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Understanding Aboriginal Families' Experiences of Ethical Issues in a Paediatric Intensive Care Environment: A Relational Ethics Perspective

by

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Abstract

The PICU environment is fraught with ethical issues, often arising from relationships between families and nursing staff. The research that examines the experience of hospitalization within PICU does not address relational ethics from a cultural perspective. Aboriginal families may experience distinct concerns, such as language barriers, cultural stereotyping, and a lack of communication with nurses. This study explored the perceived relational experiences of Aboriginal families from remote northern communities with nurses in a PICU. A case study was developed from interview data from key Aboriginal informants. Relational ethics served as a conceptual guide, with consideration for the core theoretical elements as they arose in descriptions of Aboriginal families' interactions with nurses. Informants described Aboriginal families as feeling isolated and disconnected from nurses. A lack of cultural understanding and respect was perceived. The fast-paced, technical environment was described as an influencing factor in the lack of engagement between families and nurses.

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CHAPTER ONE

Introduction

The paediatric intensive care setting is an environment fraught with ethical issues. Parents and intensive care nurses frequently encounter ethical issues concerning decision-making, alterations to parental roles in the care of the critically ill or injured child, informed consent, and parental autonomy, (Diaz-Caneja, Gledhill, Weaver, Nadel & Gerralda, 2005; Meyer, Burns, Griffith & Truog, 2002; Meyer, Snelling & Myren-Manbeck, 1998; Mu & Tomlinson, 1997; Pinch & Spielman, 1990; Miles, Carter, Riddle, Hennessey & Eberly, 1989; Carter, Miles, Buford & Hassanein, 1985; Miles, Carter, Spicher & Hassanein, 1984; Miles & Carter, 1982). In providing care to the critically ill or injured child within a paediatric intensive care setting, the nurse is faced with the unique challenge of addressing the needs of the family as they occur during hospitalization.

It is within this relationship between the intensive care nurse and the family of the hospitalized child that the concept of relational ethics is identified (Bergum & Dossetor, 2005; Bergum, 2004). Parental and familial involvement in the care of the critically ill or injured child is often fostered by the intensive care nurse, and contributes significantly to the formation of ethical relationships between the family and health care professionals. In their extensive work on relational ethics, Bergum and Dossetor suggested that to practice ethically, the health care professional must develop ethical relationships with the patient and family (Bergum & Dossetor, 2005; Bergum, 2004; Austin, Bergum & Dossetor, 2003). To do so, the intensive care nurse must develop responsiveness to and respect for the persons in their care; understanding of the experiences that shape a family's perspectives and needs must be gained.

Caring for children and families within a critical care environment often involves the care of Aboriginal families from remote, culturally distinct communities. Aboriginal families are often separated from their extended family and unique cultural environment, resulting in a distinct experience of hospitalization in the paediatric intensive care unit (PICU). Aboriginal families must accept care from primarily non-Aboriginal health care providers, and may encounter language barriers, cultural stereotyping, and an inability to communicate effectively with physician and nursing staff. The values and beliefs held by Aboriginal families and by health care providers can be profoundly different, and the mutual understanding of these perspectives is usually lacking. Consequently, the way that ethical relationships develop and are experienced may be significantly different than for non-Aboriginal families.

An understanding of the experience of hospitalization within a PICU for Aboriginal families is of particular importance for nurses within the Stollery Children's Hospital (SCH). An estimated 35% of children hospitalized at the SCH are of Aboriginal background (M. E. Hawkins, personal communication, November 5, 2006). The SCH provides care to children and their families from Northern Alberta, Northern British Columbia, the Northwest Territories, and Yukon Territory. Aboriginal families are often relocated from northern rural and reserve communities for hospitalization, and experience challenges related to geographical separation from their families and communities. Hospitalization within the SCH may be lengthy for the critically ill or injured child. Although the SCH recognizes the need for support for Aboriginal families within hospital and has developed the multidisciplinary Aboriginal Child Health Working Group with two support workers, these resources are very limited given the size of the Aboriginal population.

Research that explores the experiences of Aboriginal peoples in hospital is scant, and even fewer studies are available that focus on Aboriginal children's hospitalization. The existing research suggests that such an experience may involve isolation from the extended family and community, miscommunication between the Aboriginal patient and family and the non-Aboriginal health care providers, and a lack of understanding of cultural and social norms (Salvalaggio, Kelly & Minore, 2003; Garwick, Jennings & Theisen, 2002; Browne & Fiske, 2001; Barker & Daigle, 2000; Browne, 1995; Sherley-Spiers, 1989). Existing research examining the experience of hospitalization within PICU does not address ethical issues and relationships from a cultural perspective.

It is critical to examine the relationships that occur between Aboriginal families and health care professionals during hospitalization in PICU so that ethically appropriate, therapeutic relationships with these families can be fostered and supported. This area of research is of particular importance to nursing, as nurses provide direct care to families in hospital. It is vital for nursing staff to understand what it is like to receive care in an unfamiliar culture. With this knowledge, nurses can be more responsive to Aboriginal families, promoting the health and healing of both the hospitalized and the immediate and extended family.

Purpose of the Study

The purpose of this study was to create a case study description as a means of capturing some common relational ethics issues that developed between Aboriginal families and health care professionals within the context of a paediatric intensive care setting from the Aboriginal perspective.

CHAPTER TWO

Literature Review

Limited documentation of the experiences of Aboriginal peoples within an acute health care setting was found; the majority of research examining the health care experiences of Aboriginal populations has focused on the community setting. Parental experiences among the general population within the PICU have been examined extensively over the last thirty years using well-developed research methodologies. The findings were consistent and included ethical issues related to informed consent and loss of parental autonomy and roles as the most commonly reported parental stressors (Diaz-Caneja et al, 2005; Meyer, Snelling & Myren-Manbeck, 1998; Mu & Tomlinson, 1997; Pinch & Speilman, 1990; Miles, Carter, Riddle, Hennessey & Eberly, 1989; Carter, Miles, Buford & Hassanein, 1985; Miles, Carter, Spicher & Hassanein, 1984). Participants in such studies were typically middle class Caucasian parents of hospitalized infants and children.

The experience of hospitalization within a PICU has not been explored with attention to cultural and ethnic background or with the extended family and community as a central component in the care of the child. The PICU may present additional challenges for the Aboriginal family. Ethical issues may arise from separation from the extended family and culturally distinct community, threatened parental autonomy, and the stigmatization and discrimination of the Aboriginal population.

Informed Consent and Decision-Making in the PICU

Parental perceptions of informed consent and decision-making. Informed consent and parental autonomy in decision-making are important ethical concerns for families during hospitalization in a PICU. In a phenomenological study with primarily middle-class, Caucasian parents, Pinch and Spielman (1990) examined parental perspectives of decision-making in an intensive care setting. They found that ethical issues arose around the ability of parents to make informed decisions in the midst of an overwhelming and stressful experience. This experience rendered parents unable to understand or remember information about the child's condition, despite the expectation that they would use this information to make life or death decisions for their child. Participants did not regard decision-making as a parental role during hospitalization. Despite providing informed consent for various procedures and treatments, parents described the signing of the consent form as simply permission granting. Parents assumed that treatments suggested by health care providers were required, and thus agreed that the same should be carried out.

Aboriginal misunderstanding within the hospital environment. A misunderstanding of cultural and social norms within the hospital environment and inadequate knowledge of health conditions have been described consistently within the literature examining the experience of Aboriginal peoples in hospital (Browne & Fiske, 2001; Barker & Daigle, 2000; Sherley-Spiers, 1989). Aboriginal patients described a sense of being the outsiders intruding in the mainstream health care system (Browne & Fiske; Browne, 1995). Aboriginal patients were reluctant to seek assistance from non-Aboriginal health care providers, fearing stereotypically negative judgements (Browne & Fiske; Barker & Daigle; Sherley-Spiers). Aboriginal families' reluctance to obtain information regarding treatment options and probable outcomes may restrict their ability make informed decisions for their critically ill or injured child.

Aboriginal cultural communication patterns. Browne and Fiske (2001) conducted an ethnographic study with ten First Nations women from a reserve community and explored personal encounters with mainstream health care providers. The women felt that they were dismissed by health care providers and did not believe that their health care concerns were adequately addressed. From a First Nations perspective, common behaviours including indirect eye contact and quiet communication patterns, may be a culturally specific method of conveying respect (Garwick, Jennings, and Theisen, 2002; Browne & Fiske) In contrast, health care practitioners often interpreted these behaviours as an indication that Aboriginal patients were uneducated, passive, and disinterested in health care decision-making (Browne & Fiske). Health care practitioner perceptions of Aboriginal communication patterns may restrict interactions with Aboriginal families, limiting the involvement of the family as an active participant in the care of a critically ill or injured child.

Involvement of the Aboriginal extended family. Relationships with extended family and the community are central to the culture and lives of Aboriginal peoples, and the importance of such relationships often extends into the hospital setting (Barker and Daigle, 2000). Salvalaggio, Kelly, and Minore

(2003) examined the experience of twelve First Nations patients relocated from remote communities for dialysis treatment. These patients experienced physical and emotional separation from family, and an altered ability to maintain normal social and cultural roles. In Barker and Daigle’s study, Mi’kmaq participants wanted extended family present during hospitalization, particularly when treatment decisions were discussed. Participants felt that the cultural practice of identifying the extended family as a central social group did not coincide with the cultural norms of the hospital setting. This resulted in negative encounters between health care practitioners and extended family members about involvement in the decision-making process. Examples included physician refusal to participate in decision-making meetings that involved multiple members of the extended family and community (Barker & Daigle).

Intensive care environment cultural norms. Cultural norms within the PICU focusing on parental autonomy may limit the involvement of the Aboriginal extended family, thereby restricting the ability of such families to participate in the decision-making process in a culturally appropriate manner. Meyer, Burns, Griffith, and Truog (2002) examined parental end-of-life decision-making in a primarily Caucasian, English-speaking sample, and found that family and friends were not an influencing factor in the decision-making process. Parents relied on clinical expertise and support from physician and nursing staff, despite the availability of extended family and friends.

Threatened Parental Roles within the PICU

Loss of parental autonomy within the PICU. Admission to a paediatric intensive care unit threatens normal parental roles (Diaz-Caneja et al, 2005; Meyer, Snelling & Myren-Manbeck, 1998; Mu & Tomlinson, 1997). Parental role alteration was identified as the most stressful aspect of a PICU admission (Miles, Carter, Riddle, Hennessey & Eberly, 1989; Carter, Miles, Buford & Hassanein, 1985; Miles, Carter, Spicher & Hassanein, 1984). Parental and societal norms expect that parents act as primary care-givers and decision-makers for their children (Meyer, Snelling & Myren-Manbeck). The PICU environment presents a threat to the ability of parents to fulfill these roles, as they must depend on the intensive care nurse to provide care and comfort to their child. The inability to fulfill expected parental roles may result in feelings of inadequacy, helplessness, lack of competence and control, and vulnerability (Meyer, Snelling & Myren-Manbeck; Mu & Tomlinson). Parents related such feelings to a sense of physical and emotional separation from their child, resulting from limited decision-making abilities and opportunities to provide care (Diaz-Caneja et al; Meyer, Snelling & Myren-Manbeck). Although neither study considered cultural perspectives and influences, such a stressor on the family structure may present a particular challenge for Aboriginal families; parental separation from the extended family and community may result in a significant alteration to the normal family structure.

Stigmatization of Aboriginal parents. Aboriginal parents described an additional threat to parental roles and autonomy in the form of stigmatization and judgement from health care providers, suggesting that such perceptions lead to feelings of inadequacy and embarrassment (Sherley-Spiers, 1989). Thirty Dakota parents with experience in an acute care setting described how their encounters with non-Aboriginal clinic physicians left them feeling a sense of guilt regarding their health care decisions. The parents felt that they were blamed for their use of health care services, as though a correlation existed between the child’s illness and parental inadequacies. Participants believed that physicians saw Aboriginal parents as irresponsible caregivers, lacking the ability to meet basic needs. The researcher suggested that such negative encounters created further social distance between Aboriginal patients and health care practitioners, reducing communication and interaction. Parents described a fear that their children would be apprehended within the hospital setting, as traditional encounters with the “White man” involved the removal of children to residential schools or foster homes (Barker & Daigle, 2000).

Aboriginal Stigmatization and Discrimination

Substandard care for Aboriginal patients and families. Aboriginal patients may perceive that the treatment they receive is substandard to the care non-Aboriginal patients receive (Barker & Daigle, 2000; Sherley-Spiers, 1989). Participant narratives described longer wait times to be seen by a physician or nurse, and health concerns and questions having been ignored (Barker & Daigle; Sherley-Spiers). Aboriginal patients felt demeaned within the hospital environment, providing descriptions of lack of consideration for dignity and respect. Aboriginal patients believed that the care received could be improved by taking measures to alter their physical appearance and behaviours, such as dressing according to their perception of “White” standards and speaking to sound well-educated (Browne & Fiske, 2001). Other studies found more positive experiences. For example, Aboriginal patients in Garwick, Jennings, and Theisen’s study (2002) found health care providers to be sensitive to their needs. One possible explanation for the variation in perspectives is that Aboriginal respect for physicians and nurses as healers may result in more positive evaluation of provider services.

Cultural stigmatization of Aboriginal patients and families. Aboriginal study participants described feeling lessened as human beings by cultural stereotyping, perceiving that they were viewed as a category rather than as unique individuals with distinctive health needs (Barker & Daigle, 2000; Sherley-Spiers, 1989). Respect was equated with being treated as individuals, rather than cultural stereotypes (Browne, 2005; Browne & Fiske, 2001; Barker & Daigle). Participants expressed a need to be listened to as important members of the health care discourse, due to their knowledge of personal health concerns within a cultural context (Browne).

Quality of Research with Aboriginal Peoples

Several limitations are present in the research methodologies of the existing literature on Aboriginal patients and families in hospital. Although participants were consistently identified using purposive sample selection, sample size was often established apriori and data saturation and the identification of common themes throughout participant narratives was not discussed. Data collection and analysis occurred independently in all of the studies, with the exception of the research by Browne (1995). The researchers, therefore, did not have the opportunity to clarify the analysis and interpretation of data obtained in the interviews with subsequent study participants. Strategies to verify researcher interpretation of participant narratives were not used consistently. Browne and Fiske (2001) conducted follow-up interviews with each of the participants and Barker and Daigle (2000) presented their research findings to an expert panel including the Mi'kmaq interviewer, band council members, and Mi'kmaq health care personnel, to confirm accurate understanding of the participants' experiences.

Further limitations existed in the Aboriginal literature discussed, as each of the studies was conducted by a non-Aboriginal research team, with limited involvement of Aboriginal researchers and community members in the planning and implementation of the research designs. Browne and Fiske (2001) conducted their research in partnership with a First Nations reserve community, and the research team included a First Nations community leader. However, the role of this Aboriginal team member was not discussed, and it was not clear as to whether the Aboriginal team member was involved in the interviewing of study participants. Salvalaggio, Kelly, and Minore (2003) used a non-Aboriginal research team member to conduct interviews with study participants, but involved an interpreter in the interview process to allow participants to speak in Cree if desired. The interpreter was included in each interview and did not need to be specifically requested by each participant. Only Barker and Daigle (2000) used an Aboriginal team member to conduct interviews in the community language.

Historical Problems of Research with Aboriginal Populations

Historically, research with Aboriginal peoples has been conducted by non-Aboriginal research teams. The development of research questions and subsequent data interpretation has been conducted at the discretion of non-Aboriginal researchers, without input from Aboriginal community members (Kowalsky, Verhoef, Thurston & Rutherford, 1996). Aboriginal people have acquired a negative impression of research because the purposes and meanings of research have been alien, and the outcomes have often had unintended and harmful consequences (Ten Fingers, 2005; Castellano, 2004; Kowalsky, Verhoef, Thurston & Rutherford). Non-Aboriginal research endeavours have traditionally been viewed as attempts to establish the superiority of Western knowledge and another means of cultural appropriation (Ten Fingers). Research with Aboriginal communities has often been in direct conflict with the desire for Aboriginal populations to exercise the right to self-determination. Limiting the decision-making abilities of Aboriginal populations has contributed to the paternalistic control of Aboriginal knowledge and the disempowerment of Aboriginal peoples. Such practices have resulted in decreased ownership, control, and access to information and knowledge obtained (Ten Fingers; Castellano).

Negative or misguided outcomes of research. Research lacking direct input and control from Aboriginal community members is of limited benefit to Aboriginal participants and the community as a whole (Castellano, 2004).

Researchers and community members often have very different ideas of what constitutes social benefit and how it is achieved. Research by non-Aboriginal teams has been further criticized for subsequent use in policy and program development, which are then based entirely on an outsider’s view of Aboriginal well-being (Ten Fingers, 2005). The Committee on Native American Child Health and the Committee on Community Health Services (2004) suggested that studies focusing on Aboriginal community problems may contribute to the stigmatization of these communities, particularly if reports of findings reinforce common misconceptions about Aboriginal communities and their members. Community members may be further disadvantaged in the way they view themselves if research findings focus on the negative aspects of community life and culture, while disregarding the positive aspects of Aboriginal culture and values.

Ownership of Aboriginal culture and knowledge. The question of who owns data obtained by non-Aboriginal researchers is frequently posed. Increasingly, the Aboriginal community feels that they must be well-informed regarding their options to “protect and preserve their intellectual heritage from misappropriation and misrepresentation” (Castellano, 2004, p. 107). Aboriginal leaders have expressed concern with the privacy and confidentiality of the information collected, and have articulated serious concerns regarding who might access information and how that information might be used.

Issues of informed research consent. An imbalance of power has existed between non-Aboriginal researchers and Aboriginal study participants, raising questions regarding informed and voluntary consent. Research among Aboriginal populations is often initiated by providers of essential community services and funded by government agencies with control over resources the community depends on. Many Aboriginal peoples, therefore, consent to participation in research out of fear that refusal could result in loss of funding or services (Castellano, 2004). While informed consent by individual participants has become standard ethical practice within North American research activities, such practices may place Aboriginal cultural and moral authority at risk (Committee on Native American Child Health & Committee on Community Health Services, 2004). Many Aboriginal societies require the collective consent of the entire community before participation in research activities. Questions arise from the practice of interviewing individuals who are then presented as representing the group, without seeking permission from the group as a whole (Castellano).

Summary

Research examining Aboriginal families in hospital is remarkable in its absence. Virtually no studies have been found where the issues faced by Aboriginal families during the hospitalization of a child were examined. Although Aboriginal study participants included mothers of young children hospitalized for illness, reported findings have failed to differentiate between the experiences of patients and family members. In the literature, it was suggested that many ethical issues occurring within the paediatric intensive care environment emerge from the relationships between health care providers and family members. Yet none of the literature reviewed examined such experiences with consideration for cultural and ethnic influences. Such studies are also limited because only *parents* of hospitalized children are examined, while care of hospitalized Aboriginal peoples often involves consideration for the extended family and culturally distinct community.

The lack of literature examining Aboriginal families in the acute care setting and the cultural limitations of available research considering ethical issues within the PICU suggest an important area for nursing research. The lesson from the existing research is that nursing care of Aboriginal patients and families needs to be conducted in a culturally sensitive manner to ensure that the unique needs of these families are met. One perspective that is founded on culturally respectful principles is relational ethics.

Relational Ethics

Relational ethics emerged from the literature review as a logical theoretical foundation to guide the examination of the interactions between Aboriginal families and PICU nurses. Relational ethics describes an action ethic, and assumes that ethical practice exists in the relationship between patient and health care provider (Bergum & Dossetor, 2005; Bergum, 2004; Austin, Bergum & Dossetor, 2003). The practice of relational ethics involves behaviour rather than a judgement about human character or actions (Bergum). Ethical practice by health care providers involves making a commitment to the persons in one’s care to behave in a manner that demonstrates responsiveness and responsibility to both oneself and the other (Bergum & Dossetor; Bergum; Austin, Bergum & Dossetor). Relational ethics, therefore, focuses on examining the ethics of relationships, in particular the question of "what is the right thing to do both for oneself and for others" within the context of the relationship (Bergum, p. 485).

Bergum and Dossetor (2005) situated all relationships within a relational space, described as a moral space within which one must relate to oneself and to the other. Such relationships cannot exist exclusively, and ethical consideration must be made within the context of all mutual relationships within this relational space. As *all* relationships are the focus of understanding and examining moral life, specific attention must be paid to the quality of such relationships (Bergum, 2004). In exploring the ethical relationships between Aboriginal families and health care providers, the quality of these relationships will be examined through the perspectives of key informants with in-depth understanding of the experience of Aboriginal families in PICU. The central themes of relational ethics, mutual respect, engagement, embodied knowledge, and attention to the environment (Bergum & Dossetor), will be considered in exploring the interactions and relationships between Aboriginal families and health care providers within the PICU.

Mutual respect. The concept of mutual respect suggests that we are fundamentally connected to one another, and that our individual experiences are shaped by the attitudes of those within our environment (Bergum & Dossetor, 2005; Bergum, 2004). To achieve mutual respect within clinical interactions, "there is a need to learn ways to engage the other, the you, without reducing you to the same as me, or me to the same as you" (Bergum, p. 495). Within such interactions, we must coexist with culturally distinct individuals, while respecting the worth and dignity of another’s values and beliefs (Bergum & Dossetor; Bergum). Austin, Bergum and Dossetor (2003) suggested that cultural sensitivity is situated within the concept of mutual respect; such respect exists only when we attain the ability to listen to another’s point of view, particularly when such a perspective is different from our own. Such a process involves genuine communication in the attempt to understand another’s lived experience (Bergum & Dossetor; Bergum; Austin, Bergum & Dossetor).

Engagement. Relational engagement occurs when individuals are able to consider the perspective of another, by seeing the other person in a genuine way (Bergum & Dossetor, 2005; Bergum, 2004; Austin, Bergum & Dossetor, 2003). Engagement, therefore, requires that individuals are present with the other, and respond to the other in a sensitive manner that fosters a connection between the individuals (Austin, Bergum & Dossetor). Within a relationship, individuals must find a way to look at something together; meaning is found in these moments when the health care provider comes to recognize what it is that the patient really needs, and patient and provider come together to gain understanding (Bergum & Dossetor; Bergum). Bergum suggests that through attention to others we do not lose the self, but rather gain ourselves. Relational engagement “with others allows one to discover abilities that one did not previously know one had” (Bergum, p. 497-498).

Embodied knowledge. Relational ethics identifies a need to achieve a connection, or embodiment, between the body and mind, to ensure human emotion and scientific knowledge are considered with equal weight (Bergum &

Dossetor, 2005; Bergum, 2004). Within the health care setting, there must be commitment to who a patient is as a person, rather than just the patient's physical signs and symptoms. Embodiment focuses the attention on the patient's lived life, showing the patient as more than simply an object. Embodiment exists within the relational space; within this space are both thinking and feeling, objectivity and subjectivity, and the self and other (Austin, Bergum & Dossetor, 2003). Bergum suggested that one must be sensitive to the "embodied reality of the other person while still being true to the reality of one's own embodiment as separate and distinct" (Bergum, p. 494).

Environment. The health care environment is identified within the theory of relational ethics not as something around us, but as a living system within each of us (Bergum & Dossetor, 2005; Bergum, 2004). The environment is altered by our actions and must, therefore, respond to individual actions. It is within this environment that relationships exist, where we are intimately engaged and, as a result, continually changing and altering the environment (Bergum & Dossetor; Bergum). The responsibility of health care providers must evolve to support practice environments that allow for the development of ethical relationships between the health care professional and patient family (Bergum; Austin, Bergum & Dossetor, 2003).

Research Question

What relational ethics issues may Aboriginal families experience following the admission of their critically ill or injured child to a paediatric intensive care environment?

CHAPTER THREE

Methodology

The purpose of this study was to create a case study description as a means of illustrating some of the common relational ethics issues that develop between Aboriginal families and health care professionals within the context of a paediatric intensive care setting. This was done by expanding on qualitative data previously collected in phase one of the study, consisting of an open-ended interview with an Aboriginal parent following the hospitalization of her child in the Stollery Children's Hospital PICU. Data from this interview were analyzed using relational ethics as a conceptual guide to identify major themes in the interactions and relationships of an Aboriginal family from a culturally distinct, Northern reserve community during hospitalization in a PICU. This interview served to identify several initial issues and relational themes. The interview was conducted in Cree with the use of a translator. In phase two, elaboration of the initial relational issues was sought with key informants who had in-depth knowledge of the experience of Aboriginal families in PICU.

A qualitative research methodology was employed, as this approach to knowledge development was decided to be most appropriate for exploring and understanding a lived human experience (Caelli, Ray & Mill, 2003). The philosophy that has informed qualitative approaches assumes that there is not one objective truth, but that there may be many different, yet true, accounts of a particular phenomenon based on personal and perceived experience. Qualitative research, therefore, examines the perception of truth, and attempts to gain understanding of the world through the perceptions of those individuals within the experience of the phenomenon of interest.

Case Study

Case study methodology revolves around storytelling and enhancing knowledge through the detailed description of lived or perceived experiences, and as such, is well suited for research with Aboriginal people. Aboriginal research and experiences are often shared and published in story format (Paulette, 1993; Meili, 1991), as a method of honouring indigenous people and passing on Aboriginal history. A case study approach was well suited to the questions being addressed in this study, and was used to develop a composite family story that depicts the typical pattern of relational experiences among Aboriginal families in PICU. Case examples have also been used frequently in discussions of relational ethics to illustrate stories of relationships between health care providers and patients and their families within the health care environment (Bergum & Dossetor, 2005; Bergum, 2004).

While case study methodology has not restricted researchers to either qualitative or quantitative techniques, it always seeks to gain understanding of a singular case, such as an individual person, or a collective group, including a family, organization, or cultural group. (Yin, 2003; Sandelowski, 1996; Stake, 1994). Sandelowski suggested that “when researchers choose the case study, they are not making a methodological choice, but rather a choice of subject to study” (p. 526). The term *case study* is, therefore, used to refer to both the methodological approach to inquiry and the end product, or results of such inquiry. The case study approach is used commonly within the social sciences to gain detailed knowledge of complex social phenomena by examining the characteristics that make an individual case unique (Edwards, Bromely & Dattilio, 2004; Sandelowski; Yin).

Case study design strategies have often shared approaches to sampling, data collection, and data handling and analysis with other traditional approaches to qualitative research. Case study samples are typically purposively generated, to enable the researcher to select subjects from whom the most can be learned about the questions and issues around which the case study was generated (Stake, 1994). The criterion for selection was, therefore, the opportunity to learn specific details or perspectives, and potential research subjects were selected according to specific characteristics of interest. The drafting of the case has typically been an iterative research process (Yin, 2003). A concurrent data collection and analysis process was employed in this study, and allowed me to verify my understanding of the informants' descriptions of the experience of Aboriginal families.

Sources of evidence commonly used by case study researchers have included documentation, archival records, interviews, direct observation, participant observation, and physical archives, which provide access to rich, in-depth experiential knowledge (Yin, 2003). In this project, the research data were generated from interviews with key informants using a combination of open-ended and focused questions related to interactions and relationship issues perceived to be common in the Aboriginal family experience of a PICU. Focused questions were used to explore in detail the relationships between Aboriginal families and health care professionals within the critical care environment. During the process of data analysis, I attempted to "retain the holistic and meaningful characteristics of real life events" (Yin, p.2), while organizing this information in a manner intended to advance existing theory (Edwards, Bromely & Dattilio, 2004). In other words, the case study was placed within a theoretical framework of existing knowledge. For this study, relational ethics served as a theoretical foundation. The goal was to provide insight into how the core elements of relational ethics, including respect, engagement, embodied knowledge, and attention to the environment, existed for Aboriginal families within this specific hospital setting. To gain such an understanding, an examination of how the core relational themes of relational ethics arose within the key informants' descriptions of the experience of Aboriginal families in a PICU took place.

Methods

Setting

The study took place within the Stollery Children's Hospital (SCH) in Edmonton, Alberta, Canada. The Paediatric Intensive Care Unit (PICU), a seventeen bed unit, provides care to critically ill and injured children from both urban and rural communities throughout Western Canada. Patients ranged in age from newborn to seventeen years. Study informants included Aboriginal Cultural Support Workers employed within the SCH who worked closely with Aboriginal families of children hospitalized within the PICU, and an Aboriginal nurse with extensive knowledge of the Aboriginal experience of hospitalization in a PICU.

Informant interview locations were negotiated individually to be convenient for each informant.

Sample and Recruitment

Sample selection. A purposive sampling strategy was used to identify key professional informants with in-depth knowledge of the relationships and interactions experienced by Aboriginal families in the PICU environment. Purposive sampling enabled full and rich description of the phenomena of interest could be developed (Morse & Field, 1995). Stake (1994) suggested that to fully understand a case, a researcher must consider the case from the perspective of a variety of informants through whom the case can be known. Informants were included according to their willingness to share their knowledge of the interactions between Aboriginal families and health care professionals within the PICU. Informants were further selected based on their specific knowledge of Aboriginal families from remote northern communities. The decision to focus the case study on northern Aboriginal families was made based on my assumptions that the experience of Aboriginal families from remote locations may be very different from those families living within city locations and experience interacting in non-Aboriginal cultures. The final study sample size was determined during the iterative data collection and analysis process, as informants were added until an in-depth case description of the relational experience of Aboriginal families in PICU was developed. Sandelowski (1995, p. 180) suggested:

> An adequate sample size in qualitative research is one that permits – by virtue of not being too large – the deep, case oriented analysis that is a hallmark of all qualitative inquiry, and that results in – by virtue of not being too small – a new and richly textured understanding of an experience.

A total of three professional Aboriginal informants were included in the study. The previously collected data on which the study was developed was obtained in an interview with an Aboriginal parent who described her family's experience of having a child hospitalized in PICU. This family was from a remote northern reserve community and was required to travel to Edmonton for a lengthy hospitalization within PICU. This interview was conducted following the discharge of the child from the PICU setting.

Informant recruitment. Ongoing input from Aboriginal advisors is supported in literature examining culturally competent research with Aboriginal populations (Caldwell, Davis, Du Bois, Echo-Hawk, Shepard Erickson, Turner Goins, Hill, Keemer, Manson, Marshall, Running Wolf, Santiago, Schacht & Stone, 2002). The authors suggested that the active involvement of members of the Aboriginal community in the research process facilitates communication and enhances rapport between researchers and study participants, which may improve the quality of data collected (Caldwell et al). The professional informants included in this research were aware of the study prior to their being approached to participate, as they had served as cultural advisors for the initial parent interview and assisted in recruiting this participant. These informants were aware of the need to obtain further data to generate a more in-depth understanding of the relational issues that Aboriginal families face in PICU and had expressed willingness to participate.

Informants were contacted and provided with an information letter (Appendix A) reviewing the purpose of the study and the plan to create a composite case study description of an Aboriginal family. As these informants were known to me through professional or academic association and had worked closely with me in recruiting and interviewing an Aboriginal family during the previous data collection, consent to release contact information was unnecessary. Informants were made aware that no negative implications would result from refusal to participate and that only the research team would be aware. All professionals asked to participate agreed to be interviewed. An interview time and location convenient to each individual informant was arranged. Informants received my contact information to notify me if they decided to withdraw from the study or if a change in the interview time or location was required.

Ethical Considerations

Ethical and administrative approval. Ethical approval for the study was obtained from the Health Research Ethics Board at the University of Alberta. Administrative approval from Alberta Health Services, representing the Stollery Children's Hospital, was obtained through the Northern Alberta Clinical Trials and Research Centre.

Informed consent. Informed consent was obtained at several stages in the research process. Verbal assent was obtained from each informant prior to arranging an interview time and location. Potential risks and benefits of participation in the study were explained and informants were made aware that they were able to withdraw from the study at any time. Prior to beginning each interview, an explanation of the study was reiterated verbally and the information letter was reviewed. The opportunity for questions regarding the study was provided. Written consent was obtained from each informant (Appendix B). Informants were made aware that they could stop the interview or withdraw from the study at any time without providing a reason.

Risks and benefits to study participation. Potential risks and benefits of participation in the study were explained to each informant prior to obtaining written consent. No risks were anticipated for the professional informants, as they were asked to discuss general relationships and interactions encountered by Aboriginal families during hospitalization in a PICU. Congruent with their professional role, they were specifically asked not to share information which could identify individual families. The impact for informants was related to the time they spent participating in the interview process. No direct benefits were expected for professional informants. Benefits were anticipated for future Aboriginal families of children hospitalized in PICU.

Confidentiality. Informant confidentiality was maintained throughout the research process. Interviews took place in locations where informants had the opportunity to discuss their knowledge of the relationships and interactions encountered by Aboriginal families in the PICU environment with the assurance of privacy and without interruption. Informant confidentiality was established through the labelling of interview tapes, transcriptions, and interview notes by identification number only, which are now kept separate from consent forms within a locked filing cabinet.

Particular caution was taken to protect the confidentiality of the initial Aboriginal parent interviewed. Historically, a distrust of the intended use of research data has evolved in Aboriginal communities (Ten Fingers, 2005; Castellano, 2004; Kowalsky, Verhoef, Thurston & Rutherford, 1996). The concern has centred on the possible sharing of information with authorities who control access to resources, child custody, and the care provided to Aboriginal community members. Names and any identifying information were altered to ensure the anonymity of this parent and her family. These data were combined with subsequent interview data obtained from the professional informants to create a composite case study, further reducing the risk of the participant parent being identifiable in the research findings. As professional informants were asked to discuss typical interactions and relationships experienced by Aboriginal families, identifiable situations and family demographic information were not shared.

Data Collection

Informant interviews. Interviews were conducted with professional informants individually or in pairs, as per the individual preference of each informant. As the informants were professionals familiar with me and were fluent in English, I conducted the interviews independently, without the use of an Aboriginal interpreter. At the beginning of each interview, an explanation of the study was reviewed and written consent to participate in the study was obtained. I also reviewed my personal experience as a Registered Nursing in PICU and background information that lead to the development of the research study. Informants were assured that they could stop the interview at any time or could refuse to answer any of the questions asked during the interview.

Previous research has indicated that Aboriginal research participants have expressed a desire for investigators to listen to their stories of events, rather than adhering to strict schedules and guidelines (Caldwell et al, 2002; Kowalsky, Thurston, Verhoef & Rutherford, 1996). Such research has also suggested that participants may require time to develop comfort and trust with the interviewer and research setting before being able to discuss real issues relating to the phenomena under investigation. As the informants and I were colleagues within the SCH or Faculty of Nursing at the University of Alberta and had worked closely together in collecting the initial family data, it was assumed that such a level of comfort had been established. The interviews began by seeking the informants' general perspectives on the experience, relationships, and interactions encountered by Aboriginal families during the hospitalization of a child in a PICU, and allowed each informant to tell the story of Aboriginal families in PICU from their own perspective.

Relational ethics served as a guide in the examination of interactions between Aboriginal families and intensive care professionals. Interviews progressed to seek clarification and in-depth explanations of the relational ethics themes and issues associated with mutual respect, engagement, embodied knowledge, and environment as identified through thematic analysis of the information shared by the Aboriginal parent initially interviewed. Focused questions specifically related to the relationships and interactions encountered by Aboriginal people within the PICU were asked, as I attempted to gain further understanding of the quality of the ethical relationships between Aboriginal families and health care professionals. The interview guide (Appendix C) consisted of both focused and open-ended questions. This allowed me to ask certain questions specifically related to the core elements of relational ethics, while allowing the informants to provide their own perspectives on particular issues. While guiding questions were used to steer the direction of the interview toward the relational experiences of Aboriginal families, I was open to exploring various topics as presented by the informants (Yin, 2003). An Ecomap (Appendix D) was developed based on data from the initial family interview to provide a visual representation of relationships encountered by Aboriginal families during hospitalization. This was presented to informants towards the end of each interview to promote further discussion related to the relational experiences of Aboriginal families.

Each interview lasted one to two hours; the time frame was determined by the depth of information shared. One interview was tape recorded, as only one informant provided consent for recording. This interview was transcribed verbatim, and point form notation was also used during the interview to capture recurring information and areas for further discussion. As the remaining informants were uncomfortable with the use of a tape recorder, I took detailed notes of the information shared. Following each interview I spent time writing additional field notes regarding the information shared, as well as my reflections on the interview process and stories shared.

Data Analysis

Concurrent data collection and analysis. Data analysis occurred concurrently with the data collection process. I analyzed the data from each interview individually immediately following the interview. This allowed for the identification of relational themes to be further explored during subsequent informant interviews. I was, therefore, able to add study informants until an in-depth case description of the interactions and relationships among Aboriginal families and health care professionals within the PICU was created. The process of concurrent data collection and analysis allowed for the presentation of my preliminary conceptualizations and interpretations to study informants during subsequent interviews, permitting elaboration and clarification of my research interpretations.

Understanding relationships. A common strategy employed in analyzing case study evidence involves incorporating the theoretical propositions that led to the objectives of the case study (Yin, 2003). Relational ethics, as described by Bergum and Dossetor (2005), served as a conceptual guide throughout the process of data analysis. The core elements of relational ethics, including respect, engagement, embodied knowledge, and attention to the environment, were considered in the identification of common themes found among the informant descriptions of the Aboriginal family experience in PICU, in particular relationships and interactions with health care providers.

I chose to further focus my data analysis and case study creation on the relationship between Aboriginal families and nursing staff within the PICU. Reading the interview transcript and detailed notes revealed that this particular relationship was discussed at much greater length than relationships with other health care professionals. In addition, the interactions that Aboriginal families commonly experienced with nursing staff appeared to be very different than those interactions with other health care professionals, most likely due to the extended periods of time that nurses spend in the presence of the family at a child's bedside. My professional experience as a Registered Nurse in PICU created particular interest in these unique interactions.

Sandelowski (1996) directed researchers to avoid superficial findings, which may occur if attempts are initially made to examine all data collectively in the search for similar patterns and themes. Instead, researchers were encouraged to treat each interview transcript or set of interview notes as a unique case worthy of individual study. My initial goal was, therefore, to understand the unique features and variables of each interview transcript or set of notes individually before attempting to understand them as a group. This approach was characterised by my spending time immersed in the data, revising my understanding and interpretation of the story being told (Stake, 1994). I attempted to gain an in-depth understanding of the relational experiences of Aboriginal families in the PICU through the rereading of data to identify central themes. The use of relational ethics as a conceptual guide limited the focus of the case description to interactions and relationships between Aboriginal families and PICU nurses. Focusing the case description specifically on relational themes limited attention to other aspects of the experience of the PICU from this cultural perspective. However, case study methodologists have suggested that while a researcher should seek out the meaning held by those within the case, it is ultimately the researcher who decides what the case's own story is, and what story is reported (Stake, 1994). It is, therefore, the responsibility of the researcher to determine what aspects of the case are important, how they are interpreted, and how the case is presented. In this case, I attempted to tell the story of an Aboriginal family's interactions and relationships with nurses during the hospitalization of a critically ill or injured child within a PICU.

Data organization and identification of common themes. After reading the transcriptions and interview notes and listening to the audio-tape thoroughly, I created a data matrix of themes identified from the core elements of relational ethics. Evidence from individual sources was place within a table organized according to the four themes of relational ethics. This included the data obtained from the initial parent interview, as well as the data from subsequent interviews with professional informants. This allowed me to organize or group the data into a preliminary order (Yin, 2003). Data interpretation then occurred, to explore the quality of interactions and relationships between Aboriginal families and nursing staff within the PICU environment. Commonalities and individual differences were noted among the informants' descriptions of relationships and interactions perceived to be common within the Aboriginal family experience of hospitalization within a PICU, as well as the personal parental experience. Many aspects of the Aboriginal experience were very similar among informants and that many stories and examples alluded to analogous or identical issues. While the theoretical framework of relational ethics was used to guide which data to focus attention on, care was also taken to avoid allowing the theoretical framework of relational ethics to overwhelm the data analysis process (Yin, 2003). Aspects of the relational experience of Aboriginal families with nursing staff that expanded on the elements of the theoretical framework of relational ethics were noted for further exploration within the discussion.

Case study development. The writing of the case study was an ongoing process throughout the completion of data collection and analysis. I began attempting to write the story of an Aboriginal family experiencing the hospitalization of a child in PICU following the initial parent interview. I continually added to the case description following subsequent interviews and rewrote and revised the story as additional data was obtained. Following the creation of the data matrix, which organized the interview data according to relational themes, I reorganized the case study to allow for the discussion of the story according to the core elements of relational ethics. I chose to tell the story of an Aboriginal family in PICU in the present tense, as this helped to illustrate that while the issues presented are based on past experiences, such issues are ongoing in the present. It was my aim to engage the reader with a story that would make the experiences of Aboriginal families in PICU "real." The story was told from the third person stance, as I felt uncomfortable and ill-equipped, as a non-Aboriginal researcher, to tell the story in the Aboriginal voice. The final descriptive case study of the experience of an Aboriginal family whose child was hospitalized in a PICU environment was created using one firsthand parental account, and the cumulative second hand accounts of Aboriginal professionals. While the case study explicitly tells the story of one Aboriginal family, it implicitly tells the cumulative story of many Aboriginal families.

Rigor within Data Interpretation

Rigor within the data interpretation was promoted through the creation of a case study database. Published guidelines for work with Aboriginal communities have advocated that the researcher monitor personal feelings and emotional reactions throughout the research process, encouraging the acknowledgement and acceptance of such reactions (Kowalsky, Venhoef, Theorston & Rutherford, 1996). Yin (2003) encouraged the creation of a case study database during the data collection and analysis process, within which the researcher documents personal reflection on the aspects of the research process that led to the study’s conclusions. Bergum (2004) further emphasized the need for personal reflection, arguing that relational ethics is about understanding and knowing ourselves as we engage with others. I kept a reflective journal throughout the data collection and analysis process within which I recorded my personal impressions and ideas that arose in response to the interview process and material collected. Within this reflective journal, I also indicated personal clinical experiences and observations influencing my interpretation and understanding of the informant interview data. I, therefore, accounted for the influence of my own preunderstandings on the research findings. While reading the interview data and creating the data matrix to organize the data according to themes, I kept interpretive notes documenting my decision making process. Such notes may aid the reader in understanding the thought processes that lead to my conclusions.

Yin (2003) suggested that the case study may be strengthened through review of the final case description by the informants. The final case study was presented to a selection of the professional informants to ensure that the story told accurately depicted the relational experience of Aboriginal families in the PICU. To ensure culturally appropriate interpretations of informant interview data, the professional informants were asked if they were able to identify the relationships and interactions commonly encountered by Aboriginal families in the paediatric intensive care setting within the case study description of this experience.

Study Limitations

A limitation of the study lies in my ability, as a non-Aboriginal researcher, to create an in-depth case description of the interactions and relationships between Aboriginal families and nursing staff within the context of a PICU setting, in the absence of firsthand knowledge of Aboriginal culture and communication patterns. In addition, my limited experience in the interview process may have influenced the retrieval of rich, in-depth interview data for the creation of a thorough case study. A major limitation of the study is that it only presents Aboriginal assumptions about nursing staff and the interactions between

Aboriginal families and nursing staff. The nursing perspective on these interactions and relationships was not examined in this research.

CHAPTER FOUR

Findings

This chapter presents a composite case study that represents the experience of an Aboriginal family whose child was hospitalized in PICU. The case was created using one firsthand parental account of a family's experience, and the cumulative second hand accounts provided by Aboriginal professionals with extensive knowledge of the experiences of Aboriginal families in PICU.

The Case Study

Sarah and her husband John are from a small, remote, northern reserve community. The couple have three children, one-year old Jennifer, three-year old Lucas, and five-year old Justin. The family live with members of their extended family, including John's parents, and are within close proximity to aunts, uncles, and siblings. John and Sarah prefer to communicate in Cree, the language used primarily within their community, but are able to understand and converse in English.

Sarah and John are exhausted and very worried–Jennifer has become ill, and they have been awake for several days trying to get help for her, first at a northern nursing station, then a small northern hospital, and now they are told their daughter must go to the city to an intensive care unit for children. Jennifer must be flown to the city by a specialized transport team. Sarah and John are unable to accompany their daughter as there is no room in the plane. Sarah and John tearfully say goodbye to Jennifer as the transport team leaves the northern hospital–she has never been out of their care before. The couple are nervous, as they have never left their small community of 1500 people. They do not know how they will get to the city or how to arrange travel for themselves. The nurses at the rural hospital help them to arrange flights to the city and they travel there the next morning. Sarah and John find the city terrifying; it is big and fast paced, and there is so much traffic. They have heard many stories on the news about the crime in the big city.

Sarah and John take a taxi from the airport to the hospital to see Jennifer. In the PICU, she is attached to many machines and they see many tubes going in and out of their daughter. They are told that this is "life support" and that Jennifer is in critical condition. The doctors do not think that she will survive. They explain Jennifer's condition to Sarah and John, but use many medical terms *and language that the couple do not understand. Sarah and John don't understand the explanations of Jennifer's condition, but they are afraid to ask questions–they do not want the doctors and nurses to think that they are stupid. Sarah and John are exhausted and don't know what to do. They are given vouchers for the hospital cafeteria by the PICU social worker and are encouraged to get something to eat and drink. They go down to the crowded, noisy cafeteria, but are unsure of how to order and pay. They return to the unit without food or drink, and it is only when the social worker checks on them that they, embarrassed, reveal to her their uncertainty in navigating the cafeteria. The social worker assists them in ordering and paying for a meal. Sarah and John are told by the social worker that they will stay in a hotel twenty minutes drive from the hospital. This is the hotel where all northern Aboriginal families receive funding from Referral Services to stay. They will receive money to take a taxi to and from the hospital daily. Sarah is told that Referral Services distributes and oversees government funding for northern Aboriginal families during hospitalization in the city. That night, Sarah and John stay in a PICU parent room to be near Jennifer. In the morning, they are yelled at by the Referral Services manager because their hotel room was paid for, but not used.*

Sarah and John call their extended family and friends in the community to tell them how sick Jennifer is, and that she may not survive. Many members of the extended family and community travel to the city to provide support to Sarah and John and to say goodbye to Jennifer. When they arrive at the PICU, Sarah sees the nursing staff roll their eyes and overhears a nurse saying "Great, now we have to deal with all of these people coming in and out of the room all day long just to gawk at this child." Sarah is angry; these people are important to her and John and the nurses do not understand that this is the community's way of supporting them. Although many members of the community do not know Jennifer, they are friends of Sarah and John's or their parents.

John's father places an eagle feather and braided sweet grass on the bed next to Jennifer, and tells the nurse that these must be kept near the child at all times. The next morning, he finds these items on a table in the corner of the room. The nurse tells him that they were in the way when they were repositioning Jennifer and changing her bed linens. John's father explains that they believe these items will help to heal Jennifer by providing strength. The family believes that the sweet grass is symbolic of purification, and is used to cleanse the mind, body, and spirit, represented by the three sections in the braid. The braid also represents unity and strength, as each strand alone is not as strong as when braided together. The family sees the eagle as a powerful symbol of courage, so the eagle feathers are seen as a tool in healing. John hopes that the nurses will understand the significance of these items and be more considerate, but the next day these items are found taped to the bedside monitoring equipment. John and his father feel that the nurses do not care about how important these items are for Jennifer nor understand that keeping them near her is critical for her healing.

Embodiment

Bergum and Dossetor (2005) described embodiment as a core value of relational ethics and the need for the healing of the split between the mind, body, and spirit to be key in the development and maintenance of ethical relationships in the health care setting. Embodiment, or embodied knowledge, recognizes

> that people live in a specific historical and social context as thinking, feeling, full-bodied, and passionate human beings. Focusing on embodiment brings us back to life as we live it–that is, the integration of mind, body, and spirit. Embodied knowledge is not just the knowledge that we think about and discuss. Embodied knowledge is lived, in full subjectivity, through action (Bergum & Dossetor, p. 137).

For a relationship to develop between the nurse and the patient and family, there must be understanding of the patient’s story, and acknowledgement of the wisdom or knowledge that develops from one’s lived experience. The patient must be seen as a person.

Within the informants’ accounts of Aboriginal families’ experience in PICU, there were no descriptions of staff behaviour that suggested a commitment to an embodied body-mind-spirit perspective of the children in their care. Within this highly technical environment geared to treat physical conditions, the perceived focus of all care was on the physiological needs of the child without a strong commitment to understanding the child and family from the perspectives of the extended family, community, cultural values, and individual beliefs. This is incongruent with the need for children to be seen as cultural or spiritual beings rather than only physiological beings.

Cultural items in healing. A frequently used example of the lack of consideration for cultural and spiritual beliefs was the way nursing staff treated cultural items, such as braided sweet grass or eagle feathers, frequently left at the bedside or close to the child by family and community members. All study informants saw these as very powerful in the healing process. To be optimally effective, these items were to be left on the bed, or tied to a child's wrist, but families frequently returned to the bedside to find these items on the floor or taped to the bedside monitor. In some instances, cultural items were thrown into the laundry and could not be retrieved. The rationale staff used for removing these items was that they interfered with the physical care of the child.

These items can be compared to a child's teddy bear, which is taken everywhere by that child and perceived to have the ability to comfort and consol the child. The teddy bear is recognized and respected within the hospital culture as a treasured item, and has even been adopted as the official logo for the Stollery Children's Hospital. Few staff would question a request to have a teddy bear left with a child at all times. The sense of comfort and healing potential that it holds is universally understood in the hospital culture. Yet because Aboriginal cultural items may not be understood by non-Aboriginal nursing staff, these items may not be viewed with the same importance nor treated with the same respect.

Ironically, the power that Aboriginal families believed was given to the ill or injured child when such items were kept close to or on the child's body can be compared with the power frequently attributed to technological devices, such as a bedside monitor, by nurses in the PICU. For the nurse, the monitor can come to symbolize a necessary component of healing. This reveals a striking dichotomy between the Aboriginal values and beliefs and the critical care culture. Within the Aboriginal culture, meaning appears to be embodied in objects from nature thought to promote health and healing. The eagle feather and sweet grass are believed to empower the individual by encouraging inner strength and promoting the connection between the mind, body, and spirit. In contrast, the focus of much of a nurse's time within intensive care revolves around technological devices, such as monitoring equipment. The act of moving Aboriginal cultural items from the child and attaching them to a monitoring device disregards the inner strength and power of a person in the healing process and inadvertently symbolizes reliance only on medical technology, interventions, and treatment. This may suggest to Aboriginal families that all of the healing powers embodied by these cultural items are being attached to a piece of equipment, rather than the body. A nurse may have difficulty understanding the family's distress over this, especially if the technology exists for the nurse as an extension of the patient's body.

Kinship and maintaining connection to the patient as person. When the cultural and spiritual aspects of a child are ignored, the child is reduced to a biological function or organ, and is identified as one aspect of the body, rather than as a whole person. Such a problem may result from of the specialization and compartmentalization of medicine in today's health care system, where each health care professional is only concerned with one organ or body system

(Bergum, 2004). It may, therefore, often be left to the family to assist nurses and other health care professionals to be aware of the lived reality of a patient and to ensure that the patient is seen as more than as a medical diagnosis. Aboriginal informants explained that kinship, or maintaining a connection to the extended family and community, was a primary way to maintain a connection to the hospitalized child as a person. Maintaining this connection to the family and community while in the PICU helped to ensure that one's cultural values and beliefs remained prominent in their care, possibly promoting embodied knowledge of the patient among health care providers. However, when the importance of the body-mind-spirit connection is ignored by nursing staff caring for a child, the importance of the family and community may also be ignored. Informants saw the involvement of the extended family and community and maintaining the body-mind-spirit connection to be interdependent; family and community helped Aboriginal families to maintain a close connection to their cultural and spiritual values and beliefs.

All informants said that nurses seemed to lack understanding and respect for the concept of kinship and the role of the extended family and community in providing support to a critically ill or dying child and the family. For example, nurses in the PICU did not demonstrate understanding of the need for extended family and community members to say goodbye to a dying child, as a way of beginning the grieving process and to assist in their own healing. All informants cited multiple occasions where nurses expressed frustration with the number of family and friends coming to the bedside of an ill child. This was demonstrated through non-verbal communication such as eye-rolling, or comments made among staff members about the number of visitors continually going in and out of the unit. Study informants saw a significant cultural difference between Aboriginal and non-Aboriginal people with respect to the extended family and community. In non-Aboriginal families, only the immediate family were likely to be involved in the hospitalization of a child, while in Aboriginal families, multiple extended family and community members held equivalent importance. The perceived failure of nursing staff to understand the importance of kinship in the care of a hospitalized child and family was seen as a failure to recognize the importance of the body- mind-spirit connection in healing and recovery. This was thought to result in the failure of nursing staff to understand and connect with Aboriginal families, thereby limiting the ability of nurses to respond and engage ethically. Bergum and Dossetor (2005) suggested that nurses need to shift their attention to the patient as a human being, allowing the nurse to become aware of the patient as a person with a mind, body, and spirit, rather than simply a diagnosis. For nurses, understanding the Aboriginal individual as a person involves understanding cultural values and beliefs and involving of the extended family and community.

Despite what the doctors initially tell Sarah and John, Jennifer's condition begins to improve. Extended family and community members return home. Referral Services inform Sarah and John that funding to stay in the city will only be provided for one parent now that Jennifer is improving, so John must return home to the couple`s northern community with their two older children. Sarah remains in the city, feeling alone, and isolated from her family and community. She will miss her older children`s birthdays, and family and community celebrations. Sarah feels that she is being forced to neglect her older children so that she can remain in the hospital with Jennifer. Funding will be provided only once every four to six weeks for Sarah to return home and visit her family. Sarah *is told that she can use Telehealth technology or computers within the hospital to maintain contact with her family and to provide them with updates on Jennifer`s condition, but she finds this technology very strange and uncomfortable to use. Her family have limited computer access in their remote community, as very few people own or know how to use computers. In order to continue to receive funding for accommodations and meals, Sarah must remain in the hospital for at least six hours each day. Sarah finds it very difficult to sit at Jennifer's bedside all day, as Jennifer is intubated and sedated, and it is difficult for her to provide care for, or interact with her child. The hours pass very slowly for Sarah as she sits alone in the PICU.*

Sarah feels isolated from the other families of children hospitalized in the PICU. They are different from her in their culture, values, and beliefs and she feels that they cannot understand her. She does not reach out to anyone in the hospital and PICU, but instead tries to find other Aboriginal people from her own or similar communities. She speaks with her family weekly on the phone, and they tell her about other community members who are in Edmonton for medical care. Sarah then seeks out these people for support. They understand her, and she is able to speak with them in Cree. Even though other non-Aboriginal families have children in PICU and are going through a similar experience, Sarah does not think that they can understand this experience from her perspective.

Engagement

Informants said that isolation was a significant issue facing Aboriginal families in PICU. Isolation was experienced both from the extended family and community support systems due to physical separation, and within the hospital and PICU environments. Isolation may occur when there is a lack of connection, or engagement, between health care professionals and patients and families in the health care environment. Bergum and Dossetor (2005) stated that relational engagement exists "in the shared moment in which people have found a way to look at something together. There is power in the experience of people who have very different experiences coming to understand something together" (p. 103). All informants described a lack of relational engagement between Aboriginal families and nursing staff and they attributed this to a lack of cultural understanding and a lack of desire or interest in looking at the experience of hospitalization from an Aboriginal perspective.

Bergum and Dossetor (2005) described the initial relationship between patients and families and the health care professional as a relationship among strangers, as each come from different communities, traditions, and cultures. Only through engagement between the nurse and family do these strangers become *neighbours*. Descriptions of the nurse-patient-family relationship provided by study informants suggested that engagement rarely occurs between PICU nurses and Aboriginal families. Any relationships that developed remained superficial relationships among strangers. For engagement to occur and an ethical relationship to develop, person-to-person contact must occur, and the nurse must come to know the child and family beyond the hospital setting. Responsiveness to the needs of the patient and family is required – not just physical needs, but the needs of an individual as a person with unique values, culture, and traditions (Bergum & Dossetor).

Ethical communication. If understanding and responsiveness are to occur, dialogue and conversation must take place between nurses and Aboriginal families. Conversation and dialogue require the nurse to listen and hear, to understand the experiences of Aboriginal families, as well as the values, cultures and traditions that influence and affect one’s experience of critical illness and hospitalization. Conversation is much more than just verbal communication; it is also the non-verbal communication of touch, body language, and silence (Bergum & Dossetor, 2005). One informant made the point that non-verbal communication was often very important in preventing engagement and the development of ethical relationships:

> The non-verbal language of staff is so clear; the way they stand, the way they look, the way they roll their eyes, that is what families' pick-up on. And staff are not even aware half the time. And maybe it is part of the environment, when you are dealing with a critical situation, you don't have time to be all open and friendly, you are right to the body and you are right there. But this is the point of entry, where you start to build that relationship, and it doesn't take two seconds to say "Hey, we have got your daughter, just give us five minutes, go outside and be with your family and then we will have you come back." I know it sounds simple, but sometimes, our common sense, it is out the door (Aboriginal Nurse).

The informants noted that Aboriginal families recognize the PICU environment as highly technical and fast-paced, often involving many critical situations for hospitalized children that require immediate lifesaving physical care and interventions. Nurses were seen to have little time to spend with families in the development and nurturing of ethical relationships. However, Bergum & Dossetor argued that engagement *can* occur when nurses are present and fully engaged in *each* available moment. The quality of engagement that occurs between nursing staff and families during brief periods of time may be more important than the quantity of time spent minimally engaged. A lack of engagement means that the patient and family feel abandoned and alone: "Relational space calls for engagement with one another, for without engagement the patient is alone, no matter how many professionals are present" (Gadow, 1999).

Shared culture rather than shared experience. Despite feeling isolated and alone in the PICU environment, the Aboriginal parent explained how she further isolated herself by not seeking to engage with staff or other families of children in the PICU. She indicated that she did not want to interact with the "White man," and was much more comfortable seeking support from other Aboriginal people from her own or neighbouring communities, even if they had no understanding of the experience of having a child hospitalized in PICU.

It is common to observe parents of infants and children hospitalized in the paediatric intensive care setting supporting on another (Miles et al, 1984). The shared experience of hospitalization appears to link these families in a supportive network, despite apparent differing values, beliefs, community, or cultural background. Yet the same does not appear to be as true for Aboriginal families. A shared hospital experience did not seem to connect Aboriginal families to other non-Aboriginal families in PICU; a shared culture and value system appeared to be more important to Aboriginal families in connecting and engaging.

Sarah appreciates the physical care the nurses provide to Jennifer, but describes her interactions with the nursing staff in PICU as limited and disconnected. While she sits for hours at the bedside watching the nurses provide care to her daughter, they rarely explain that they are doing, or what the alarms on the many machines mean. Sarah wants to continue to provide care to Jennifer as she did at home, but she does not know what she is allowed to do and does not want to overstep her boundaries. She tries to change Jennifer's diaper, but is sternly told not to – the nurse has a routine and a way she likes things done, and does not want this practice interrupted. Sarah feels that the nurses have all of the power in this environment, and that she no longer has any control over any aspect of her daughter's care. Sarah sees the nursing staff interacting frequently with non-Aboriginal families, engaging in conversations about the hospital *environment, the care of their children, and their lives outside of the hospital setting, yet they make no effort to converse with her. Sarah says she feels ignored and nonexistent while at Jennifer`s bedside. Sarah feels she is ignored because she is Aboriginal and thinks that she is being judged and stereotyped because of her ethnicity and culture.*

Mutual Respect

Mutual respect in relational ethics describes the concept that we are all fundamentally connected to one another; our experience of the world is shaped by the attitudes of others towards us, and the attitudes we hold towards others (Bergum, 2004). Mutual respect in the health care environment requires the respect for and value of diversity. Individuals must be treated with acceptance for unique differences, while at the same time allowing for the recognition of similarities. If we are unable to see ourselves as similar to the other, a complete loss of relationship occurs (Bergum & Dossetor, 2005). Bergum (2004) suggested that respecting the knowledge, beliefs, and values of the other is difficult when nurses remain grounded in their own perspectives and do not understand the value of different perspectives and experiences. The Aboriginal parent said she felt ignored at the bedside, and believed that this was the result of being judged and stereotyped because she was Aboriginal. One study informant suggested that nurses may devalue the cultural knowledge and beliefs of Aboriginal people because of stereotypical views and assumptions regarding the Aboriginal population. Nurses may be unaware that they hold these views and assumptions:

> We are so caught up in our own ideologies that it is really hard to look outside of ourselves. Our health care systems are not really conducive to

> that kind of critical reflection. Not just reflection, but reflexive–questioning why do I hold these assumptions? Why do I make the assumption that if an Aboriginal person is in a car accident, there is automatically drinking and driving? We need to challenge those stereotypes (Aboriginal Nurse).

Mutual respect can only begin with self-respect and self-awareness (Bergum & Dossetor, 2005). Therefore, there is a strong need for nurses to engage in independent critical reflection; to come to know their own beliefs and assumptions about Aboriginal people, and why they hold such attitudes and preconceptions. For nursing staff to truly understand and respect *the other*, in this case the Aboriginal patient, family, and community, they need to understand and respect themselves (Bergum, 2004). Bergum and Dossetor encouraged nurses and other health care professionals to ask the question: *Who am I?*

> The question of *self-knowledge* is the raising of consciousness of our tacit commitments and prejudices, as a matter of moral consciousness. The question *Who am I?* is a question of humility, of self in relation to others – not in a self-effacing way, but in a self-understanding way. This attitude of humility is not a virtue that can be cultivated by oneself, but is a relational, inquisitive openness to find out more about our own values, beliefs, and sense of rightness (Bergum & Dossetor, p. 82).

Ethical practice in a health care environment requires nurses and other health care professionals to move beyond just providing technically competent care to engaging in ethical, culturally aware and competent relationships.

Human understanding. The informants made the distinction that Aboriginal families wanted to be recognized as Aboriginal, but not reduced to the cultural stereotype of an Aboriginal person. How the Aboriginal person is viewed may be based on stereotypes perpetuated in the media, without awareness of that person as an individual with unique values, beliefs, and personal perspectives. While cultural understanding is important, so is being viewed and understood as a human being: "It is not just a cultural understanding, it is a human understanding. It is being treated *humanly*, as a human being, with these particular values and beliefs" (Aboriginal Nurse).As one informant explained, "When these people come in, they come in as individual human beings, regardless of race. Regardless of where you come from, or what colour your skin is, our bodies all work the same" (Aboriginal Nurse). It is within this view of the Aboriginal patient and family as *human beings*, rather than cultural stereotypes, that nurses may see the similarities between themselves and Aboriginal people, often separated by differences in cultural values and beliefs. Bergum and Dossetor (2005) suggested that while one cannot walk in another's shoes and understand their unique personal experience, we have all walked in shoes, and can, therefore, walk beside the other and talk with them to gain knowledge and understanding of this individual experience. When similarities among the seemingly distinctive and unique can be seen, mutual respect can exist and flourish.

Mutual power within relationships. Within the concept of mutual respect, the idea of mutual power exists, describing the power or autonomy that each individual has to make decisions for them self. Within a health care environment, health care professionals hold the balance of power, due to their knowledge and expertise, ability and authority, and the rules and procedures of the health care setting (Bergum & Dossetor, 2005). Without careful attention to issues of power, patients and families can feel powerless in making decisions regarding their own treatment and care. Such feelings of powerlessness occur when an ethical relationship between the patient and family and the health care provider does not exist. Bergum & Dossetor explain that

> when relationship is absent, doing something technical is, at times, the only possible response. The narrow focus on technical care, body systems, and laboratory tests, in the face of human suffering of the whole patient, eventually dehumanized both the patient and the caregivers: these people forget *who they are* (p. 95).

Informants said that Aboriginal families felt powerlessness, due in part to the unequal balance of power within the health care environment, but also as a result of the historical imbalance of power between the "White man" and the Aboriginal people. All informants noted that the "White" nurses had considerable authority over Aboriginal families. While some authority was related to their knowledge and expertise in the health care field and their understanding of the PICU cultural norms, much of this power was based on the historical interactions between Aboriginal people and the "White man." Study informants frequently referred to ongoing intergenerational trauma related to the apprehension of Aboriginal children and subsequent placement in residential schools. According to informants, Aboriginal parents were generally reluctant to ask questions of nursing staff and other health care professionals for fear of appearing uneducated or stupid. These qualities were associated with being a “bad parent” and the fear of apprehension of Aboriginal children and placement within the child welfare system.

The Aboriginal parent said that she had a very limited role in her child’s care. While previous studies have found that loss of parental autonomy was a significant source of parental stress during hospitalization in intensive care (Meyer, Snelling & Myren-Manbeck, 1998; Mu & Tomlinson, 1997), this may be magnified for Aboriginal families. While all families are unable to provide hands-on care in PICU, Aboriginal families were reported to fear that this would lead them to be judge as bad parents. One study informant suggested that common Aboriginal communication patterns, such as the often described lack of eye contact, may not be a demonstration of respect for health care professionals as frequently thought, but rather a demonstration of fear and mistrust. Such communication patterns may be an intergenerational product of residential schools, where Aboriginal children were taught never to challenge authority figures by looking them directly in the eyes.

Sarah is confused and frightened by the medical equipment and frequent alarms in the PICU. She does not understand what all of the equipment is for, and no one explains what the alarms on these machines are. Sarah is afraid to interrupt the busy nurses to ask them to explain. She finds the culture, routines, and structure of the PICU environment to be intimidating and overwhelming. She says that she does not fit in to this busy, fast-paced, highly technical setting, where the focus is primarily on meeting physical needs. She says that the nurses are too busy to spend time talking with her or providing support. They just want to get their work done.

Environment

Interactions and relationships are influenced by the environment within which such relationships develop and interactions take place. To understand the relational environment, or health care system, we must see that each action we take affects the whole system (Bergum, 2004). Bergum claimed that the relational environment is within each of us, a living system that is changed through our daily actions. The structure and culture of the health care environment affects the quality of interactions and relationships that develop between PICU nurses and Aboriginal families. For ethical relationships to develop and exist, nurses must consider how the environment is affected in each ethical moment. Relational ethics is the creation of an environment where ethical reflection can take place. This requires nurses to consider the personal, as well as the scientific, during each interaction with a patient and family. Yet many health care environments are characterized by a lack of time, resources and staff (Bergum & Dossetor, 2005).

All study informants said that Aboriginal families do not believe that nurses take the time to understand Aboriginal families in PICU, to come to know who they are and how their culture, values, and beliefs influence how they experience the hospitalization of their child. Informants thought that the structure and culture of the PICU environment prevented nursing staff from having the time and opportunity to connect with families on more than a superficial level. According to the informants, Aboriginal families saw the nursing staff as extremely busy, and they did not want to interrupt the work of the bedside nurse to ask questions or engage in conversation.

Burnout and relational engagement. One study informant, an Aboriginal nurse closely involved in the hospitalization of several community members in PICU, suggested that, over time, nurses working in PICU may become overwhelmed by the stressful nature of caring for critically ill and injured children, as well as families in crisis situations. Bergum and Dossetor (2005) acknowledged the difficulty that nursing staff experience working within a relational space, where one remains aware of the emotions, feelings, and personal connections of the patient and family:

> Attention to the feeling body, the body that is affected by suffering and by death, is a hard place to be, especially for healthcare providers who encounter life's tragic moments so frequently. Healthcare professionals have learned, or have been distinctly taught, to be objective and to keep emotions controlled in order for rational objectives to have full sway in decision making (p. 153-154).

Within this relational space, nursing staff may be faced with difficult ethical challenges when working with patients and families with different cultural influences and life experiences (Bergum & Dossetor). Nursing staff resistance to developing connections and relationships with these families may serve as a protective mechanism to avoid burnout in this stressful environment:

> I can't even imaging working in PICU on a daily basis, I just can't imagine. You burn out, and then you become solid, and it doesn't matter who comes through the door; you are just there to do your job and go home at the end of the day. And I don't think we can blame them for that.

> It’s the structure...We need to invest more in our RNs, because as human beings, we can only be expected to work so hard for so long. And it doesn’t matter who you are, black, red or white, you’re going to shut down. And then it doesn’t matter who you are caring for. That is what I see, and that is what I see as a big part of the problem. You just shut down (Aboriginal Nurse).

Bergum and Dossetor (2005) suggested that while such a scenario may be the reality of many health care environments, this reality could be changed if attention to ethical relationships was made a primary commitment by nurses and other front line health care professionals. Burnout among nursing staff may actually occur when caregivers distance themselves from patients and families and begin to treat them as faceless objects (Bergum & Dossetor). In such situations, caregivers also become faceless practitioners present only to carry out professional responsibilities, and they are in turn seen by patients and families as merely objects. A lack of engagement and relationship with patients and families may cause nurses to lose meaning in their work. The creation of a relational space where ethical relationships can exist is dependent upon connections between people, institutions, agencies, and other structures. Creation of this relational space is extremely challenging, as it is a space where certainty does not exist, and one must be comfortable with ambiguity, rather than constant control within the environment (Bergum & Dossetor).

The social worker in PICU tells Sarah that there are Aboriginal cultural support workers available in the hospital. She arranges for Sarah to meet with them. Sarah wonders why none of the nurses mentioned these resources earlier, and wonders if the nurses are even aware of these resources. A cultural support *worker attends the meetings that Sarah often has with the doctors to talk about Jennifer's condition, treatments, and care. The cultural worker is able to translate many of the medical terms and explains the information in a way that makes sense to Sarah. She feels more comfortable and confident asking questions with this support.*

Eventually, Jennifer is ready to be discharged from the hospital, but her ongoing medical needs mean that it will be impossible for her to return home to the remote reserve community where the family lives. The resources to meet her complex medical needs are not available in this remote area, and the doctors tell Sarah and John that Jennifer must be near a major hospital. Sarah and John are told that they should place Jennifer in medical foster care in the city so that she will be close to medical facilities. The foster family will likely not be of Aboriginal background. The couple are afraid that they will lose their daughter to the welfare system, but feel powerless. If they want to keep their daughter in their care, Sarah and John must move their family away from their community. They would lose their entire support system and would be completely alone in the city. They do not know how they would provide for their family outside of their community. Sarah and John make the difficult decision to place their daughter in foster care and return home to the reserve community. They are unsure of when they will be able to make the long journey to visit Jennifer, due to financial limitations. Jennifer's health has declined and there remains a strong possibility of further hospitalization and treatment.

This "ending" to the composite case of Jennifer and her family is a common reality for many Aboriginal families of children with complex and ongoing medical needs, as was underscored by the stories told by all of the study informants. Families in similar situations often had no concrete knowledge of what the future may hold, and had to live with such uncertainty regarding both the health of the child, as well as the structure of the family. So much was unknown for the families described; they often wondered if their child would ever return home with them, and if not, where the child would live and if they, as parents, would ever be able to remain an important and prominent part of their child's life. Aboriginal families may not have anyone to turn to for answers, in part because health care providers may also be equally uncertain about a child's future health care needs, but also because families may feel they cannot trust those directly involved in the child’s care.

CHAPTER FIVE

Discussion

From a relational ethics perspective, respect for and value of diversity, a healing of the split between the mind, body, and spirit, the establishment of a genuine connection or engagement, and a practice environment which supports dialogue and conversation are essential to relationships between health care providers and the patients and families in need of such care (Bergum & Dossetor, 2005). The interviews that informed the case study of an Aboriginal family hospitalized within a PICU environment suggest that such ethical relationships do not often develop between these families and nursing staff. Instead, informants perceived that both Aboriginal families and non-Aboriginal PICU nurses viewed the differing group as *the other*, with markedly different cultural values and beliefs. While informants said that PICU nurses tolerated some practices of Aboriginal culture and beliefs, the nurses were seen to disapprove and not understand of the importance of these practices for the child's healing. Aboriginal families and nursing staff, therefore, remained disconnected and disengaged; the interactions that took place were of a superficial nature with limited human connection.

The Other

In PICU, a failure to see similarities, and a focus on differences between Aboriginal families and nurses, contributed to the process of othering by both Aboriginal families and nurses. Each group was seen to foreground the distinction between themselves and the other; what they saw first was dissimilarity rather than commonalities. The othering that existed between Aboriginal families and nurses appeared mutual; both families and nurses saw themselves as distinct and separate from the other. Canales (2000) described *othering* as a process of engagement through which we perceive those different from the self as the *other*. Canales explained that one comes to know the self through differentiation and contrast from the other; by identifying traits and characteristics of another, one comes to distinguish personal identify. A focus on those characteristics that make Aboriginal families and PICU nurses different may have prevented each group from seeing what makes them similar as human beings. Informants described both PICU staff and Aboriginal families as seeing themselves as separate, or distinct, from the other group, based on differences in culture, values, beliefs, and experiences. No informants described genuine mutual respect within the relationships between Aboriginal families and PICU nurses; they were seen as remaining disconnected, as they did not appear to understand the others' experience and perspective, nor did there seem to be active effort to gain understanding. Bergum and Dossetor (2005) stipulated that mutual respect cannot exist in a relationship until both parties are able to see the human experience as a shared experience – nurses and Aboriginal families must see themselves as persons who are connected to one another as human beings, working together to ensure the best interest of the hospitalized child.

Perhaps the different ways in which Aboriginal and non-Aboriginal people learn and come to understand the world influences the ability of Aboriginal families and nurses to engage with one another in a respectful manner. According to the informants, Aboriginal people share knowledge through storytelling, often passed down through generations, serving to honour indigenous history and traditional wisdom. In contrast, the knowledge and technical expertise valued within the PICU was primarily obtained in the academic or clinical setting. Storytelling and intergenerational knowledge may lack credibility within the fast-paced and highly technical PICU environment where evidence-based practice is emphasized. Subsequently, nurses may not value or respect the Aboriginal cultural perspective. The pace of Aboriginal storytelling and sharing of intergenerational knowledge may be a larger issue; critical care nurses may not have the time or patience for the slow pace of Aboriginal storytelling as a method of learning. The lessons presented in Aboriginal stories may be lost to nurses and other health care providers who expect instant concise information.

Stereotyping. Othering is often based on cultural stereotyping. Members of a particular cultural group may be seen, not as unique individuals, but as stereotypes applied to all members of that group. Canales (2000) described stereotypes as

> shared perspectives of the dominant majority that are produced and sustained through primarily dominant-controlled communication channels – verbal, visual, and technological. Through these communication processes, stereotypes become part of established norms and are perpetuated through group members’ adherence to them (p. 22).

Informants described stereotyping and reliance on misconceptions within interactions between nurses and Aboriginal families. A large part of the nurses' stereotyping was the perception that being Aboriginal was a uniform way of being. Informants believed that nurses' lack of engagement in meaningful relationships with Aboriginal families resulted in a failure to gain experiential knowledge of individual Aboriginal people and families. Nurses were seen to not realize the significant differences among Aboriginal people based on where they were from, their band and community, the degree of isolation from other cultural groups, as well as individual personality traits and characteristics. As a result, nurses were perceived to rely on stereotypical representations of Aboriginal people to guide their interactions with family and community members, despite the frequent inaccuracy of such conceptions. Interestingly, while informants spoke of Aboriginal families' experiences with stereotyping and marginalization because of their race, families appeared to perpetuate stereotypical views of the "White man," or non-Aboriginal nursing staff, based on previous generations' behaviours and interactions. Reliance on these stereotypes by both nursing staff and Aboriginal families to predetermine individual characteristics may significantly shape and limit the interactions and engagement that take place between during the hospitalization of an Aboriginal child in PICU.

These stereotypes and misconceptions of the Aboriginal person may not be all that influence the interactions between Aboriginal families and nursing staff. Nurses may have beliefs about what constitutes "normal" behaviour and attributes of any family hospitalized in the PICU. Based on personal values, nurses may believe that certain behaviours and practices are socially acceptable during the crisis situation of hospitalization. Aboriginal families may have attributes and behaviours incongruous with the nurse's stereotype of how a family in PICU should behave and interact. Nurses may direct the care they provide to Aboriginal patients and families based on their own stereotypes of the socially acceptable behaviour (Canales, 2000). One study informant provided an example of nursing staff restricting the information they provided regarding a child's condition to only the biological parents, even though the child lived with members of the extended family. Such a process was referred to as a family adoption. While these family members were not legal guardians, they were essential in the care and upbringing of the child, and were deeply offended by the lack of respect they received in the hospital.

The visible other. Othering and stereotyping may be significantly influenced by the visibility of one's differences, such as skin colour, accent, or language (Canales, 2000). For Aboriginal families in PICU, their skin colour, physical attributes, accent, language, names, and community may make them easily identifiable as *the other*. These visible attributes may mean that the process of differentiating the Aboriginal patient and family from oneself may begin before the nurse has even been introduced to the patient or family. The ability to hide one's differences or remain invisible within the PICU setting may lessen or eliminate the extent of othering for Aboriginal families. Goffman called this *passing* (1963). Informants described situations where Aboriginal families attempted to remain invisible or less noticeable at a child's bedside by trying not to draw attention to themselves. Examples included not asking questions of nursing staff and not initiating or engaging in conversations with staff and other families in the unit. Previous studies with Aboriginal people in hospital have suggested that Aboriginal families may use measures to alter their physical appearance and behaviours, such as dressing according to their perception of “White” standards and speaking to sound well-educated to better fit into the non-Aboriginal health care setting (Browne & Fiske, 2001).

Power within Relationships

Within the interactions and relationships established between Aboriginal families and PICU nurses, the process of othering was influenced by an imbalance of power. Informants viewed nurses as authority figures, seen to wield considerable power over Aboriginal families. Nurses’ power was derived from health care knowledge, technical skill and expertise, understanding of the PICU cultural norms, and their authority to enforce rules and regulations. According to Canales (2000), the use of power within relationships influences the experience of othering in two distinct processes: exclusionary othering and inclusionary othering. When exclusionary othering occurs, those in power within a relationship use their power for domination or subordination, causing the other to feel alienated and marginalized. Such a process may result in decreased self-esteem for patients. The process of inclusionary othering involves nurses and patients or families sharing power to construct connections and relationships, resulting in coalitions and a sense of community. Inclusionary othering requires recognition and respect for different world views and valuing diversity. The nurse must, therefore, recognize the value of Aboriginal knowledge.

From the perspective of study informants, the interactions between PICU nurses and Aboriginal families were primarily exclusionary – nursing staff were perceived to focus negatively on characteristics that made Aboriginal families different, creating feelings of isolation and stigmatization for these families while at a child’s bedside. Nurses were seen to lack understanding of and the desire to learn about Aboriginal culture. Existing theories on social interaction suggest that the understanding of different cultures and perspectives may lack value and importance within the health care setting. Critical social theory, which offers a means to examine the power in social relationships, is based on the premise that certain groups in a society are in controlling positions, and hold greater power, prestige, and status than oppressed groups (Bradbury-Jones, Sambrook & Irvine, 2007). The role of the nurse as health care provider and expert has resulted in nursing staff being perceived as dominant in interactions with Aboriginal families. Critical social theory suggests that nurses, as the dominant social group, do not see understanding Aboriginal families as valuable knowledge. Therefore, nurses may feel no need to be aware of, or understand, the less powerful social group, in this case Aboriginal patients and families.

As the less powerful social group, Aboriginal families are expected to understand and adhere to the cultural and social norms, rules, and regulations of the PICU. Aboriginal families from isolated northern rural or reserve communities are at significant disadvantage while in PICU, as they hold significantly less power and are unfamiliar with the health care culture. The essential dynamic of the nurse-patient-family interaction may, therefore, be based on the fact that the nurse is seen to have the overall responsibility for the care and well-being of the child patient. The family is not in a position to challenge that authority (Sumner & Danielson, 2007).

Medical foster care. The informants frequently mentioned the threat of the removal of an Aboriginal child from the care of the family and placement in medical foster care as an example of the ultimate power and authority that exists in relationships between nursing staff and Aboriginal families. All informants said that medical foster care was a common and profound fear for families from remote or rural locations. Due to limited medical and health care resources in many northern areas, Aboriginal communities may not be able to meet the needs of medically fragile children following discharge from the tertiary care setting. A child may be placed in medical foster care, often with a non-Aboriginal family, close to necessary health care facilities and resources, while parents and extended family members return home to their northern community.

Informants compared the placement of Aboriginal children in non-Aboriginal foster families to the apprehension and placement of Aboriginal children in residential schools during the 1850s to 1960s. During this period of Canadian history, it was thought that Aboriginal children could be “civilized” and “westernized” through the separation from their parents and community and simultaneous instruction in religious education. The era of residential schools resulted in the loss of Aboriginal culture, heritage, and language for several generations of children, as well as mistreatment and abuse (Richardson & Neilson, 2007). Study informants repeatedly emphasized how Aboriginal people continue to suffer the intergenerational trauma that resulted from the placement of Aboriginal children in residential schools. Generations of children were removed from normal family life and failed to learn the social skills necessary for family interactions. Traditional values, beliefs, parenting and family skills were not handed down, and much of the struggle that Aboriginal people now face is thought to stem from the apprehension of so many Aboriginal children (Richardson & Neilson). Non-Aboriginal people, including nursing staff in the PICU, may see this as ancient history that needs to be set aside. Informants thought that nurses underestimated the intergenerational impact that residential schools have had on Aboriginal people, and lacked understanding of how residential schooling continues to affect interactions with non-Aboriginal people.

Informants said that the fear of history repeating through the removal of Aboriginal children and placement in medical foster homes significantly affected how Aboriginal parents and extended family related to non-Aboriginal nursing staff. All informants said that families of children with complex and ongoing medical concerns feared that they would appear uneducated, stupid, or uncaring because they did not understand medical terminology or were uncomfortable interacting in the hospital. Ultimately, they feared that these perceived failures would result in their children being removed from their care. They avoided asking questions of nursing staff or interrupting their work to prevent appearing ignorant or disrespectful of nursing staff who were seen as authority figures. Although children placed in medical foster care are not routinely forcibly removed from the community as they were during the height of the residential school era, informants said that Aboriginal parents felt that they had no choice but to give up their children. Families were seen as powerless in the decision making process. Choosing for a child to remain in their care following discharge from the hospital could mean moving to a large city near medical resources, and giving up their entire way of life, extended family, community, and support systems. With the associated loss of all their personal resources, they would be unable to provide for the entire family and maintain a more traditional way of life.

Tolerance

Despite describing a lack of power and limited authority for Aboriginal families in PICU, all study informants described situations in which cultural practices were permitted within the intensive care setting, suggesting a degree of tolerance on the part of nursing staff. Tolerance describes the ability to accept something despite disapproving of it. The term tolerance is used to describe attitudes which are moderately respectful of behaviours, practices, or values that are disapproved of or considered to be wrong, to some degree, by those in the majority (Forst, 2004). The concept of tolerance continues to ascribe the majority of power to the dominant social group, in that those in the majority tolerate, thereby granting permission, for those in the minority to live according to their beliefs (Forst). Tolerance was described extensively by Voltaire in 1763 in *A Treatise on Toleration,* which argued for religious freedom and tolerance. Voltaire described tolerating or accepting different religious beliefs while still looking disapprovingly at beliefs other than his own. The concept of tolerance continues to be seen as a fundamental property of our society; tolerance, openness, and acceptance of other individuals, cultures, values, and beliefs is taught, emphasized, and even expected. Yet, at its core, the concept of "tolerance collides with a fundamental intolerance towards others" (Blonmaert & Verschueren, 2002, p. 79). Tolerance is, in fact, a paradox in that it argues for toleration of that which is intolerable (Gillon, 2005).

At a minimum, health care providers are expected to tolerate and provide care to all individuals, despite differences in behaviours, attitudes, and beliefs, provided that such individuals are not abusive or violent (Gillon, 2005). Yet, the focus of attention remains on differences between groups, rather than similarities and perpetuates the view of the other. To tolerate different values and beliefs, one must still identify them as different. Tolerance appears to have guided many of the interactions between Aboriginal families and PICU nurses. While nursing staff permitted cultural practices important to Aboriginal families, such as the placement of cultural items near a child, or visitation by many extended family and community members, such practices were merely tolerated, rather than understood and respected. Comments and gestures made by nursing staff were seen as indications of nurses' disapproval of such cultural practices. The stories shared by study informants suggested that nurses may have believed the values and social norms of the PICU were more important and took precedence. Fear that accepting deviations from one's social and cultural norms may threaten one's own values and beliefs may have reinforced nursing disapproval of Aboriginal cultural practices (Blonmaert & Verschueren, 2002).

Threshold of tolerance. Blonmaert and Verschueren (2002) described a *threshold of tolerance* – that is, we, as individuals and a society, have limitations to tolerance. We will tolerate deviations from our own values and traditions, but will not become submissive to the other nor allow our tolerance to threaten our own identity or existence. The threshold of tolerance implies that one can only tolerate so much before a line is crossed and another's way of being is allowed to interfere with one's own. Blonmaert and Verschueren suggested that tolerance means that those in the minority have the right to do anything, as long as it doesn't bother those in the majority or fail to fit in with the dominant social principle and cultural norms. For example, cultural items placed on the bed or near a child, only to be removed and taped to monitors, thrown on the floor, or inadvertently tossed in the laundry illustrate how nurses are willing to accept these aspects of Aboriginal culture, provided such items do not interfere with unit norms and practices, such as linen changes or repositioning.

The notion of the threshold of tolerance is based on the assumption that some degree of diversity is problematic (Blonmaert & Verschueren, 2002). The threshold of tolerance exists when cultural, ethnic or religious diversity is no longer tolerable; the threshold is variable and is established when one's personal practices are seen to interfere with another's. Ultimately, the dominant social group may tolerate the behaviours and beliefs of the less dominant group, but with the expectation that members of this group will make efforts to conform, or fit in with the majority (Forst, 2004; Blonmaert & Verschueren). Intolerance may be openly expressed for those who fail to make efforts to conform. Maintaining connections to aspects of Aboriginal culture, such as speaking Cree, may help Aboriginal families to feel connected to their cultural roots and home community, but also serves to distinguish and separate them from non-Aboriginal nursing staff. Nurses may perceive this as a means for families to remain isolated within their own social and cultural group, rather than engaging and interacting with staff and other families in the PICU. Rather than a lack of desire to fit in, Aboriginal families may feel unable to adapt to the PICU environment due to lack of understanding of the PICU culture and norms of social interaction and feeling that they are fundamentally different from non-Aboriginal people.

Disengagement. Tolerance suggests a non-reflexive strategy of dealing with the other; if one merely tolerates the beliefs and values of another, it is not necessary to understand or respect another's perspectives. In fact, tolerance does not require the consideration of another's perspective. Within PICU, tolerance has contributed to nurses and Aboriginal families remaining disengaged. Nursing staff were described as tolerating the values and behaviours of Aboriginal people, without considering the perspectives and experiences that influenced these beliefs and practices. Informants' accounts provided no evidence of ethical dialogue and conversation, nor were there accounts of nursing staff and Aboriginal families listening to or hearing the other. Despite spending hours within close proximity to bedside nursing staff, Aboriginal families remained isolated from these nurses and felt no connection to those individuals providing care to their children.

The lack of engagement and genuine connection between Aboriginal families appears to exist on either side of the relationship – nurses may feel great distance from Aboriginal families, resulting from the lack of verbal and non-verbal interaction initiated by these families. This may result in nursing staff feeling that they do not have the opportunity to get to know family and community members on a more personal level. Informants specifically described how Aboriginal parents and families made little effort to initiate conversation with non-Aboriginal nursing staff, and tried to remain invisible at the bedside. To learn about specific Aboriginal cultures and practices may require an extra degree of reaching out, making it easier to simply tolerate the cultural practices. Yet if nurses only tolerate Aboriginal cultural practices and values, they will never understand the influence of such values and beliefs on the experience of hospitalization in a PICU, nor involve Aboriginal values in the care of hospitalized children. Ethically appropriate, culturally competent care will, therefore, fail to be provided to Aboriginal patients and families.

Expectations within the PICU

While the informants' descriptions of the interactions between nurses and Aboriginal families depicted PICU nurses as authority figures with considerable power in such relationships, one must also consider the larger hierarchy of power within a critical care setting. Bedside nursing staff may feel that they lack the ability to alter the power structure within such a hierarchy, where medical practitioners and hospital administrators set out expectations of patient care and practice standards, as well as the expected roles and responsibilities of nursing staff. The imbalance of power within the relationship between nurses and families may be supported and maintained through the adherence to commonly accepted cultural and social norms within the health care environment (Sumner & Danielson, 2007). Nurses may feel that they do not have the power to act outside of established health care norms. In PICU nursing staff may be reluctant to hand over any care of the child to parents and extended family, as they may view patient care as primarily their own role and responsibility. To involve the parents and family as active members of the health care team would require nursing staff to engage in active dialogue with the patient and family. Nurses may be reluctant to do so, as they may feel required to uphold the focus of nursing care on objective assessment, diagnosis, treatment of illness, and expected outcomes rather than caring for the humanity of the patient by coming to know their lived experience and history (Sumner & Danielson). Such a practice is not limited to interactions with Aboriginal families, as nurses may see this as their role and responsibility in interactions with all patients and families.

Implications for Nursing Practice

There is a need for nursing staff within the PICU to recognize the difference between stereotyping and understanding a culture. While Aboriginal families wish to be recognized as Aboriginal people, they feel marginalized and stigmatized by the stereotypes that continue to be perpetuated within the PICU environment. Instead, informants expressed the desired of Aboriginal families to be considered as human beings whose Aboriginal culture, values, and beliefs influence how they view and experience the world. Nurses must recognize that

Aboriginal people may differ significantly based on their culture and community and acknowledge the need to come to understand each family individually. The experience of hospitalization within a PICU and the needs of each individual Aboriginal family may differ significantly.

To begin to understand and respect the importance of Aboriginal culture and values, nurses must engage in the process of critical self reflection to understand their own perspectives and feelings regarding Aboriginal people, as well as the reasons that they hold such perspectives. It is only through self awareness and understanding that nurses can begin to set aside the stereotypical views and misconceptions of Aboriginal people that they may hold and begin to understand the many complexities influencing Aboriginal families hospitalized in a PICU environment. Without an understanding of the cultural and community values that influence the experience of Aboriginal families in hospital, nurses will be unable to engage in ethical relationships with these vulnerable families. Unfortunately, Aboriginal families perceived that within the PICU culture little value was placed on listening to and understanding the cultural and spiritual aspects of Aboriginal people.

Critical self-reflection and self-knowledge can rarely be cultivated by oneself; such reflective practices require environments where these practices are encouraged. For the process of understanding and respecting Aboriginal people and culture to begin, there needs to be a shift in the culture of the PICU environment as a whole to place increased emphasis on culturally competent care. Nurses need to be encouraged to engage with families in dialogue regarding culturally appropriate care in an effort to develop mutually agreed upon methods to incorporate Aboriginal cultural practices into the care of Aboriginal children. For this to occur, ongoing cultural education among nursing staff within the PICU may be required. Presentations given by community elders or Cultural Support Workers during staff education sessions may provide nurses with the basic knowledge of Aboriginal culture necessary to begin to consider the Aboriginal world view. Such understanding may provide staff with the comfort level required for entry into conversations with Aboriginal families. Engaging with families in meaningful dialogue needs to be encouraged and the time for nurses to do so needs to be provided. Perhaps Aboriginal Support Workers and Cultural Workers could assist in bridging the gap between nursing staff and Aboriginal families, providing introductions between the group and promoting conversation.

Nurses in leadership positions within the PICU must acknowledge and promote the importance and value of humanness, both that of the patient and family, as well as of the nurse. Nurses must see beyond the strict roles of *patient* and *nurse* to acknowledge each individual as a human being engaged in dialogue of care and healing. Only when nurses are able to view their own humanness will they be able to also acknowledge the Aboriginal patient and family as human beings in need of care and compassion. This may be challenging within a highly technical and fast paced PICU environment. Nurses may struggle to provide holistic, family-centred care across different cultures, while providing the necessary physical care to a child hospitalized with life-threatening illness or injury. Simple questions asked by nursing staff such as “What is important to know about your child?", "What are you concerned about?", or "What is confusing for you?" may be all that is needed to convey to an Aboriginal family that they are recognized first for their humanness. Recognition of Aboriginal patients and families first as human beings is the initial step in establishing and nurturing relational ethics.

Suggestions for Future Research

The case study description of the Aboriginal experience of PICU and the exploration of research findings reveal a need for further research regarding the relationships between Aboriginal families and PICU nurses. While the case study revealed many important ethical issues that arise in such relationships, it presented data from a very limited sample of Aboriginal families and professionals involved in the support of these families. Further data collection with a larger sample, in particular additional family participants, is essential in further examination of the relational issues between Aboriginal families and PICU nurses. In addition, exploration of such relationships from the perspective of PICU nurses is needed to further identify the factors influencing the establishment of ethical relationships.

Dissemination of Study Results

The study results are presented here in my Master of Nursing Thesis. An offer has been made to present the research findings to physician and nursing staff at the Paediatric Intensive Care Unit at the Stollery Children's Hospital. Publication of the results of the study will be sought in nursing and health ethics journals. All study informants were offered the opportunity to receive a copy of the transcript of their interview, as well as copy of the results of the study, and the same was provided as requested.

Conclusion

The case study presented reveals the experience of an Aboriginal family during the hospitalization of a child in a paediatric intensive care setting as one of isolation and disengagement from nursing staff. Aboriginal families were described by study informants to have felt no connection to those providing care to their critically ill or injured children. Informants indicated that these families often felt stigmatized and marginalized because of their Aboriginal heritage. Such findings suggest that the concepts of relational ethics have played a limited role in the interactions between Aboriginal families and non-Aboriginal nursing staff in the PICU and that ethical, culturally competent relationships have not often developed. While the expectations of nursing care within this critical care environment are often focused on the physical aspect of caring for a hospitalized child, the findings reveal a need for therapeutic care of the Aboriginal family as a whole, with particular attention to cultural influences. Respect for Aboriginal culture and perspectives may help ensure a healing environment where the development of therapeutic relations between Aboriginal families and nursing staff can occur.

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Appendix A

Information Letter

PROJECT TITLE: Understanding Aboriginal Families Experiences of Ethical Issues in a Paediatric Intensive Care Environment (PICU): A Relational Ethics Perspective

MN Student:	Katherine Fisher, RN, BScN	Pager (780) 401-0819
Research Team:	Dr. Lynne Ray, Faculty of Nursing	(780) 492-7558
	Dr. Wendy Austin, Faculty of Nursing	(780) 492-5250
	Dr. Malcolm King, Faculty of Medicine	(780) 492-6703
	University of Alberta, Edmonton, AB	

Why are we doing this study?

It is very difficult for families when their child is hospitalized in PICU. For Aboriginal families who are separated from their family and community, there can be many more issues and difficulties. We are interested in gaining an in-depth understanding of these issues, particularly related to the relationships between Aboriginal families and health care professionals within the PICU. We hope that understanding these issues will allow us to develop strategies for health care professionals to provide more appropriate care for Aboriginal families.

What will happen?

1. If you are interested in participating in the study, Katherine will arrange a time to meet with you to discuss the issues and difficulties you have observed for Aboriginal families in PICU.
2. Prior to the discussion, you will be offered the opportunity to ask any questions that you may have about the study and will be asked to sign a consent form.
3. During the discussion, you will be asked to discuss the issues and difficulties you have observed for Aboriginal families in PICU. We are particularly interested in the interactions and relationships between Aboriginal families and health care professionals within the PICU. The interview will be tape recorded, if you give permission. If you are uncomfortable with being tape-recorded, Katherine will take detailed notes of what you say.
4. The meeting will last 1-2 hours.
5. Katherine may request to speak with you again to clarify information you provided or to ask additional questions.

6. Katherine will use the information you discuss to create a case description to tell the story of a typical Aboriginal family in PICU.

What will it mean for you to be part of the study?

We do not anticipate any direct benefits for you from your participation in this study. Our hope is that future Aboriginal families of children in the PICU will benefit from what we learn from you. There are no predicted risks for you from your participation in this study, as you will be asked to speak generally of the experience of Aboriginal families in PICU. The one drawback of the participation will be the time required of you to be interviewed.

What will be done with the information?

The audiotape and transcribed copy of your interview will be stored in a locked file drawer at the University of Alberta for seven years following the completion of the study. Your name and any identifying information will be removed from the typed copy of your interview. Only the interviewer will be aware of your identity. Other research team members will know your professional role only.

The information collected from your interview and other study participants will be analyzed and discussed in a paper prepared by Katherine. A case study will be developed to tell the story of a typical Aboriginal family of a child hospitalized in a PICU. This case study will also be shared with health care professionals at the Stollery Children's Hospital, in published papers, and at conferences. The final report may contain your actual words but will not include any identifying information.

It's your choice!

You are free to withdraw from the study at anytime, without providing any reason. You may choose not to answer some questions. At any time you may request that the tape recorder be turned off or that your interview not be audio taped.

Do you have questions?

If you have any concerns about any aspect of this study, you may contact the Patient Concerns Office of the Capital Health Authority at (780) 482-8080. This office has no affiliation with study investigators.

Kinanâskomitin—Thank You!

Appendix B

Consent Form

PROJECT TITLE: Understanding Aboriginal Families Experiences of Ethical Issues in a Paediatric Intensive Care Environment: A Relational Ethics Perspective

Part 1: Researcher Information

Principal Investigator	Lynne Ray, University of Alberta	(780) 492-7558
MN Student:	Katherine Fisher, Master of Nursing Student	(780) 401-0819
Committee:	Dr. Lynne Ray, Faculty of Nursing	(780) 492-7558
	Dr. Wendy Austin, Faculty of Nursing	(780) 492-5250
	Dr. Malcolm King, Faculty of Medicine	(780) 492-6703
	University of Alberta, Edmonton, AB	

Part 2: Consent of Participant

	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached Information Letter?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss this study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time?		
Has the issues of anonymity and confidentiality been explained to you?		
Do you understand that you can request the tape recorder be shut off at any time?		
Would you like a report of the research findings sent to when the study is done?		
Do you agree to be contacted again to answer follow-up questions?		

Part 3: Signatures

This study was explained to me by Katherine Fisher.

I agree to take part in this study.

Signature of Research Participant	Date	Printed Name

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

Signature of Investigator	Date

Appendix C

Interview Question Guide for Professionals

Initial Questions

1. Can you describe what the experience of hospitalization in PICU is like for Aboriginal families?
2. What is it like for Aboriginal families to have a child in PICU?
3. What are some of the common issues that Aboriginal families describe?
4. How do Aboriginal families describe their interactions with health care professionals in PICU?
5. Can you describe any positive aspects of PICU that Aboriginal families encounter?
6. What advice would you give to the hospital staff about how to take care of families with a child in PICU?

Questions Developed from Interview with Aboriginal Family

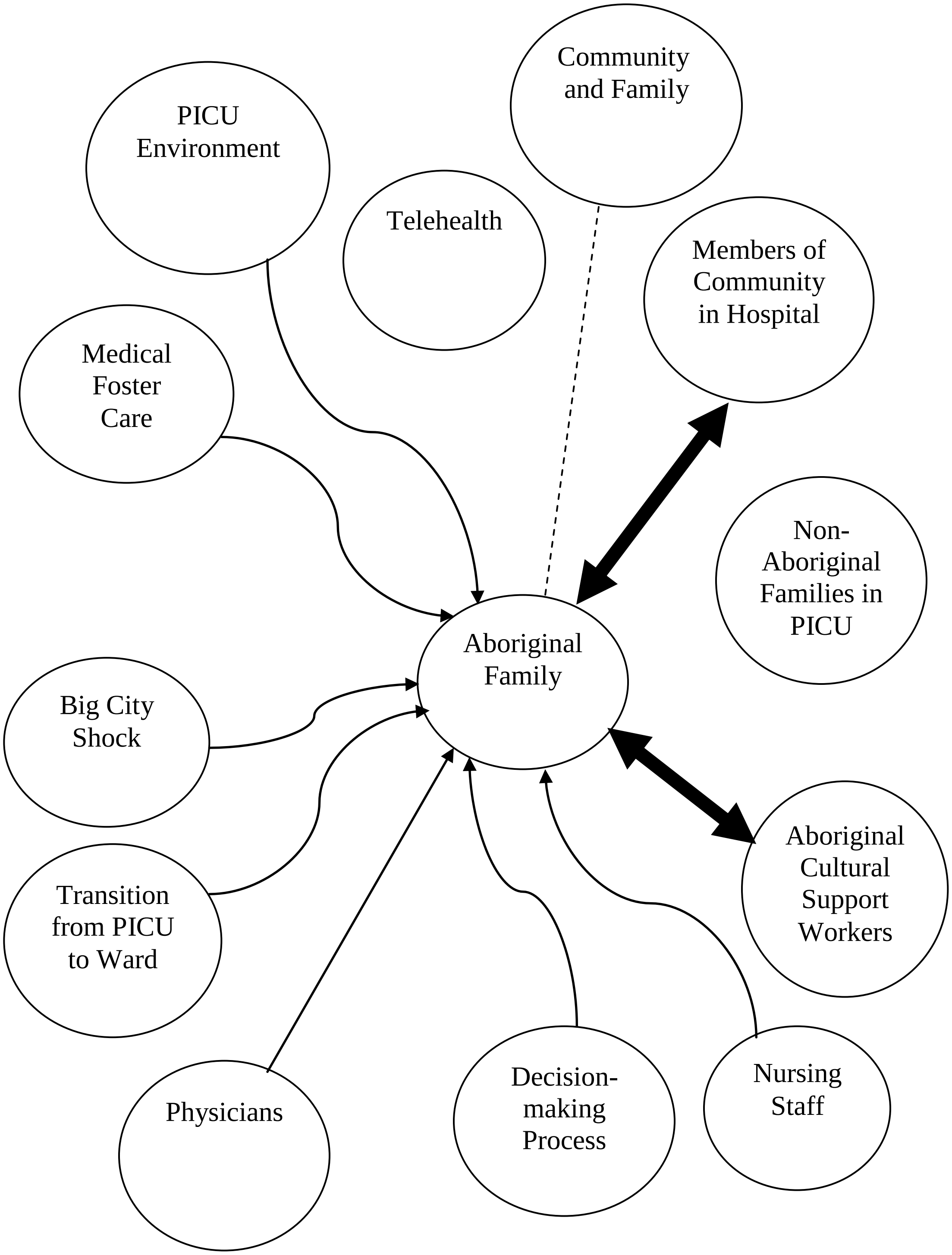
1. Can you describe the issues and challenges that you have observed Aboriginal families to encounter when they travel from a remote or reserve community for the hospitalization of a child in the PICU?
    a. What strategies are used by Aboriginal families to ``survive`` the city and PICU environments.
2. What is the PICU environment like for Aboriginal families?
    a. What challenges do you see them encountering in the PICU environment?

   b. What positive things do you see being done for families in the PICU to improve their experience?

3. How do Aboriginal families describe their interactions with nursing staff in the PICU? How do Aboriginal families describe their interactions with physician staff in the PICU?
4. How are travel and accommodation costs covered for Aboriginal families from remote or reserve communities?
   a. What problems can arise in providing funding for Aboriginal families?
5. What is the transition like for Aboriginal families in moving from PICU to the ward setting?
6. How do Aboriginal families make decisions regarding the care of their child while in PICU?
   a. Are community elders, etc involved in decision making?
7. Are there cultural restrictions on discussing sensitive topics, such as the death of a child?
   a. Can you explain the background on these restrictions?

Appendix D

Ecomap



Ecomap Legend

⤴ Stressful relationship

----------- Strained relationship

⟷ Strong relationship characterized by mutual respect and engagement

No relationship