. This will take place at the time of the interview, and will take about 10 minutes to complete.

3. **Voluntary nature of the study.**
I understand that my participation in this study is voluntary. If at any time I wish to withdraw from the study, I may do so without further obligation. If I wish to drop out of the study at any time, all the data I have provided will be destroyed and none of the data I provided will be used in the study. I have complete control as to how much information I wish to share during the interview and demographic questionnaire, and may refrain from answering any questions without prejudice or consequence.

4. **A description of the risks.**
I understand there is no undue risk or harm to me associated with taking part in this study. If at any time I become uncomfortable, the interviewing will stop and be resumed at another time when I am comfortable to do so.

5. **A description of the benefits.**
I understand there are no direct benefits to me in association with taking part in this study. Sharing in my experiences in this study may provide for learning of other nurses, researchers, professionals in healthcare, and families in order to provide for better nursing care for our adult population and nursing education for potential and existing nurses.

6. **Measure to protect confidentiality.**
I understand that none of my supervisors or colleagues at Health Sciences Centre will be made aware of my participation in the study. I understand that my name, address, or any other identifying information will not appear on the interview transcripts, demographic questionnaire, field notes taken by the researcher, final written paper, or in any publications of the paper. Instead code numbers will be used. I understand that only the student and the student's supervisor, Dr. Roberta Woodgate, will read the interviews. I understand that all data including the audiotapes, interview transcripts, field notes, and demographic information, will be stored in a locked filing cabinet and computer protected by a password known only to Belinda Mayer. I understand that all data will be destroyed following completion of the study.

Note: All information gathered will be kept confidential with the exception of legal requirement for disclosure (i.e. abuse situations). The researcher of this study has legal obligation to report any situations involving abuse.

7. **The research findings.**
   I understand that findings from this study may be presented at a health conference or professional meeting or published in a professional journal. In all instances, my identity and my name would not be revealed to anyone. I understand that I may request and receive a copy of the study findings.

8. **Compensation.**
   I understand that I will receive an honorarium in the amount of $20.00 at the end of the interview(s) I provide. I understand that if I choose to withdraw from the study I am entitled to keep the honorarium provided.

Your signature on this form indicates that you have clearly understood the information regarding participating in this study, and that you choose to participate. You are free to withdraw from the study at any time, or refrain from sharing any information you choose without prejudice or consequence. You are invited to ask any questions which will clarify or help you understand any process or portion of the study until you are satisfactorily informed.

Please direct any questions or concerns to Belinda Mayer (researcher) at 204-669-7004 or bixbyand@shaw.ca, or Dr. Roberta Woodgate (thesis chairperson) at 204-474-8338 or Roberta_Woodgate@umanitoba.ca.

I consent to take part in this study yes____

Printed name of participant_____

Signature of participant_____

Date_____

Printed name of witness_____

Signature of Witness_____

Date_____

The findings of this study will be available upon completion.

I would like a summary of the results mailed to me: Yes____ No____

If yes, please mail the results to me at this address (include postal code):

_____

_____

_____

APPENDIX C

INTERVIEW GUIDE

1. Can you please tell me what a typical day is like for you on your unit and then talk about a not so typical day?

   Probes: Walk me through a typical day on your unit? Walk me through a day that is not so typical?

2. Can you please tell me the type of patients that you care for?

   Probes: What type of patient care activities are you responsible for?

   How do these activities vary depending on the type of day that you are having?

3. Can you please tell me the type of interactions you have with the families of the patients that you care for?

   Probes: How do these interactions vary depending on the type of day that you are having?

   Can you please tell me the type of experiences that you have had with the families of some of the patients that you have cared for?

   Can you tell me of a positive outcome from when you involved a family?

   Can you tell me of a negative outcome from when you involved a family?

4. Everyone has their own definition of family. Can you please tell me how you define family?

5. How does your definition of family fit with how you practice as a nurse?

   Probes: What role(s) do you think families should have in the care of adult inpatients?

   What kind of influences do you think families have in the care of adult patients?

What kind of influence do you think culture has on the family and care of adult patients?

How relevant is patient-centred care to your area of practice?

What changes would you like to see with respect to the role(s) that families have in the care of adult patients?

What kind of support have you been required to give families in their roles?

What kind of role do you think family may have on the health of an adult patient?

6. Patient-centred care is a term that is often associated with the care of adult patients. What does patient-centred care mean to you?

   Probes: How does your understanding of patient-centred care fit with how you practice as a nurse?

   How relevant is patient-centred care to area of practice?

   What do you feel facilitates patient-centred care? What do you feel hinders patient-centred care?

   What does family-centred care mean to you? Or client-centred care? What other terms do you use to describe care of a patient?

7. What role(s) do you feel families have in patient-centred care?

   Probes: How much do you feel families impact on patient-centred care?

   What role(s) do you feel families **should** have in patient-centred care?

   What role do you routinely give to family in the care of your patients?

8. Overall, what changes would you like to see when it comes to how you practice as a nurse in your area?

   Probes: How would the changes affect patient-centred care?

How would the changes affect families of patients?

9. If you had to create your own model of nursing care, what would it be like, keeping in mind how the patient is defined?

   Probe: What would you call it?

10. How has your own past experience influenced how you perceive the role of family in the care of adult patients?

    Probe: What role have you played as a family member in the hospitalization of adult patient?

    What have your experiences been working with nurses when you have been a family member of an adult patient?

11. Is there anything else you would like to add that was not addressed or discussed?

12. Are there any additional questions which you think we should be asking during this interview? Were there any issues/areas which we have not covered which you think we should cover?

APPENDIX D

DEMOGRAPHIC QUESTIONNAIRE

1. What area in the hospital do you work as a nurse? _____
2. How many years have you worked on this unit? _____
3. How many years have you worked as a nurse? _____
4. What areas have you worked in as a nurse? _____

   _____

5. What is your employment status?

   ☐ Full-time

   ☐ Part-time

   ☐ Casual

6. How many hours do you work a week? _____
7. How old are you? _____
8. What is your nursing education background?

   ☐ Diploma

   ☐ Bachelor's Degree

   ☐ Master's Degree

   ☐ Family Education Sessions/Workshops/Training Sessions/Courses/Certificates

   ☐ CNA Certification

9. What is your gender?

   ☐ Female

   ☐ Male

APPENDIX E

DEFINITIONS OF THEMES

Life Outside of Illness

Definition: There are factors affecting the patient's and family's well-being that are outside of their illness and hospitalization. and these factors are influential on the patient's and family's experiences in the healthcare system.

Example Quote: "I mean, you're caring for that individual on a rudimentary level, but you really need to address that family, because they're the ones facing huge decisions, and probably financial burden, like they have huge issues to deal with...there is still a huge impact on their lives".

Need for Information

Definition: A reciprocal need for communication involving healthcare providers, patients and their families to optimally facilitate treatment of the patient in a collaborative, transparent way.

Example Quote: "Trying to stick with PHIA, and our Code of Ethics, well...I mean we do all the time, but in return what we get are that people are upset and frustrated. Not upset with us, but frustrated, because we can't give them information at the time that they want it".

Time Gets in the Way

Definition: Time constraints for the healthcare provider are perceived barriers to the effective provision of quality healthcare.

Example Quote: "You're not responsible for [the family's] care, but you are really, because they need your time. Before they can leave at night they need to know their mom is safe...that takes a lot of extra work...you need to say "please don't interrupt me when I'm working". It was always upsetting, because you are trying to do your job, and they're interrupting".

Being There

Definition: The role of the family in the care of the adult patient, as perceived by the patient, family, and healthcare provider.

Example Quote: "Every little bit helps. Most people are really good about it. Like they want to help...Sometimes family call and say "how is so and so?", and you feel like saying "well, you never come and visit, so why don't you make the effort to see them and they you'd know?" It's not like everyone lives outside of the city, I'm sure".

Patient Control

Definition: The degree to which a patient exercises control over their experiences in the healthcare system.

Example Quote: "Ultimately, it is the patient that makes the decision, and even if you may advise them that it's not in their best interest, that it is not healthy for [them], ultimately it's their choice and their decision. You can give them the pros and cons, but they have to make that decision for themselves".

It Depends

Definition: The inability to fully conceptualize the meaning of an experience. Interactions and experiences cannot be predictably defined and therefore cannot consistently be replicated.

Example Quote: " My experience with family is unconditional support around all issues. I am very lucky. That is my experience with family, grandparents, parents...I accept it, but I feel badly for people who don't have unconditional support, or people who have such disenfranchised lives, like such serious injection drug users who can't help themselves, the alcoholics who can't help themselves...it's very sad. I understand it's an addiction for a lot of them, and that's what creates this disenfranchised life for a lot of them, but you can only do so much. And over time, I've accepted this".

Choice

Definition: The family's right to choose whether or not to be part of the patient's social network, participating in the care of that patient.

Example Quote: "Sometimes depending on the [patient's] age, the family has had to withdraw in order to be safe. The patient is too destructive to the family, so to maintain contact with the patient, and for their own health they need to separate...that's their personal choice. You know, you can't make them become involved".

Gatekeepers

Definition: The competition between who has the most power over the patient. Ultimately, the gatekeeper with the most power wins in each situation.

Example Quote: "Much of nursing is trying to find the balance between our real moral limitation, and what is best for the patient and the family. You know, you're always trying to find that balance, so that everybody agrees it's safe, everybody agrees it's appropriate, but we're not totally listening to what the family wants. In the case of a guy who we tried to get back to the reserve...the team worked really hard to make that happen because that is what the family wanted, and then...in the end the resources are not

available, and it just couldn't happen...there are a lot of limitations put on nursing that sorta impairs our ability sometimes to help the family".

Feeling Valued

Definition: The desire for every person to be acknowledged and respected in the care of the adult patient, regardless of whether they are the patient, family or caregiver.

Example Quote: "Some people are there, and other people just can't cope or whatever, you know, or they start coming less or more sporadic...you can't blame the families for their circumstances, I mean, because you don't know what's going on in their beyond..."

"In some situations the family member doesn't take you for being very important anyways, and they only want to talk to the doctor. I think that's really ignorant. I mean, when a family or patient is acting like that, like they want to talk to the doctor, well of course I'm going to get upset. I mean, I'm here all day, and I want to tell them that they should be happy that they have me here".