

The Lived Experience of Family-Centred Care by Primary Caregivers of Critically Ill Children
in the Pediatric Intensive Care Unit

By

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Abstract

The unexpected admission of a child to the pediatric intensive care unit (PICU) creates feelings of uncertainty, distress, and fear and is a devastating experience for primary caregivers. Health care providers must address primary caregivers' concerns to enhance primary caregivers' coping abilities. While a family-centred approach to care can assist in diminishing uneasy feelings experienced by primary caregivers, this philosophy of care is not consistently used in everyday practice. The PICU is a unique area of care that focuses on restoring the health of critically ill children with the use of machines and equipment. However, the use of technology for life sustaining measures creates additional responsibilities for health care providers, potentially compromising the quality of patient care. There is evidence to support that the involvement of the primary caregiver in the care of the critically child can address the gap that commonly exists between technology and holistic patient care. Furthermore, involvement in care increases primary caregivers' satisfaction with the care their child receives and may also improve patient outcomes. Most importantly, the involvement of primary caregivers in the care of the critically ill child encompasses a family-centred approach to care.

By increasing health care provider's awareness of family-centred care within the PICU, primary caregiver's needs may be more effectively addressed during this devastating and vulnerable time. Health care providers are key players in the promotion of family-centred care in the PICU; however, they are often faced with multiple challenges and barriers. Increasing health care providers' awareness around the components of family-centred care can facilitate its implementation into practice by understanding how primary care givers define and experience

family-centred care. Accordingly, a qualitative study guided by the philosophy of hermeneutic phenomenology was conducted to elicit a detailed description of the lived experience of family-centred care from the perspective of the primary caregiver.

Participants in this study consisted of those primary caregivers who had previously had a child admitted to the PICU. Participants were recruited from a large mid-western hospital. In total nine primary caregivers ranging in age from 33 to 44 years with the mean age being 37 years participated in the study. Nine of the participants were mothers and two were fathers. All participants took part in semi-structured, open-ended interviews. A total of nine interviews were conducted with two of the interviews involving both parents. Demographic data and field notes were recorded. All field notes and interview data were transcribed. The transcripts were reviewed repeatedly for significant statements in an attempt to find meaning and understanding through themes. The data analysis revealed the essence of the lived experience of family-centred care to be *being present*. Three themes communicated the essence and included: (a) physical presence, (b) participation in care and, (c) advocating. Three themes from the data emerged around how primary caregivers defined family-centred care and included: (a) collaboration, (b) being updated and, (c) continuity of care. Finally, primary caregivers identified four conditions that needed to be in place to experience family-centred in the PICU which included: (a) being present for rounds, (b) caring behaviours, (c) feeling welcomed and, (d) support. The findings from this study may be used to guide policy around family-centred care and improve on, or bring new insights around interventions related to family-centred care. Future recommendation for nursing practice, education and research are presented. .

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Table of Contents

Abstract.....	ii
Acknowledgements.....	iv
List of Appendices.....	viii
List of Tables.....	viii
Chapter One: Introduction.....	1
Purpose and Research Objectives.....	1
Significance of the Problem.....	2
Assumptions.....	3
Definitions of the Study’s Major Concepts.....	3
Chapter Summary.....	4
Chapter Two: Literature Review.....	5
Technology and the PICU.....	5
Family Stressors within the PICU.....	8
Common Stressors in the PICU.....	9
Environment of the PICU.....	9
Altered Parental Role.....	10
Uncertainty.....	11
Loss of Connection.....	11
Family-Centred Care in Pediatrics.....	13
Components of Family-Centred Care in the PICU.....	15
Participation in Care.....	15
Collaboration.....	17
Caring and Empathetic Behaviours.....	20
Effective Communication.....	22
Presence.....	24
Health Care Providers and Family-Centred Care.....	26
Implications for Research.....	27
Chapter Summary.....	28
Chapter 3: Conceptual Framework.....	30
The Synergy Model.....	30
Chapter Summary.....	33
Chapter 4: Research Design.....	34
Methodology.....	34
Husserl’s Transcendental Phenomenology.....	35
Heidegger’s Hermeneutic Phenomenology.....	35
Appropriateness of van Manen’s Philosophy for this Study.....	36
Research Method.....	36
Research Design.....	37

Sample Recruitment and Access.....	37
Criteria for Sample Selection.....	37
Sample Size.....	38
Participant Access.....	38
Sample Recruitment.....	38
Data Collection Methods.....	39
Demographic Form.....	39
In-Depth Individual Interviews.....	39
Field Notes.....	41
Research Setting.....	41
Data Analysis.....	41
Methodological Rigor.....	42
Credibility.....	43
Dependability.....	43
Confirmability.....	43
Transferability.....	44
Authenticity.....	44
Ethical Issues.....	45
Autonomy.....	45
Non-malificence.....	46
Beneficence.....	46
Justice.....	47
Risks and Benefits.....	47
Chapter Summary.....	48
Chapter 5: Findings.....	49
Introduction.....	49
Description of Participants.....	49
Main Findings.....	50
The Essence of Primary Caregivers' Lived Experience.....	50
Physical Presence.....	51
Participation in Care.....	55
Advocating.....	56
Themes.....	58
Collaboration.....	59
Being Updated.....	61
Continuity of Care.....	66
Conditions Needed to Experience family-centred care in the PICU.....	69
Being Present for Rounds.....	69
Caring Behaviours.....	70
Support.....	74
Feeling Welcomed.....	77
Chapter Summary.....	79

Chapter 6: Discussion of the Findings.....	81
Being Present.....	81
Physical Presence.....	85
Participation in Care.....	87
Advocating.....	89
Family-Centred Care.....	90
Collaboration.....	90
Being Updated.....	92
Continuity of Care.....	95
Factors Needed to Experience Family-Centred Care in the PICU.....	97
Feeling Welcomed.....	97
Caring Behaviours.....	99
Support.....	100
Conceptual Model.....	102
Methodological Strengths and Limitations.....	104
Recommendations.....	105
Nursing Practice.....	106
Education.....	108
Research.....	109
Chapter Summary.....	110
References.....	111
Appendices	
A. Letter of invitation.....	129
B. Interview Guide.....	131
C. Demographic Form.....	133
D. Consent Form.....	135
E. Official Access Approval from Children`s Hospital.....	138
F. Official Ethical Approval from Education/Nursing Research Ethics Board.....	139
List of Tables	
Table 1: The Research Process.....	140

Chapter I: Statement of the Problem

Introduction

The admission of a child to the pediatric intensive care unit (PICU) is a devastating experience for the family and primary caregiver creating feelings of distress, uncertainty and helplessness (Holmes, 2004; Just, 2005). These feelings that are perpetrated can be addressed by implementing a family-centred approach to care. This approach requires the involvement of the family in the many aspects of the child's care; however this involvement is often challenging in the PICU environment (Frazier & Warren, 2010; Tommilson, et al., 1999). The heavy reliance on the use of technology for life sustaining treatment can take away from holistic patient and family care. Despite the potential conflict between quality patient care and the use of technology, there is evidence to suggest that family involvement in the care of the critically ill child can be beneficial for both the health care provider and the primary caregiver. Through the collaboration among the health care provider, the family and the use of technology, a synergy can be created increasing primary caregivers' satisfaction with care and improving patient outcomes (Gordin & Johnson, 1999).

Purpose and Research Objectives

Phenomenological research aims to address the lived experiences of everyday life (van Manen, 1990). The purpose of this qualitative hermeneutic phenomenological research study was to discover the subjective meaning of the lived experiences of family-centred care by primary caregivers who had a critically ill child admitted to the PICU. A more in depth understanding around the meaning of family-centred care will provide guidance for health care providers in promoting a holistic approach to care and assist in closing the gap that exists between the use of technology and direct patient care.

The main questions of this study that were addressed included:

- (1) How did primary caregivers who had a critically ill child in the PICU define family-centred care?
- (2) How did primary caregivers who had a critically ill child in the PICU experience family-centred care?
- (3) What conditions needed to be in place that would help to promote family-centred care for primary caregivers who had a critically ill child in the PICU?

To achieve an in depth understanding of what it is like having a child admitted to the PICU, primary caregivers were invited to describe and share their personal lived experience to provide a greater understanding of what family-centred care meant to them and help inform health care providers of primary caregivers' common needs.

Significance of the Problem

Family-centred care is an essential component of pediatric nursing and offers many benefits to primary caregivers, families, and children within the PICU (Frank & Callery, 2004; Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2004; Jay, 1977; Mitchell et al., 2009; Neal et al., 2007; O'Haire, Creamer, Hill & Welham, 2005; Seidman, et al., 1997; Tughan, 1992; Woodfield, 1997). However, despite these noted benefits, a family-centred approach to care is not consistently implemented in current pediatric practice. While the PICU is a unique area of care, the technological aspects of the unit create challenges in the implementation of family centred-care into daily practice. In addressing these challenges, findings from this study provided further understanding around the most common stressors experienced by primary caregivers in the PICU. Furthermore, this study provided a more in depth understanding around the components of family-centred and the barriers experienced around implementing this philosophy into

practice. Finally, this study provided insight for health care providers around overcoming the barriers to the implementation of family-centred care into practice. The findings from this study may also be used to guide policy around family-centred care and improve on, or bring new insight around interventions related to family-centred care. Although several studies on family-centred care exist in multiple areas of care, there is a need for further research around the benefits of family-centred care specifically in the PICU setting.

Assumptions

It is important to be explicit about the assumptions underlying any research study. Assumptions for this research study were based upon the philosophical beliefs and characteristics of qualitative research through the philosophical framework of van Manen (Speziale & Carpenter, 2007; van Manen, 1990). Within this study the underlying assumptions are: (a) phenomena are understood in different ways due to multiple realities that exist and create unique meaning for individuals, (b) primary caregivers are the experts in identifying and describing their experience of family-centred care in the PICU, (c) the admission of the child to the PICU has an effect on all family members but has the most devastating consequences for the child's primary caregiver.

Definitions of the Study's Major Concepts

For the purpose of this study the major concepts of this study were defined as the following:

Family-Centred Care: care of the patient involving collaboration with the physician, resident, nurse, primary caregiver, and patient in care planning and decision making. It involves

including families in the care of the patient and facilitating parents in maintaining normal care practices as much as possible (Nethercott, 1993).

Primary caregiver: may not necessarily be the biological parent(s) of the child and may include any extended family member or individual who is responsible for the primary care and upbringing of the child (Nethercott, 1993).

PICU: a specialized practice area where critically ill infants, children, and adolescents are commonly intubated and ventilated, requiring continuous hemodynamic and cardio respiratory monitoring (Tughan, 1992).

Critically ill child: an unstable child who is admitted to the PICU for monitoring or emergency procedures and where the child's prognosis is uncertain (American Academy of Pediatrics, 2006).

Chapter Summary

Chapter one provided a rationale around the importance of researching the experiences of primary caregivers' who have had a child admitted to the PICU and the meanings primary caregivers assign to family-centred care. Understanding primary caregivers' needs and experiences will benefit both health care providers and primary caregivers within the PICU setting. Following chapter one, chapter two focuses on the current literature around family-centred care in the PICU and the relationship among primary caregiver's, healthcare providers, and the use of technology in the PICU which provided the grounding for this research study.

Chapter II: Literature Review

Chapter two provides a concrete foundation for exploring the experiences of primary caregivers who have had a child admitted to the PICU. This section will provide an in-depth review of the literature on family-centred care and discuss the effects that technology has on the family. Common stressors experienced by primary caregivers at the point at which their child has been admitted to the PICU are explored. A discussion on the common elements of family-centred care will follow. Finally, implications for practice are discussed with recommendations for further research on family-centred care in the PICU.

Technology and the PICU

An area of care that relies greatly on the use of technology for patient care is the pediatric intensive care unit (PICU). The PICU uses state of the art and up to date equipment and technology in the care of critically ill children including the use of ventilators, the use of monitors for a continuous display of the patient's vital signs, blood gas analysis, and the use of computers for patient charting and learning (Mann, 1991).

The number of pediatric intensive care units worldwide has grown significantly over the last few decades. The first children's intensive care unit was built in Gothenburg, Sweden in 1955 in response to the major Polio outbreak. Subsequent PICUs were established throughout Europe and North America in the 1960's (Austin, Keleevic, Goble & Mekechuk, 2009). The ultimate goal within the PICU is to restore quality of life for critically ill children using machines and various types of equipment to keep the child alive. While recent technological advancements have greatly improved, many aspects of patient care rely heavily on the use of technology which can result in additional challenges. For instance, greater reliance on technology can create

additional responsibilities for health care providers in that technology can add to an already busy workload (Foglia & Milonovich, 2011; Gordin & Johnson, 1999). Nurses are challenged with balancing their time and responsibilities to include care of the child and the family as well as addressing the technological demands of the PICU. Furthermore, a heavy reliance on the use of technology can limit health care providers' creativity and critical thinking (Bosque, 1995) and can create greater fear and anxiety for the patient and the family. This anxiety is a result of the crowding and noise from the machines and equipment in the PICU which may lead to sensory overload (Halm & Alpen, 1993; Mann, 1991).

While the use of technology is increasing in health care today, a clear definition of the concept is lacking. An understanding of the constituents of technology is essential in nursing as technology is an evolving phenomenon that influences health care providers' actions, competencies, and plan of care with families and patients. Additionally, health care providers are faced with the use of technology in their everyday practice and must learn how to care for their patient and maintain technological competence. This technological competence contributes to the effective use of machines and technology in practice and assists health care providers with interpreting the technological world around them. Technology takes on multiple meanings within nursing and has been defined as physical objects within the environment such as tools and machinery and is considered a form of knowledge in which meaning is awarded to an object (Barnard, 1996). Furthermore, technology is considered a complex interrelationship among numerous influential characteristics which include machinery, equipment, chemicals, science, values, and politics (Barnard, 1999).

The use of technology in health care has greatly increased over the last decade and has transformed both nursing practice and the work place. Significant challenges in the delivery of

care have resulted (Barnard & Sandelowski, 2001). More frequently, technology is being used to save lives and improve quality of life for patients. This technological prevalence in health care is considered an extension of the scientific paradigm (Gadow, 1984); however, the humanistic characteristics of caring in nursing must not be forgotten. While nursing is both an art and science, a strong reliance on the technological environment of today's health care often fails to address the former. If health care providers are to encompass the true essence of nursing, both realms must be addressed. Hawthorne and Yurkovich (1995) contend that technology and caring are compatible and nurses must find a way to integrate technology and caring in a harmonious fashion by combining the technological aspects of the surrounding environment with the humanistic characteristics of caring.

Patient care is a humanistic component of the PICU and has been described as the reliance on aesthetic, ethical and personal knowledge, consisting of attention to patient's objective and subjective needs. Patient care is also considered a shared human condition between the nurse and the patient; however, the scientific realm of technology in the PICU can take away from these caring characteristics dehumanizing the patients' and families' experience within the PICU. Cooper (2003) refers to "technological caring" whereby technological competence is blended with those characteristics of caring for optimal patient care. Technology must not become a barrier to quality patient care rather technology and patient care must become one.

Future research initiatives must address to further understand how to reduce the negative impact technology can have on patients and their families. The impact of technology in the PICU can be addressed by implementing a family-centred approach to care creating a synergy between, the patient and the family, the health care provider and the technology of the PICU.

Family Stressors within the PICU

Critically ill children who are admitted to the PICU frequently require intubation with mechanical ventilation in addition to continuous monitoring to detect the slightest change in condition. The admission of a child to the PICU is a devastating experience for the family and causes greater distress than an admission to a general hospital ward (Board, 2003). This distress is most likely due to the acuity of the unit and the uncertainty about the extent of the child's illness. The unpredictability experienced by primary caregivers leads to fear, anxiety, denial, guilt, vulnerability and powerlessness (Hickman, Daly, Douglas & Clochesy, 2010). While primary caregivers experience great distress when their child is admitted to the PICU, health care providers have the responsibility to offer coping strategies because excessive stress from primary caregivers can negatively impact the child (Hickey & Rykerson, 1992; Miles & Carter, 1985). Thus, when primary caregivers are able to cope they become crucial to the child's recovery and well-being. Bailey et al. (2005) noted the way in which parent's behaviours can be transferred to the child delaying their recovery and causing them to regress. This delay in recovery reinforces the need for health care providers to support primary caregivers in reducing their stress levels while in the PICU. Addressing primary caregiver's stressors encompasses a family-centred approach to care. Understanding the unique needs of each family is essential and an increased awareness of the common stressors experienced by primary caregivers will provide insight for health care providers. While a great deal of the literature addresses the common stressors experienced by primary caregivers (Board, 2004; Haines, Perger & Nagy, 1995; Holmes, 2004; Just, 2005; Miles, Carter, Riddle, Hennesy & Eberly, 1989; Myer, Snelling & Myren-Manbeck, 1998; Seidman et al., 1997; Woodfield, 1997), more research is needed on how to effectively

address the needs of the family specifically within the PICU. The most common stressor noted within the literature will be discussed in the next section.

Common Stressors in the PICU

The most common stressors noted within the literature include the environment of the PICU, the altered parental role, uncertainty, and a loss of connection with the child.

Environment of the PICU

The physical environment of the PICU is a great source of stress for primary caregivers. The sight of the technology surrounding a sedated or comatose child, the smell of the sterile hospital environment, and the sound of the normal operation of the PICU can be overwhelming for primary caregivers (Holmes, 2004; Just, 2005; Myer et al., 1995). Myer and colleagues contend that primary caregiver's anxiety can in fact be reduced by preparing the caregiver for what to expect in the PICU (2009). In contrast, Hickey and Lewandowski (1980) suggests that the severity in the ICU environment can be the decisive stressor for parents. Interviews conducted with the parents of 59 different children who underwent open-heart surgery revealed that the greatest source of stress was the physical environment, despite receiving pre-op teaching on what to expect (1988).

The physical environment of the PICU also includes the altered appearance of the child which creates a great deal of stress for primary caregivers. Nevertheless, health care providers must promote a sense of normalcy in the appearance of the child to help primary caregivers cope more effectively (Guzetta, Clarke & Wright, 2006). In a study by Tommilson, Swiggum and Harbaugh (1999) on parental coping in the PICU, parents felt relieved when their child appeared clean and groomed, had familiar items from home such as stuffed animals or toys around them and were covered with a blanket. These parents were more likely to experience a sense of relief

when they saw their child appeared warm and comfortable. Similarly, in a study by Meert, Briller-Schim, Thurston and Kabel (2009) on parental needs in the PICU, one parent shared the importance of their child looking like a baby despite being hooked up to various machines and equipment. Myer et al. (1998) also suggested providing PICU staff with a picture of what the child previously looked like to foster a sense normalcy. This sense of normalcy in the PICU helped the primary caregivers feel more at ease and experience less anxiety.

Altered Parental Role

The literature consistently states that role alteration is a major source of stress for parents when their child is admitted to the PICU (Amico & Davidhizar, 1994; Eberly, Miles, Carter, Hennessey & Riddle, 1985; Haines, et al., 1995; Just, 2005; Seidman et al., 1997). Technology, machines, and equipment create a barrier to the provision of care to the child. Primary caregivers frequently struggle with how to take care of their sick child due to the unfamiliar and overwhelming environment of the PICU (Board, 2003; Haines et al., 1995; Just, 2005). These feelings create what is referred to as role conflict. This conflict occurs when the primary caregiver role changes in such a drastic manner that caregivers grieve the loss of their previous role with their healthy child, and learn to face the overwhelming challenge of a new role of caregiver to a critically ill child (Harvey, 1992; Hickey & Rykerson, 1992). If the primary caregiver can accept the new role of caring for a critically ill child, they can better participate in their child's care, overcome feelings of fear, and experience increased confidence. In short, the caregiver is ready to take on the role of caring for a critically ill child.

Uncertainty

Uncertainty is defined as an acute and ongoing or pervasive fear of possible illness consequences such as death or reoccurrence (Stewart & Mitchel, 2000). Feelings of uncertainty

are common among primary caregivers who have a child admitted to the PICU (Eberly et al., 1985; Haines et al., 1995; Maxton, 2008; Miles & Carter, 1985; Seidman et al., 1997). Moreover, Miles and Carter (1985) have noted that the intensity of parent's distress and anxiety related to the admission of their child to the intensive care is directly related to the stability of the child's condition. Parents were more distressed in circumstances in which the child was most critical. Eberly and colleagues (1985) conducted a study to compare the anxiety levels of parents of those with a planned and an unplanned admission to the PICU. Anxiety scores were greater in the group of parents whose child's admission was not planned when compared to an elective admission, reinforcing the distress uncertainty creates. Uncertainty also creates fear around the child's survival and future. Primary caregivers are always concerned the child may experience disability that may cause limitations upon survival, or that the child may not return to their previous healthy state (Haines et al., 1995; Miles & Carter, 1985; Seidman et al., 1997). Hospital staff cannot eliminate the uncertainty primary caregivers experience in the PICU, however, health care providers can ease feelings of uncertainty by keeping primary caregivers informed and updated on their child's condition (Maxton, 2008). It is essential that health care providers understand what is needed during this time of uncertainty by providing the best care to the patient and the primary caregiver.

Loss of Connection

Pediatric hospitalization is problematic because the hospitalized child is often separated from their caregiver (Flint & Walsh, 1988). Factors that disturb the child and caregiver relationship significantly affect the child's social, emotional and psychological development as well as caregiver's self esteem (Farrell, 1989). Separation from the hospitalized pediatric patient has negative consequences for families which causes anxiety, increased tension and

may affect the development of the relationship between the child and the primary caregiver (Farrell, 1989; Flint & Walsh, 1988; Leavitt et al., 1999). Primary care givers share a unique bond with their child and this connection becomes altered when the child is admitted to the PICU, for primary caregivers are frequently asked by health care providers to leave. Primary caregivers commonly feel as though they are abandoning their child by leaving their child's side especially when death is imminent. Naturally, primary caregivers want to be able to say good- bye. Breaking the child and caregiver connection under such circumstances affects the grieving process as well as caregiver's ability to cope with the child's death if they were not able to say an appropriate goodbye (Meert et al., 2009). While most children in the PICU are sedated or unconscious, caregivers still feel they are able to make a connection with their child.

While Board and Wegner (2003) contend that primary caregivers experience anxiety and coping in similar patterns, Just (2005) claims that each family is unique and experiences stress in different ways in the PICU. Therefore, staff will find it difficult to anticipate family's needs without a thorough assessment of each family's unique needs. Further research is needed to provide a realistic knowledge base of the common physical symptoms and emotional reactions to a child's admission to the PICU. Staff cannot unrealistically anticipate stress symptoms at this time as humans react in different ways to stressful stimuli such as loss of life or health status. While further research is needed on methods to address primary caregiver's stressors in the PICU, components of family-centred care can provide certain coping strategies for primary caregivers. Thus, a greater understanding around the components of family-centred care is essential in the provision of quality care in the PICU. The most common elements noted within the literature are discussed in the next section.

Family-Centred Care in Pediatrics

The family is the child's main source of strength and support during hospitalization which greatly influences the child's health and wellbeing (Frank & Callery, 2004; Mitchell et al., 2009; Neal et al., 2007). Family-centred care in pediatric health has evolved over the last century, even more rapidly over the last decade, and is considered a standard for quality patient care. Historically, families were seen as hindering patient care, so common practice was to separate parents from their sick child during hospitalization (Tughan, 1992). Children were admitted to the hospital without their parents and visiting was prohibited. During such a time, nurses were considered a "surrogate mother" to the child, and parents were not allowed or encouraged to be involved in their child's care (Nethercott, 1993). However, it was later realized that separation of the parent from the child failed to address developmental, psychological, and social needs of the child (Jolley & Shields, 2009; Shields & Tanner, 2004). World War II seems to be the catalyst for a change in this matter. The effects of the separation of children from their parents during this time were studied as large numbers of orphans were being placed in institutions. This separation consequently led to behavioural problems that were carried into adulthood as well as long lasting significant psychological trauma (Jolley & Shields, 2009; Shields & Tanner, 2004). In response to these behavioural and emotional effects, the British government assembled a committee to explore children's hospital care which led to the development of the Platt Report, a document that reinforced the need for mothers stay with their child during hospitalization. This new practice led to the development of the National Association for the Welfare of Children in Hospital in the United Kingdom which is known today as the Action for Sick Children. Subsequently, the Institute for Family-Centred Care was founded in 1992 in the United States. This organization had input in and influence over policy

and child health initiatives, especially those related to family-centred care. In the early 1990s, children's hospitals in Europe and North America also began routinely accommodating and encouraging parents to remain with their child while in hospital realizing benefits not only for the child, but the primary caregivers, families, and health care providers.

By including the family in the care of the child, a synergy can be created between the technological demands of the PICU and the needs of the patient and family which results in a holistic approach to care. Holistic care includes understanding common stressors that primary caregivers experience when their child is admitted to the PICU (Gordin & Johnson, 1999). Primary caregivers can be the link that bridges the existing gap between technology and humane care. The health care provider's responsibility is to assist in comforting primary caregivers, who frequently find the unfamiliar and chaotic environment of the PICU overwhelming and very distressing. A family-centred approach to care will address the common stressors primary caregivers experience while in the PICU (Evans & Madsen, 2005).

Family-centred care offers several benefits to the patient and the family by decreasing the length of the child's hospital stay and resulting in fewer re-hospitalisations (Mitchell et al., 2009). This care strategy also leads to improved family and patient outcomes and an increase in patient and family satisfaction with care (Arango, 2011; Petersen, Cohen & Parsons, 2004). Shields and Tanner (2004) contend that involving family in the care of their loved one decreases health care costs by promoting a more effective use of healthcare resources. Effectiveness increases when the primary caregiver partakes in the direct care of the child while the health care provider focuses on the technological demands of the PICU. While family-centred care offers many benefits to families, it is still inconsistently used in practice (Foglia & Milonovich, 2011). This inconsistency is partially due to the lack of a clear definition of the concept of family-

centred care resulting in difficulty of its application into practice (Frank & Callery, 2004). With the realization that each family will have their own meaning of what encompasses a family-centred approach to care (Shields & Tanner, 2004), a more in depth look into what family-centred care mean in the PICU setting is warranted.

While a great deal of the literature reinforces the benefits of family-centred care for patients and families, this approach to care is not practiced enough in today's health care setting within the various institutions. The most common components of family-centred care and the way in which these components can be implemented in practice, as well as the impact of family-centred care on primary care givers and families will be addressed in the next section.

Components of Family-Centred Care in the PICU

A better understanding of the components of family-centred care will enhance health care providers' ability to implement this kind of care into practice. Each component should be defined and understood as to how each of these elements can be applied into practice. The main components that have been noted in the literature include: participation in care, collaboration, empathetic and caring behaviors, effective communication and presence.

Participation in Care

The literature consistently states that participation in the child's care offers benefits to primary caregivers and families (Garrouste- Orgea et al., 2010; Hopia et al., 2004; Jay, 1977; Nethercott, 1993; O'Haire et al, 2005). A study on the effects of family-centred care and self efficacy in mothers in the PICU revealed positive effects from participation in care. The mothers who were able to take part in their child's care experienced greater satisfaction with their child's care and had better coping mechanisms than those mothers who were not involved in care

(Harvey, 1992). Admission of the child to the PICU alters the role of the primary caregivers; however, participation in care allows parents to relinquish their role. The primary caregiver also experiences a loss of control when the child is in the PICU; however, taking part in the child's care can re-establish a part of the authoritative role the primary caregiver has in the child's life. Upon not being able to participate in their child's care, primary caregivers are forced to trust the professionally trained health care providers to take care of their sick child (Just, 2005). The inability to participate in the child's care creates stress, anxiety, role confusion, and guilt. Primary caregivers often feel they have failed to provide a protective role to their child, and these feelings of inadequacy may create further distance from the child for fear of doing more harm than good (Amico & Davidhizar, 1994). By participating in the child's care, primary caregivers have the opportunity to resolve feelings of uncertainty and may in fact gain satisfaction in relation to their PICU experience. Thus, health care providers must support participation in care by empowering primary caregivers to achieve care goals. While the majority of primary caregivers want to be a part of their child's care while in the PICU, some parents chose not to from the fear and uncertainty of what to do in such a foreign environment (Harvey, 1992; Sanjari, Shirazi, Salemi, & Shogi, 2009).

While the concept of family-centred care has previously focused on the caregiver's ability to remain at the child's bed side while in hospital, today the concept focuses more on family involvement and active participation in the child's care (Frazier & Warren, 2010). Therefore there must be clarity as to how families would like to be involved in the care of the child in the PICU. Each family's needs are unique and must be assessed on an individual basis. Health care providers must assist primary caregivers in defining their role with their child in the PICU environment to understand the extent to which caregivers want to be a part of the child's

care (Just, 2005; Sanjari et al., 2009). Some ways to get caregivers involved in the care of their child include activities that they did at home when the child was healthy such as changing a diaper, bathing, or turning and rubbing lotion on the child's skin (Tommlison et al., 1999). To increase primary caregivers' comfort level in accomplishing care activities, they must have an understanding of the equipment and tubes surrounding the child to increase their confidence (Jay, 1977).

Although participation in the care of the hospitalized child benefits families and primary caregivers, the child may also benefit. However, there is a lack of research on the child's perception of primary caregiver participation in the PICU. This may be due to the child's level of sedation which affects the child's ability to remember their experience in the PICU. Although family participation in care offers multiple positive outcomes, many health care providers are still reluctant to embrace this practice for a variety of reasons including inadequate staffing ratios, hospital or ward policies, and care focused on the highly technological equipment to stabilize the child (Hopia, 2004). Research on overcoming these barriers will help in encouraging primary caregivers to effectively participate in their child's care.

Collaboration

Collaboration was another essential component to family-centred care noted within the literature (Frost, Gange-Cleveland, Kersten & Irby, 2010; Galvin, 2000; Gordin & Johnson, 1999; Mitchell & Chaboyer, 2010). Collaboration consisted of a multidisciplinary team approach that created a synergy between health care providers, primary caregivers, and the technological environment of the PICU (Galvin, 2000). Collaboration offers many benefits to families such as being a part of the decision making process around their child's plan of care and advocating for their child.

Collaboration is enhanced by the development of a strong and healthy relationship between the primary caregiver and the health care provider (Axelsson et al., 2005; Frost et al., 2010; Gordin & Johnson, 1999; Mitchell & Chaboyer, 2010). However, in the PICU establishing a relationship may be difficult due to high turnover and decreased time to get to know the family and to facilitate the development of a relationship (Evans & Madsen, 2005). The development of a relationship between the health care provider and the primary caregiver is influenced by several factors including the way in which the care provider approaches their practice, staffing levels and the quality of working relationships between nurses and doctors (Harrison, 2010). Initial contact with families and a good introduction can affect the way in which primary caregivers will deal with their anxiety and stress, and can also affect the development of trust in health care providers (Axelsson et al., 2005). Thus, it is important that health care providers from all disciplines introduce themselves in order to eliminate confusion.

The development of a relationship between the health care provider and the family in the PICU also fosters continuity of care (Meert et al., 2009). Continuity of care can be achieved by assigning the same nurse to the same family as much as possible (Graham, Dvora, Pemstein & Curley, 2009). However, this consistency may be difficult to attain at times due to nursing shortages and shift workers. Unfortunately, a nurse who is unfamiliar to the family can create great anxiety making collaboration in care a difficult task (Frazier & Warren, 2010; Hopia et al., 2005).

Another way to enhance collaboration is by participating in daily rounds in which caregivers from different disciplines meet around the patient's room to discuss the patient's progress and plan of care for the day. Participation in rounds assures parents are getting the information they need and provides them with the opportunity to advocate for their child.

Advocating for the child is essential as children are often too young and too sick to make complex, legal, and medical decisions (Davidson et al., 2007; Meyer et al., 1998, Pruitt, Johnson, Elliott & Polley, 2008). Landry, Lafrenaye, Roy and Cyr (2011) conducted a study comparing the benefits of family presence during rounds versus other methods of information delivery regarding the patients' status. It was noted that families preferred rounds as a method of information delivery when compared to other methods when being updated on their loved ones health condition. In a study by Boie, Moore, Burmett & Nelson (1999), the ability to collaborate with health care providers offered primary caregivers power and control during a time when they felt helpless and were unsure how to help their child. In fact, one parent from a study by Maxton (2008) appreciated being able to tell health care workers to stop CPR on their child. Taking an authoritative role in decisions affecting their child's care provided primary caregivers with a sense of reassurance. Similarly, an observational study conducted by Aronson, Yau, Helfaer and Morrison (2009) demonstrated the positive impact on presence during rounds in which parental anxiety levels were reduced as caregivers remained informed about their child's condition and plan of care. These parents felt more at ease, asked more questions and, experienced greater satisfaction with care. While primary caregivers wanted to be present for rounds, certain individuals felt pressured into making decisions too quickly (Jacobowski et al., 2010). Similarly, health care providers were also not always comfortable involving primary caregivers in rounds as they felt rounds would be lengthened and would take away from teaching opportunities. Furthermore, the dissemination of bad news among a large group of people could be challenging for health care providers and may be difficult to accomplish (Aronson et al., 2009). These concerns result in a lack of support from health care providers in involving primary caregivers in daily rounds (Frazier & Warren, 2010). From personal experience as a nurse in the PICU, having

primary caregivers present for rounds has been a positive experience for both caregivers and health care providers as their presence allows for an exchange of information about the patient, and in fact, enhances learning opportunities for both primary caregivers and health care providers. Presence during rounds also contributes to trust and fosters the relationship health care providers have with primary caregivers. While participation in rounds is a positive experience, more research is needed on overcoming barriers to having primary caregivers present for rounds. As well, more research is needed on the process of involving families in decision making around their child's care to enable health care providers to empower primary caregivers to be a part of the team.

Caring and Empathetic Behaviours

The literature consistently shows that empathetic and caring behaviours from health care providers reduces stress and anxiety experienced by primary caregivers who have a child in hospital (Harbaugh, Tommilson & Kirschbaum, 2004; Meert et al., 2009; Seidman et al., 1997). Caring behaviours were displayed by health care providers through expressing positive emotion, cuddling the child, and being helpful, nice, and personable (Harbaugh et al., 2004). Caring behaviours also consisted of health care providers who demonstrated a sincere interest in the child's health and well-being. (Harvey, 1992), and who were technologically competent and knowledgeable when caring for the child (Vandell-Walker et al., 1997).

In addition to caring for their child, primary caregivers appreciated when there was sincere interest from health care providers in meeting parents' needs while in the PICU. In a study by Axelsson et al (2005), a parent commented on how the littlest favour such as receiving a glass of water or being asked if they were hungry made them feel truly cared for. Assisting primary caregivers in meeting their personal and basic needs were equally important to feeling cared for.

Furthermore, primary caregivers could better care for their child and cope upon feeling cared for by health care providers. A study conducted by Meyer et al (2009) on parental needs in the PICU revealed that as the physiological needs of parents were met, the greater parents' desire was to participate in their child's care. As a result, meeting basic needs such as hunger and sleep are essential to providing for the child. Additionally, parents may feel guilty leaving their child or the hospital for a break; however, parents need reassurance from health care providers that it is alright to leave the unit if needed (Harvey, 1992).

Caring and empathetic behaviours from health care providers also reassured parents that their child was receiving the best care possible which enhanced parents comfort around leaving their child. Caring behaviours also fostered primary caregivers' trust in health care providers and the ability to cope with the stress incurred from their child's admission to the PICU. Additionally, in circumstances where primary caregivers were not able to care for their child, relief was experienced upon being reassured their child was receiving empathetic and gentle care (Tommlison et al., 1999) and primary caregivers felt more comfortable leaving the unit to take a break (Harvey, 1992).

While primary caregivers appreciated caring behaviours from health care providers, the literature notes that not all parents experienced a caring approach while in the PICU. In a study by Jolley and Sheilds (2009), one parent commented on how the care being given to the child appeared "affectionless" and "inhumane". Similarly, a parent from another study commented on how when empathetic behaviours were lacking, greater anxiety was experienced (Meert et al., 2009).

Primary caregivers also experienced caring behaviours when health care providers were respectful of the decisions and the choices made by the family. Complex decisions are frequently

made in the PICU creating a potential for ethical dilemmas especially with end of life care. Conflict may arise between the health care provider and the family resulting from conflicting beliefs and values. However, a supportive environment must be maintained despite opposing opinions (Nethercott, 1993).

Several factors may have an influence on health care provider's behaviour including stress, workload, and fatigue. However, understanding the negative impact that these "non-caring" behaviours can have on primary caregivers requires health care providers to act sensitively toward families and patients.

Effective Communication

Effective communication is also an important component of family-centred care especially in circumstances in which the child's prognosis is unknown (Farrell, 1989; Sanjari et al., 2009; Seidman et al., 1997). Effective communication enhances primary caregiver's ability to understand the child's condition (Haines et al., 1995) and consists of the delivery of information in a manner that is not overwhelming for primary caregivers (Galvin et al., 2000). Keeping the primary caregiver informed of the child's condition contributed to a better understanding of the child's illness and provided parents with a sense of hope and the development of trust with health care providers (Farrell, 1989; Holmes, 2004; Meert et al., 2009; Sanjari, et al., 2009, Seidman et al., 1997). When families don't understand what is happening with their child they may become uncooperative, angry, demanding and unwilling to listen to health care providers (O'Haire, 2005; Stanik, 2005). Too often parents are not clear on the medical decisions being made by the health care team due to a lack of information or misunderstanding on what is being said (Nethercott, 1993). Therefore, the care provider must take the time to clarify and appropriately explain the information being given to the primary

caregivers. In fact one parent referred to what the physician was saying as “gibberish”, claiming the physician was in a hurry to relay information and did not take the time to see if the parents truly understood what was being said (Tommlison et al., 1999).

Primary caregivers also expressed a need for honesty and frequent updates on their child’s status. Parents from a study by Tommlison et al. (1999) did not appreciate when health care providers altered information to make it sound better in the dissemination of bad news. Families want the most accurate and up to date information about their child. Withholding relevant information from primary caregivers can lead to anger (Meert et al., 2009).

While the literature reinforces the need for good communication, challenges exist including cultural and language barriers. These barriers can make it difficult to effectively relay information to families of critically ill children (Sanjari et al., 2009); however, a translator and further training in cultural diversity may enhance health care providers’ understanding of the various cultural behaviours. Consistency in information delivery can also be a challenge as a result of the involvement of multiple health care professionals’ in the care of the critically ill child. Information may be presented by various professionals resulting in mixed messages and misunderstandings for families (Vandall-Walker et al., 2007). However, collaboration among health care providers will assure the family receives consistent and honest updates on the child’s status.

Presence

Primary caregivers indicated that the ability to be close to the child was deemed to be one of the most important aspects of family-centred care (Board, 2004; Dingeman, Myer, Mitchell & Curley, 2007; Eichhorn, et al., 2000; Harvey, 1992; Maxton, 2008; Mc Gahey-Oakland, Lyder,

Young & Jefferson, 2007; Miles & Cater, 1985; Seidman et al., 1997). In a study conducted by Miles & Carter (1985) on the most common coping strategies used by parents during their child's hospitalization to the PICU, 92% of the parents interviewed said that being with their child was the best method to decrease their anxiety. Presence is especially important in the PICU where parents frequently experience feelings of uncertainty, as parental presence offers reassurance the child is still alive. Presence has been defined as having visual or physical contact with the patient (Eichhorn, et al., 2000). Furthermore, presence is spiritual, enriches the shared human experience, and preserves the holism, dignity, and integrity of the entire family (Clift, 1996; Dingeman et al., 2007; Guzetta et al., 2006). One of the benefits to being present includes the ability to participate in care providing feelings of comfort, reassurance and decreased anxiety for parents (McGahey-Oakland et al., 2007). Presence also fosters the connection shared between the child and the primary caregiver (Hessel, 2009). Although it is uncertain whether the child senses the primary caregiver's presence upon being unconscious and sedated, primary caregivers believed the child knew they were present. Caregivers also felt reassured being able to calm and soothe their child, and they believed that being with their child had a positive impact on their child's emotions, health, and well-being (Tinsley et al, 2010).

Presence also reinforced for parents the seriousness of their child's situation and brought to reality the extent of their child's illness (Meyer, et al., 1998). Upon being denied access to their child, primary caregivers began to wonder what was happening with their child. What primary caregivers imagined was happening to their child was often worse than reality. Remaining with their child under such circumstances creates a sense of relief for primary caregivers (Robinson, et al., 1998), and allows parents to see firsthand that everything possible

was being done to help their child, ensuring the best outcome that is possible (Guzetta et al., 2007).

Open visitation in the PICU is essential and will address primary caregiver's need to be present with their child. Historically, families were restricted from visiting their children in hospital resulting from infection prevention strategies, patient confidentiality, and crowd control. Health care providers at that time also believed that open visitation took away from time needed to accomplish tasks, and made the provision of care to the child more difficult (Frazier & Warren, 2010). Many of these preconceived beliefs are based on tradition rather than current research (Flint & Walsh, 1988; Vandijck et al., 2010), and while visiting rights are becoming increasingly flexible, challenges still exist. Evidence based written policies around visitation in pediatric hospitals are lacking and would be a solution in addressing the barriers to allowing open visitation in the PICU, thus, further research is warranted.

Despite the benefits of presence in the PICU, controversy around this practice exists. Health care providers often question whether parental presence does more harm than good for primary caregivers. Health care providers feel they should "protect" primary caregivers by keeping them out of the unit (Maxton, 2008; Mc Gahey-Oakland et al., 2007); however, there is evidence to show that keeping parents from their child can be more psychologically detrimental than allowing them to stay (Board, 2004; Harvey, 1992; Seidman et al., 1997). Similarly, Blair (2004) noted that parents who were prevented from being with their critically ill child experienced more psychological difficulties than those parents who remained present with their child. This was especially true in the unfortunate event that the child did not survive. Additionally, primary caregivers feel that they have a right to be with their child in the PICU during both stable and unstable circumstances (Maxton, 2008; Mc Gahey-Oakland et al., 2007);

consequently, health care providers must respect this wish and accommodate parents who choose to remain present.

Although presence is important for primary caregivers, there are circumstances where primary caregivers prefer not to be present (Beckman et al., 2002). Parents were more likely to remain with their child during procedures such as an IV start or a blood draw, and less likely to stay during more complex procedures such as a lumbar puncture or intubation (Beckman et al., 2002).

While the literature states presence in the PICU is beneficial for families, longitudinal studies may further enhance health care providers' understanding of the effects of presence on primary caregivers. Interviewing parents post discharge and comparing parents' thoughts on presence in the PICU may further clarify whether their presence was beneficial in the PICU. Further studies around presence where the child did not survive are also warranted and will further contribute to the body of knowledge around presence. Maintaining the child and caregiver connection is especially important when death is imminent so families can experience death together, reinforcing parents' need to be present with the child in the PICU

Health Care Providers and Family-Centred Care

Family-centred care is becoming increasingly endorsed by health care providers in multiple areas of care. While healthcare providers are becoming more open to involving families in the care of the hospitalized child, barriers still exist. Health care providers have found involving families in the care of the child interferes with patient care, is not a part of their job, and increases job stress (Jolley & Shields, 2009; Jones, Parker-Raley, Maxson, & Brown, 2011; Nethercott, 1993; Petersen et al., 2004). Health care providers are also reluctant to involve

primary caregivers in the care of their child for fear of litigation (Beckman et al., 2002; Mangurten et al., 2006; McClement, Fallis & Pereira, 2009; Nibert & Ondrejka, 2005; O'Brian et al., 2002). However, parental participation in care may in fact reduce the risk of litigation as primary caregivers are able to see firsthand what is happening with their child reducing the risk of claims of false accusations (Henderson & Knapp, 2005; Power & Rubenstein, 1999).

Health care providers' concerns can be addressed by increasing staff awareness around the benefits and components of family-centred care as many health care providers experience a lack of knowledge to adequately support primary caregivers' needs (Hickey & Lewandowski, 1988). Thus, further education on family interaction and on the components of family centred-care is needed.

Additionally, while health care professionals may understand and value family-centred care, implementing the concept into practice may be challenging due to inadequate staffing, hospital policies, care that is focused on technical procedures, and organizational barriers such as a lack of support from management (Just, 2005; Petersen et al., 2004). Health care professionals from all disciplines must be on board in the implementation of family-centred care into practice.

Implications for Research

Family-centred care must continue to be developed through research in order to determine which interventions work in practice, and to identify the interventions that need further refinement. Furthermore, a clear and consistent definition is essential in providing clarity and a more in depth understanding around family-centred care which will assist health care providers with implementation of the philosophy into practice. McGrath, Samra and Kenner (2011) have noted that there are gaps in the research around family-centred requiring further investigations on the short term and long term implications that family-centred care has for

families. Furthermore, there is a need for more literature on family-centred care specifically related to pediatrics and the PICU. Mitchell and Chaboyer (2009) state knowledge gained from other areas, including the adult population and non ICU settings, can be applied to the pediatric population and in the PICU setting; however, discretion is advised as the PICU is a unique and specialized area of care with a specialized population. More recent qualitative studies on family-centred care in the PICU are needed since a great portion of studies around this topic were conducted in the 1980's. With the increase in technological dependence over the last few decades, health care providers' perceptions of family-centred care may have changed.

Additionally, the increasing importance of evidenced based nursing practice indicates a need for more practice guidelines around family-centred care practices in the PICU. An evidence based practice guideline will offer further support in the application of family-centred care into clinical practice. It will also provide health care providers with a better understanding of the benefits that a family-centred approach to care offers to families and parents (Frank & Callery, 2004). Mc Grath et al. (2011) contend there is also a need for more randomized controlled and clinical trials for family-centred developmental strategies as these types of studies are considered to be at the highest level of evidence. However, in order to understand the true essence of family-centred care and how the philosophy should be implemented into practice, qualitative studies are more effective. Therefore, this qualitative phenomenological study will provide an understanding on how primary caregivers experience family-centred care in the PICU.

Chapter Summary

While there is a great deal of literature on family-centred care in nursing, more research is needed. Understanding the common stressors experienced by primary caregivers in the PICU can help health care providers address families' needs. Moreover, by incorporating a family-

centred approach to care based on the families' needs, primary caregivers' ability to cope with having a child admitted to the PICU is enhanced. Health care provider's ability to support primary caregivers can be achieved by implementing a family-centred approach to care. The next chapter is a discussion of the conceptual framework that was used to guide this study.

Chapter III: Conceptual Framework

Phenomenological research consists of exploring the essence of individuals' lived experience which cannot be predicted, as each experience is unique, and is explained, felt and experienced through the eye of the beholder (van Manen, 1990). Thus in order to gain an understanding of the lived experience of family-centred care, the Synergy Model was used to enlighten, rather than predict how primary caregivers, health care providers, and technology work together to optimize, rather than compromise, quality patient care in the PICU. The intent of this model was not to place bias around primary caregivers' personal reflection of their lived experience, as some may have searched for meanings in their experience based on the proposed model. Rather, it was used to demonstrate the relationship between the phenomena of this study to guide and further understand how common stressors experienced by primary caregivers in the PICU can be addressed with a family-centred approach to care.

The Synergy Model

In its earlier phase, the Synergy Model served as a structure for the basis of the American Nurses Associations certification exam to identify competencies inherent in critical care nurses (Mc Ewen & Wills, 2007). According to this model, a synergy is created when nurses' competencies are in synch with the patient's and family's needs. When a synergy was achieved, patients and families experienced greater satisfaction with the care they received. The assumptions of this model are as follows:

- 1) Family characteristics are of importance to health care providers
- 2) Nurses competencies are important to patients and families
- 3) Patient and family needs drive nurse competencies

- 4) When patient and family characteristics match and are in synch with health care provider competencies

For the purpose of this study, health care providers' competencies consisted of awareness around the most common stressors experienced by primary caregivers in the PICU which included: 1) the PICU environment, 2) the altered parental role, 3) uncertainty of prognosis and outcome. and 4) separation from the child. The ability to address these common stressors could be achieved by implementing the components of family-centred care. The most common components of family-centred care identified by primary caregivers included: 1) participation in the child's care, 2) collaboration, 3) caring behaviours from health care providers, 4) being updated and, 5) presence. Health care providers' competencies and plan of care must therefore be adjusted to meet the unique needs of each family.

The Synergy Model was chosen to guide this study to demonstrate the relationship between family-centred care in the PICU and family's unique needs which drive the health care provider's competencies and characteristics. Thus, according to this model it is assumed that health care providers would adjust their care to assure family-centred care was delivered to meet the needs of primary caregivers in the PICU.

Although family-centred care and direct patient care can come into conflict with the technology in the intensive care setting, Johnson and Gordin (1999) state a synergy can still be created. Collaboration between health care providers, primary caregivers, and the use of technology can come together as a whole to improve patient outcomes and increase satisfaction with care (Johnson & Gordin, 1999). Similarly, Mc Ewen and Wills (2007) contend synergy is the collaboration among phenomena that will produce an effect that is greater than the sum of their individual effects. Participants in this study reinforced the importance of working

collaboratively with health care providers to attain the best care for the child. Thus when health care providers and families worked together, rather than individually, there was greater satisfaction with care and better outcomes. The purpose of this study was to attain a greater understanding of how a family-centred approach to care creates a synergy through the collaboration between primary caregivers, health care providers and the use of technology in the PICU.

The Synergy Model has been successfully used in multiple settings since its initial use by the American Association of Critical Care Nurses in 2005, reinforcing its reliability. For example it was used to conduct nursing rounds (Mullen, 2002), for interdisciplinary planning (Annis, 2002), and has been used by educators in academic and clinical settings (Keplow, 2002). Cohen et al., explain how a group of clinical nurse specialists utilized the model to move successfully from a unit-based practice environment to a multisystem practice environment by using the components of the synergy model for multidisciplinary collaboration (2002). The model was also used by a military nurse for optimizing outcomes for Iraqi patients where the plan of care and competencies were based on the needs of the patients and required special attention to cultural differences (Freyling, Keston & Heath, 2008).

The Synergy Model serves as a guide in defining the relationship health care providers have with the patients and families in an area with high technological dependence such as the PICU. The Synergy Model helps address the research questions of this study by providing a process in understanding and reaching the unique needs of primary caregivers in the PICU. Primary caregiver's experiences around family-centred care and a more comprehensive understanding of the conditions that enhance family-centred care will be detailed in this study. Attaining a synergy is essential and as health care providers further understand primary care

givers' needs in the PICU, they will be more effective at incorporating a family-centred approach to care in such a technologically dependent environment.

Chapter Summary

This chapter explains the Synergy Model developed by the American Critical Care Nurses Association. The model proposes that the primary caregivers, healthcare professionals, and technology in the PICU can work together as one, decreasing stress and improving primary caregivers' satisfaction with care. This study aims to address how primary caregiver's needs are met by health care professionals who incorporate family-centred care into their practice. A family-centred approach to care will prevent the technological demands of the PICU from getting in the way humane, high quality direct patient care and assure satisfaction with care and optimal outcomes.

Chapter IV: Research Design

The following chapter provides insight on the research methodology used to guide this study. The philosophical framework of van Manen (1990) is explained and is the methodology, whereas the process for carrying out the research is the method. The method description consists of the research design, sampling and sample criteria, recruitment of participants, the research setting, data collection methods, approach to data analysis and strategies to achieve trustworthiness as well as ethical considerations. Finally, the risks and benefits of this study for primary caregivers are discussed.

Methodology

This section of the chapter addresses the research methodology used for this study and addresses the reasons why heuristic phenomenology was used in understanding the lived experience of family-centred care by primary caregivers who have had a child admitted to the PICU.

Phenomenological inquiry can take many different forms (Maggs-Rapport, 2001) and it is therefore essential to understand the philosophical underpinnings of phenomenology to provide a deeper understanding of how this methodology contributes to a particular research study. The philosophical underpinnings of hermeneutic phenomenology are discussed next.

Phenomenology is a human science that is considered a philosophy as well as a method (Maggs-Rapport, 2001). Contrary to the quantitative paradigm which involves concrete empirical data, qualitative data looks at individual's subjective and interactive experiences. Van Manen's heuristic phenomenological inquiry was used to guide this study to understand primary caregivers lived experience of family-centred care in the PICU. Two founding authors of van

Manen's phenomenology include Edmond Husserl and Martin Heidegger. These key authors will be discussed next.

Husserl's Transcendental Phenomenology

Edmond Husserl was a mathematician and was considered the "father" of phenomenology. He believed that phenomenology was the essence of the lived experience within the real world. According to Husserl, phenomenology consists of "the rigorous and unbiased study of things as they appear in order to arrive at an essential understanding of human consciousness and experience (Dowling, 2007, p. 132). He also believed that to acquire the true essence of an experience, bracketing was necessary whereby the researcher's preconceptions, beliefs and previous knowledge about a phenomenon were put aside (Dowling, 2007).

Bracketing was Husserl's attempt to objectify the human experience which he believed provided scientific rigour important to the empirical paradigm (McConnell- Henry, Chapman & Francis, 2009). Husserl's transcendental phenomenology was descriptive in nature and thus described the lived experience.

Heidegger's Hermeneutic Phenomenology

Martin Heidegger was a student of Husserl and was enthralled by the concepts of phenomenology, however disagreed with some of what Husserl believed. Heidegger developed his own philosophy of phenomenology which he called the hermeneutic phenomenology. This differed from Husserl's in that it focused on understanding and interpreting the phenomena rather than describing it. Heidegger also rejected Husserl's concept of bracketing and believed that the world should be examined "pre reflectively". Therefore the researcher's beliefs and knowledge around a phenomenon was an essential component to the interpretation of the meaning of that phenomenon, and prior knowledge contributed to the interpretation of the

essence of the phenomenon (Dowling, 2007). Thus the lived experience to Heidegger was an interpretive process.

Appropriateness of van Manen's Philosophy for this Study

Van Manen's Heuristic phenomenology was used to guide this study consisting of both Husserl's descriptive phenomenology and Heidegger's interpretive phenomenology. According to van Manen, in order to gain a full understanding of a phenomenon derived from an experience, the experience must be both described and interpreted (1990). Additionally, hermeneutic phenomenology is "essentially a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomenon appearing in text or written word" (Speziale & Carpenter, 2007, p. 88). For the purpose of this study, the nature of understanding family-centred care from a primary caregiver's perspective was accomplished by describing and interpreting data from the interviews conducted with primary caregivers. The personal voices and experiences of the primary caregivers provided the most accurate and rich data around the essence of family-centred care. This phenomenological perspective provided a deeper insight into the nature and meaning of the human experience, with a theory to guide the process, rather than producing empirical generalizations that were formulated into theories, such as Husserl believed (van Manen, 1990). This methodology has also been adopted by a wide range of health care professionals and used in many different research settings reinforcing its versatility, validity and analytic strength (Maggs-Rapport, 2001).

Research Method

The following section will discuss the research design that was used in this study to arrive at information-rich data. The study sample, setting, data collection methods, and approach

to data analysis, ethical issues, and issues of methodological rigour are addressed in the next section.

Research Design

A qualitative research design was used for the purpose of this study to arrive at a detailed description of primary caregivers' lived experience of family-centred care in the PICU. The work of van Manen (1990) was used to guide the data collection, analysis, and interpretation. Van Manen's six methodological themes were used to structure the research process into specific research activities (see Table 1)

Sample Recruitment and Access

The criteria for sample selection, sample size and process for participants' access and recruitment are described next.

Criteria for Sample Selection

This study took place in a PICU at a large mid-western hospital. A database of all admissions to the PICU was accessed by an intermediary within the PICU. The intermediary was asked to assist with choosing the various families from the database that met inclusion criteria for this study. Inclusion criteria included: (1) caregivers whose child survived their PICU experience, (2) caregivers of children who were not post-operative patients, (3) caregivers whose child had been in the PICU for more than three days, and (4) families who lived no more than 80 kilometres outside of Winnipeg. Initially, a data base of admissions of families who had been discharged from hospital for more than three months but where no longer than a year had passed since discharge was created. Within this category, 40 charts were pulled and only 10 letters of invitation were sent out from this group. From the 10 letters that were sent out, only one

response was attained requiring a look into admissions further back in time. Therefore, families who had been discharged from hospital where at least three months had passed but no longer than four years had passed since discharge were added to the data base. There were 296 charts pulled from this category, and only 40 of the 296 charts pulled met the study's inclusion criteria and had letters of invitation sent out. A response from nine participants was attained.

Sample Size

A purposeful sample was used for this study and although the suggested sample size was 10 to 12, the actual number of participants for this study was eleven. However, data saturation was attained and is achieved when there is replication of information and there are no new themes or essences emerging from the participants (Patton, 1990). Therefore, a large enough sample size was attained to elucidate the richness of the individuals' lived experience.

Participant Access

Participant access was sought through the Children's Hospital Access and Impact Research Committee and the University of Manitoba Education/Nursing Research Ethics Board. A letter requesting permission to access primary caregivers with a child previously admitted to the PICU was requested and sent to each committee. Please refer to Appendix E and Appendix F for a copy of the approval forms from both committees.

Sample Recruitment

Based on the research criteria, a data base was developed and sent to medical records to retrieve primary caregivers' respective contact information by pulling the patient charts. From the charts, the child's name and the primary caregiver's name and address were attained. Letters of invitation were sent out by medical records (see Appendix A) in envelopes with postage provided by the student upon approval from the Chief Administrator Officer at the Health

Sciences Centre in Winnipeg. Those caregivers who were interested in participating in the study, were asked to contact the student by telephone or by e mail. Appropriate contact information was provided on the letter of invitation including the student's phone number and an e mail address.

Once the student was contacted by potential participants, the study and its purpose was explained in further detail and potential participants could agree or decline to participate in the study. No participants declined upon initial contact, therefore a convenient place and time was arranged for an interview. Study information and consent forms were distributed prior to the interview. Participants for this study included primary caregivers whose child had been discharged from the PICU for at least three months in order to prevent contacting them too soon after the experience reducing the risk of creating feelings of distress.

Data Collection Methods

For the purpose of this study, three data collection methods were used which included a demographic form, in-depth individual interviews, and the student's personal field notes.

Demographic Form

A demographic form was developed specifically for this study that primary caregivers were asked to fill out before the interview began (see appendix D). The form took approximately five minutes to fill out. This form allowed the student to see the various characteristics of each participant after the interview had been conducted as these characteristics could have influenced some of the responses in the interview.

In-Depth Individual Interviews

To understand the lived experience through phenomenology, primary caregivers of children admitted to PICU participated in a digitally recorded interview. A semi-structured open-

ended, face to face, individual interviewing technique was used to provide an in-depth understanding of the essence of primary caregiver's experiences and beliefs around family-centred care in the PICU. This type of interview structure is considered more of a conversation than a formally structured interview providing greater opportunity for primary caregivers to explain their experiences without any bias from the researcher (Marshall & Rossman, 1989). An open-ended interview guide was developed by the student and her advisor based on the literature review and their past clinical experiences (see Appendix C). There were a total of nine interviews conducted and total of 11 participants who took part in this study. Two of the nine interviews that were conducted included both the child's primary caregivers. Participants in these two interviews felt it was important they both be a part of the interview process. They shared the experience of having a child in the PICU together and both had valuable input about their experience in PICU. The other seven interviews that were conducted included only one of the child's primary caregivers.

Probes were used as necessary during the interviews to assist in explaining the details of lived experiences, but not in a manner that affected participant's own personal responses. Only one interview was conducted with each primary caregiver. The length of the interviews ranged between approximately 45 minutes to an hour. All interviews were digitally recorded with the permission of participants as their direct words were the essence of their experience. Following each interview, verbatim transcriptions were completed by a hired transcriber. Transcribed interviews assisted the student in developing a more in depth data analysis and contributed to a better understanding of the data (Speziale & Carpenter, 2007). A follow-up telephone call took place with each participant approximately one to two weeks after the interview had been

conducted to allow for any additional thoughts or comments from the primary caregivers. However no participants had any additional information to add from the previous interview.

Field Notes

The third source of data collection consisted of field notes which were written during and immediately following each individual interview. Field notes consisted of recording data and observations made by the researcher during the interview process (Mulhall, 2002). Field notes included information about thoughts, feelings, and insights prior to, during, and after each interview and analysis session. As well, a description of the location of the interview, the interactions between the interviewer and interviewee, and any other pertinent information about the data collection process was noted. Field notes are helpful in keeping a record of insights, patterns and reflections gained from the interviews (van Manen, 1990) and they enhanced the data analysis process consisting of objective observations made by the student during the interview process.

Research Setting

The setting for qualitative data collection and interviews is often in the field, in other words where the phenomena of interest occurred (Speziale & Carpenter, 2007). In order to achieve the most accurate and in-depth information from the participants, interviews were conducted in a place that was most comfortable for the primary caregivers, free from distractions and interruptions. Seven of the nine interviews took place in the primary caregiver's home, one was conducted at the University of Manitoba and another one took place in a coffee shop.

Data Analysis

The data analysis process took place concurrently with data collection. Interpreting the

interview data demonstrates each participant's unique experience while attempting to understand the true essence of a phenomenon (Speziale & Carpenter, 2007). Data from the interviews were transcribed verbatim and subsequently analysed using van Manen's selective highlighting approach. This consisted of isolating thematic statements which assisted the student to make sense of what was said by the participants (van Manen, 1990). Using all the phrases and sentence clusters as well as the field notes, textual data was reduced until essential and incidental themes emerged. Having arrived at the essential and incidental themes, there was then a process of interpretation and description. This was accomplished by shifting focus between the parts and whole transcripts and between individual and group transcripts. As this study is part of a Master of Nursing thesis project, collaborative analysis took place with the student's advisor who provided guidance and experience in thematic analysis. Collaborative analysis ensured that interpretation of the material was an appropriate representation of what the participants shared. Field notes taken by the student were also analysed and they added depth to the information from the interviews, validating important points made by the participants. The end result of the data analysis process was a narrative description of primary caregiver's experiences and beliefs around family-centred care in the PICU. This description, which resulted in the development of the essence and themes, was co-created by the student and her advisor. Additionally, data collected from the demographic form was summarized using descriptive methods.

Methodological Rigor

The terms rigor and validity are not used within the naturalistic paradigm as seen in the positivist paradigm. This is due to the difference in philosophical underpinnings between both inquiries. Trustworthiness is used in qualitative research to demonstrate the degree of confidence to which the researcher has in their data (Lincoln & Guba, 1985). Trustworthiness

will be assessed using the model developed by Lincoln and Guba (1985) which will address credibility, dependability, confirmability, transferability and authenticity.

Credibility

Credibility refers to the confidence of the truth one has in the data. A research study must be carried out in a believable and realistic way (Lincoln & Guba, 1985). In order for the researcher to attain credibility, prolonged and sustained engagement with subjects is essential. This was done with the use of a personal open-ended interview lasting anywhere from 45 minutes to an hour which allowed the student and the participants to develop a relationship.

Dependability

Dependability can only occur once credibility has been established (Speziale & Carpenter, 2007). Dependability refers to the dependability of the data and the ability to replicate findings over time (Lincoln & Guba, 1985). Participants were asked during and immediately following the interviews if the student's interpretation of their experience was in fact reflective of what the experience was like for them. A follow up phone call also gave the participants a chance to add to the information if they wanted and served to validate that the findings represented participants' experiences. Continued discussion, revision and regular communication with the student's advisor helped determine dependability within this research study.

Confirmability

When two or more independent individuals feel that the data obtained is accurate, meaningful and relevant, confirmability is achieved (Polit & Beck, 2008). This assures that the researcher has appropriately interpreted the data and has not altered information with personal

bias, in other words that the data obtained reflects the participant's voice. One method to assure confirmability is an audit trail which consists of the student recording activities overtime to allow another person to follow the researcher's activities. This was achieved in this study through the use of field notes to make the researcher's thoughts explicit.

Transferability

Similar to external validity in the positivistic paradigm, transferability refers to the extent to which data attained from the study can have meanings in another. To assure that readers can apply the information to other situations, the researcher must be able to provide "thick descriptions" of data so the reader can understand the research process and findings to apply the information to different settings with greater ease (Polit & Beck, 2008). For the purpose of this study, transferability was achieved by assuring that participants understood the processes that would occur to determine how the interpretation of the data was achieved. Comprehensive field notes were also documented to provide ample descriptive data within the findings for others to evaluate the ability to find similar meanings within other contexts.

Authenticity

Authenticity includes the researcher's ability to accurately and faithfully report research findings from a study (Lincoln & Guba, 1985). Going back to the research participants to validate study findings enhanced authenticity. This was done with a follow-up telephone call two to three weeks after the interview took place. This helped in truly conveying the participants' lived experiences.

Ethical Issues

Nursing research consists of research involving human subjects therefore details to ethical principles must be understood to practice ethically sound research. Researchers have a duty to protect human rights, requiring a great deal of knowledge around ethics in qualitative research. Prior to conducting this study, approval was granted from the thesis committee, the University of Manitoba Education/Nursing Research Ethics Committee and Child Health Access Committee. Additionally, the student practices under PHIA and the Canadian Nurses Association code of ethics which focuses on five key ethical principles including autonomy, non-malificence, beneficence, justice, and confidentiality.

Autonomy

Autonomy refers to the ability to be a self-governing person who has decision making capacity (Speziale & Carpenter, 2007). Autonomy has been conceptualized within health care by informed consent (Patton, 1990). For the purpose of this study, informed consent was obtained from all participants through the signing of a consent form (Refer to Appendix E). The student assured that participants were aware that their participation was voluntary and that they could withdraw at any time throughout the study without penalty. Additionally, participants must be given true and precise information around the study without being threatened or coerced into participation (Hewitt, 2007). The researcher must not effect or control the potential participants' decision to become a part of the study. Therefore participants were asked to contact the student rather than the student contacting them to refrain from having any influence on their decision to participate. Participants were presented with a consent form to sign by the student who assured that participants understood the study. The student took the time to answer any necessary questions the participants had before proceeding with the interview.

Non-malificence

Non-malificence includes preventing harm, thus the researcher must assure that they or the research itself will not cause harm or discomfort to participants (Polit & Beck, 2008). Due to the qualitative nature of this study the student engaged in relationships with participants to gain a sense of trust and understanding about their personal, lived experience. The student was cognisant that remembering events which occurred in the past could have psychological side effects for participants. Polit and Beck (2008) state that the psychological consequences of remembering devastating events can be subtle, however the student was still sensitive to participants' needs. The families who were interviewed for this study were at minimal risk for harm; however, it could have occurred where they became distressed from bringing up old memories. If they felt that they needed additional support because of increased psychological distress, the student would have offered them a resource to receive counselling if necessary. Klinik, located at 545 Broadway Avenue provides free drop-in counselling services which could have been offered to primary caregivers if needed. None of the participants from this study required further support or counselling.

Beneficence

Two key features of beneficence include confidentiality and anonymity (Speziale & Carpenter, 2007). For the purpose of this study, anonymity is virtually impossible due to the nature of the data collection methods. The personal one-to-one relationship that the student has with the participants makes autonomy and confidentiality impossible. However only the student had contact with the participants and data was disseminated in a way that no other members of the population would be able to tell who the participants were for this study. In order to maintain confidentiality no names were attached to any of the methods of data collection, rather code

numbers were used on the demographic forms, transcripts of the interviews, and within the field notes. Only the student and the student's advisor had access to the digitally recorded interviews and only the student had access to the raw data. All information was kept in a locked cabinet in the researcher's home and all data was completely destroyed after the study was completed.

Justice

Justice includes equality whereby each individual is entitled to fair treatment (Polit & Beck, 2008). The selection of participants for a study must not be chosen based on the participant's status or type of group they belong to, but rather based on research requirements. Demographic information was not looked at until after primary caregivers had consented to participate in the study. Justice also encompasses an individual's right to privacy which was addressed in the confidentiality section of this chapter.

Finally it is essential the researcher treat the individuals who decline from the study in a non prejudicial manner (Polit & Beck, 2008). While no participants withdrew from this study, the student would have treated those who declined in a fair manner..

Risks and Benefits

It is essential that the risks of a study using human subjects not outweigh the benefits (Polit & Beck, 2008). Participant risk in this study was minimal however, the student was aware that primary caregivers could have experienced some uncomfortable feeling during the course of the interview. Benefits of the study included primary caregiver's ability to talk about their lived experience in the PICU which could have served as a coping mechanism. Additionally primary caregivers were happy that they had someone to talk to about their experience, that their voices were being heard, and that there was possibility for change.

Chapter Summary

A qualitative phenomenological study was used for this study guided by van Manen's methodology (1990). The data was gathered for this study through in-depth, semi-structured interviews, demographic profiles, and field notes. The research setting took place in a mutually agreed upon place free from distractions and van Manen's human science method was used to analyze the data from the interviews. Methodological rigor, ethical considerations and the risks and benefits to conducting this study were also discussed.

Chapter 5: Findings

Introduction

Chapter five presents the findings of this phenomenological study. The chapter begins with a description of the participants, followed by a description of the essence of family-centred care by primary caregivers in the PICU. Data analysis revealed the essence to be *being present*. Three themes that emerged from the interviews supporting this essence are then described and include: (a) physical presence, (b) participation in care, and (c) advocating. Factors that need to be in place to experience family-centred care in the PICU are then discussed which include: (a) being present for rounds, (b) caring behaviours, (c) feeling welcome, and (d) support.

Description of Participants

The following section provides a description of primary caregivers' demographic characteristics followed by the demographic characteristics of their children.

In total, there were 11 primary caregivers who participated in this study. Two interviews consisted of both of the child's primary caregivers: however, demographic information was collected from only one primary caregiver per interview. The ages of primary caregivers ranged in age from 33 to 44 years with the mean age being 37 years. Nine of the participants were mothers and two were fathers. Eight of the nine participants were employed full time with the exception of one who worked part-time. Two of the nine participants interviewed did not work. Six participants lived within the city and three lived in rural settings outside of Winnipeg. The following are the demographic characteristics of the children of primary caregivers who were

interviewed. The length of time elapsed since the child's admission to the PICU was between one to four years. Five of the nine children were admitted to the PICU for respiratory illness including viral pneumonia, aspiration pneumonia, cast bronchitis and croup. One child was admitted with bacterial meningitis. Two of the nine children were admitted with heart failure. One child was admitted with renal failure. The children's ages upon admission to the PICU ranged from four days old and seven years old with the mean age being two years. Children's ages upon the time of the interview ranged from one to seven years of age. The children's length of stay in the PICU was between six days and up to two months.

Main Findings

The essence of the lived experience of primary caregivers who have had a child admitted to the PICU is presented in this section. The following research question is addressed:

- 1) How do primary caregivers who have had a child admitted to the PICU experience family centred-care?

The Essence of Primary Caregivers' Lived Experience

The essence of the lived experience of primary caregivers who have had a child admitted to the PICU is described as *being present*. *Being present as first discovered and defined by Woodgate in her work of families of children with cancer*, (Woodgate & Degner, 2003; Woodgate, 2006; Woodgate, 2006; Woodgate, 2008) was defined by participants as maintaining a sense of presence with their child by physically being there with their child and emotionally being there for their child.

Primary caregivers' desire to *be present* was evident from the moment of admission to the PICU until the child's discharge from the hospital. This desire was reinforced by primary

caregivers who refused to leave their child's side and needed to be with their child under all circumstances: however, being with their child was not always possible. Primary caregivers were asked to leave by health care providers under certain circumstances causing participants feelings of distress.

Primary caregivers' need to *be present* was greater when their child's condition was unstable and their child's prognosis was uncertain because uncertainty contributed to feelings of anxiety, distress and helplessness. However, *being present* gave primary caregivers emotional reassurance by knowing their child was receiving adequate care. *Being present* also allowed primary caregivers to maintain a sense of connection with their child fostering the bond shared between the child and the caregiver.

Like being able to be there and see what people are doing and the fact that so many people are working to make him better was impactful for us. (Mother # 1)

But that's my kid I want to make sure that and I know everybody's professional and all the people who are doing all their things on him are professional and they're very good at what they do but its still, its, it's frustrating, I want to make sure he's okay and he was paralyzed so I knew he didn't really know what was going on anyway and he didn't even know I was there but its, its...(Mother # 4)

Cause we actually thought when we went into PICU that okay, he's out of emergency, he's in a good place, he'll, he'll be better now you know. You know like he's got the right people looking after him. (Mother # 1)

Being present was reassuring for primary caregivers and enhanced their ability to cope with the devastation of their child's admission to the PICU. Participants from this study experienced *being present* by being physically present, participating in their child's care regime, and advocating for their child.

Physical Presence

Physical presence was referred to by primary caregivers as being in the same proximity as their child in addition to having visual contact with their child. Physical presence allowed participants to *be present* with their child by remaining physically close to their child to see what was happening. This proximity offered emotional reassurance to primary caregivers that their child was receiving appropriate care. Physical presence meant being there with the child and not necessarily having an active role in the child's care. Primary caregivers appreciated the chance to remain physically present with their child as much as possible.

So I always made sure that I knew as much as I possibly could what was going on with "C". And you know what kind of care they were going to take so when it, it was just better for me to be right there with him. (Mother # 4)

But that we were allowed to stay in the room when it was happening, I think if we would have been told you got to get out, I think the tone for us probably would have been a lot different. (Mother #1)

Like being able to be there and see what people are doing and the fact that so many people are working to make him better, was impactful for us. (Mother #2)

Yeah, yeah I don't know, I mean we ended up you know sitting in that chair beside his bed anyway and probably had our head on his bed and if we dozed off then we dozed off. But we just honestly didn't want to leave. It just wasn't even a factor, like either "J" was in there or I was in there. (Mother # 1)

Physical presence also included touching and holding the child. This physical contact allowed primary caregivers to *be present* as they believed their touch offered a sense of comfort for their child. In cases where the child was sedated, primary caregivers still believed their child could sense their presence despite having no response from the child to acknowledge their presence.

And I think he, he could still kind of hear us and kind of sense us there. You know what I mean and he needed more than, um he needed his mom there, he needed to know even though he was paralyzed I think he needed to know that we were there and we were with him. (Mother # 4)

I mean I can't even, I mean we spent the majority of our time in "L's" room just sitting beside his bed and just hanging out there holding his hand. (Mother # 1)

Primary caregiver's experienced several barriers to be able to touch and hold their child while in the PICU. When the child was in isolation, participants were required to wear gowns, goggles, and masks for infection control purposes. This equipment made it difficult for primary caregivers to have direct physical contact with their child and participants experienced difficulty in *being present* with their child. The inability to be close to the child created feelings of distress in primary caregivers.

No, no I'm okay, um that was really hard cause it just, you know not having that, feeling him through gloves was not the way you want to do it. And it was awful cause I couldn't touch him. You know I couldn't feel his skin and that was...It's been two years yeah. (Mother # 9)

And it was frustrating then too because of all the H1N1 and everything, we always had to get all masked up and everything. Well yeah I mean I'm in, I'm in these goggles and I'm in these gowns and gloves and everything, and so when they were, I, I would just take everything off. It's uncomfortable and it, you know you keep fogging up. And you can't get close to him and say you know mommy's here and stuff. (Mother # 4)

Furthermore, the medical equipment within the PICU was also a barrier to getting close to the child. The various machines and tubes did not allow for close physical contact with the child and the equipment also made it difficult for primary caregivers to participate in the child's care.

Um, only after she was, after the tube was taken out were we able to touch her. So, once they took it out, then I was, but pretty much she—and she wanted to, right? So that was kind of hard too—But you can't do that when they have the tube in, so. So as soon as she took it out, it was nice because they have the chair in there so I was able to sit down and, you know. Carry all those cords with us, but it was good, yeah. All those IV lines and monitor cords. (Mother # 7)

But on PICU they, he was just so all hooked up and stuff like that. He didn't need to be, he couldn't be held, you know what I mean? Like he was all, he was just trying to get better. (Mother # 6)

The tubes, the, the IV's, the monitors, the this the that the well you can't touch him here and you can't do this to him and he's got to stay asleep so he doesn't pull the respirator out which he would have. (Mother # 5)

While being physically present allowed primary caregivers to *be present*, not all primary caregivers were given this opportunity. Health care providers asked primary caregivers to leave the unit during procedures, rounds, shift change, and patient transfers. However, upon being separated from their child, primary caregivers did not know what was happening with their child. This uncertainty created feelings of distress.

The thing I didn't like is when "C" first crashed um when we brought him up from the ward up to the PICU um I just expected that I'm staying with him and they were like, okay you guys wait in this waiting room. And we'll let you know kind of what's going on. (Mother #4)

And that was the longest, that was, I understand they have to do their work and it's imperative that they have all their space and no questions to do their work, but I felt so alone and so isolated. And just waiting for that phone call to say, yeah you can come in, he's fine now. (Mother # 5)

Yeah. So what was her name she was so good, anyway um yeah so she walked us over and then we had to sit in the waiting room at PI for them to set him up. That was really hard because again we were just in, in the dark right we didn't know what the heck was going on. So emotionally it was, yeah it was terrible cause you just don't know. It was brutal cause you don't know what to expect. (Mother # 3)

While separation from the child was difficult, some participants felt comfortable leaving the unit such as during invasive procedures. Several primary caregivers found it too difficult to watch what was being done to their child and became emotional upon staying present.

You just want to be available, or at least just, I don't know, you know what in hindsight thinking about it I probably wouldn't have stayed there because it was hard to watch those things. It's hard to watch the, the invasiveness and... me yeah, that, that is hard to see that. Um so I was okay with stepping out. (Mother # 3)

Uh for sure one time um it was a, an emergency situation where um she had to get a central line put in and uh so I mean I wouldn't want to be in the room when that's being done anyway. (Mother # 8)

We left the room. I couldn't stay in the room and you know what at that point there was gosh I'd love to say ten to fifteen people in the room. And I just couldn't watch it. Emotionally I couldn't watch them do that so. (Mother # 3)

While some primary caregivers were comfortable leaving the unit, others would have appreciated the freedom to come and go from the unit as needed. However, having this freedom was not always an option for primary caregivers.

So I got to come and go a lot. So I didn't have to um, I didn't have to sit with him for like four or five hours at a time because then I'd have to drive all the way home and come back. So I would sit with him for an hour, I'd go for coffee, I'd read my book, I'd come back for another hour and then I'd go lie down in that room and then I'd come back, so I could spend the night and come and go as I pleased. (Mother # 8)

So they did the chest tube and I think at some point maybe her lungs or her breathing—because I was there when it happened and I remember that nurse was trying to increase her oxygen when that little monitoring thing kept going off. And she kept putting it—I remember seeing that—I just got too scared and I kept leaving and then I'd come back. (Mother # 7)

Participation in Care

Participation in care was another way by which primary caregivers experienced *being present*. Participation in care was referred to by participants as being actively involved in the child's care while in the PICU. Participation in care allowed primary caregivers to *be present* with their child and for their child by assuming an active role in daily care activities. Being a part of the child's care was reassuring for primary caregivers as they could maintain a piece of their role as caregiver to their child. Some primary caregivers were even given the opportunity to help with nursing care and nursing assessments.

Um and they, they would let me do things like um check for tube placement or you know feed him, those sorts of things. Or the Doppler oh cause after the heart cath he got a clot in his leg of course so then, uh they'd give me the little Doppler to find the heart; you know the pulse in his foot. And you know sometimes they couldn't find it so they'd be like,

here mom you give it a whirl so yeah it was nice to just be involved in little ways like that. (Mother # 3)

If something isn't done right away I'll go and get it myself, no matter what it is. When he was so sick I was doing his IV pumps, I was adjusting his oxygen. (Mother # 5)

They, um, I think one time we did. Or one time I think I asked because I was kind of feeling like her sheets and that were dirty. I do remember feeling that one time, and I think I just, I took it upon myself to do it myself, because they were busy stuff, so maybe they were just busy that one day, but, yeah. Otherwise I'd just do it myself. But I thought for the most part she was very well taken care of. (Mother # 7)

While most primary caregivers appreciated the opportunity to be a part of the child's care, one participant found it difficult caring for a child who was critically ill. This mother wanted to take care of her child the same way that she did before her child became ill. This mother wanted to partake in what she felt were normal parenting activities such as breast feeding and bottle feeding her child.

At that point, originally we were breastfeeding then we moved to bottles so that they could see what he was getting cause they only wanted him I think to have like an ounce let's say mixed with the formula, and then he was still losing weight, so then we moved to uh to tube feeding. That was awful, just because you want to be doing what other mom's are doing right. (Mother # 3)

Advocating

Advocating was another component to *being present*. Primary caregivers referred to advocating as being the voice of their child and having the ability to question care when they felt it was not appropriate. Due to their illness, age, and level of sedation, the children in PICU were not able to express their needs. Therefore, primary caregivers wanted to *be present* to ensure their child's needs were being appropriately met.

Yeah you, you lose the role of parent and you become the advocator. That was hard. You have to relinquish your role. (Mother # 3)

Even before C was born somebody told me that you're the voice of your child so. So get in there, know everything you can and don't be afraid to speak for your son so I wasn't. And then everybody around like doctors and nurses knew that I wasn't just going to be a

pushover mom that you could just say, oh it will be okay, it will be okay, because yeah. (Mother # 4)

Oh I think just really um just really speaking up about you know even though even if your child is um sedated or whatnot, like you can sort of tell by you know just watching the monitors, watching how they react to things, like really questioning what's, and being a part of, like you definitely, like not being afraid to ask what is going on and questioning like is that test you know necessary, you know if we just had one, you know things like that. You just need to really advocate for, for your child and not be afraid to question what's happening and obviously not in a rude way but uh...(Mother # 9)

As advocates for their children, primary caregivers could also *be present* for the child by addressing concerns and issues related to their child's care. Primary caregivers' *presence* also allowed them to be there for their child by assuring these issues were appropriately resolved. When concerns were present, primary caregivers would address them by talking to the charge nurse about what was bothering them. Primary caregivers felt their concerns were addressed when they were given an apology or when the care provider with whom they had an issue was no longer assigned to care for their child again.

So that was, immediately I just, I had had to speak to the charge nurse and then we discussed what went on, why we were, you know in the situation we were in, or why we were mad and what we're mad about. And then she went and talked to the nurse. That didn't turn out so well. Uh, not between us and the nurse but the nurse at the time yeah, she was clearly upset and she was taken off of watching "N. (Father # 2)

Well, two of the nurses just stayed outside. So the thing is beeping and woman is talking. And I'm like looking at her and she's having a conversation with somebody else and "L"'s coughing and those things are beeping and, um, at some point she came in and, I mean, it was probably only not even minutes or anything, And by the time she gets all suited up, because you have to put gloves, you have to put a robe on And then one of the other nurses did that again, so I complained to them and I just said, you know, I'd appreciate if you came in the room when that's happening because I don't feel comfortable that you're—the amount of time it takes you to get dressed and whatever. But I also told her I felt like she kind of took her time. And, um, so I don't know if they did it on purpose, but that nurse was never taking care of "L" after that. (Mother # 8)

By expressing their concerns, primary caregivers felt they were advocating for their child and they felt more involved in their child's care, allowing them to be there for their child. Since

the child could not communicate, being the voice of their child gave primary caregivers a sense of reassurance.

Furthermore, having their concerns addressed in an appropriate manner provided primary caregivers with the feeling that they were being listened to. As a result, primary caregivers felt that they were successful in advocating for their child since once their concerns were addressed, there were changes to the child's care. However, when primary caregivers felt like they were being ignored, feelings of anger and aggression developed. These feelings developed as a result of not being able to enact change resulting in feelings of inadequacy and helplessness in primary caregivers' ability to advocate for their child.

And when you, and you see more of patients advocating or families advocating for themselves and when you don't include them in that process then that's when things certainly get more aggressive and more adversarial because people feel like they're not being listened to and they're and so then you start to see sometimes every decision get challenged um because they haven't felt like they've been included. (Mother # 9)

And, and so if people have more of an awareness that they're going to be listened to and that they're going to be included, then I think there's no reason for that negative energy, you can just feel positive about what the team is trying to do for you and for your child and so to take advantage and to be aware that you know everyone has the best interests of the entire family at heart. (Mother # 8)

Like I think people often get aggressive in a healthcare setting because they're expected that they won't be listened to, and so that aggression can be good, but it can also work against you. But um the family as well and to just allow that to be a positive experience instead of having to feel like somehow you have to fight for the rights of your child. (Mother # 9)

When health care providers addressed primary caregiver's concerns, a more positive atmosphere was maintained facilitating primary caregivers' ability to cope with having a child in the PICU.

Themes

The next section will address research question number two which is:

- 2) How do caregivers who have had a child admitted to the PICU define family-centred care?

Three themes that contribute to the definition of family centred-care have emerged from the interviews including: 1) collaboration, 2) being updated, and 3) continuity of care. These components of family-centred care, as described by the participants of this study fostered primary caregivers' ability to *be present* for their child and with their child. By experiencing collaboration with the health care team, being updated by health care providers and experiencing continuity of care, primary caregivers felt reassured their child was getting appropriate care as they were able to *be present* for and with their child. *Being present* allowed primary caregivers to know what was happening with their child at all times, have input into decision being made around their child's care and maintain a healthy relationship with health care providers. When these components of family-centred care were not in place, primary caregivers experienced feelings of distress as they could not *be present* for their child and with their child. Thus a family-centred approach to care was not achieved. The following section discusses how each component of family-centred care as described by participants of this study relates to the essence of *being present*.

Collaboration

Collaboration was referred to by participants as working as a team with health care providers in effort to achieve the best outcomes for their child. This team work consisted of health care providers who treated primary caregivers in a non-hierarchical fashion and incorporated the whole family as an integral part of the child's care. Collaboration provided

primary caregivers with piece of mind when the health care team would share their thoughts relating to the child's plan of care, rather than being told how things were going to happen. Collaboration provided an opportunity for primary caregivers to offer input around their child's care plan and emotionally, primary caregivers felt satisfied.

Collaboration was also defined by participants as having health care providers who involved the family in the decision making process. Collaboration allowed primary caregivers to *be present* for their child by taking an active role in decisions related to the child's care. One way by which primary caregivers felt included in their child's care and decision making was by feeling like a part of the team and feeling welcome to give their input.

Nurses were amazing, really supportive, really um yeah they just made us feel like part of the team and not an outsider and you know, I think in that respect everybody was so good. (Mother # 3)

And, and having you know giving you peace of mind that yes you're a part of the team as well. To know what's happening and they explained things and you just felt like you were a part of that team. (Mother # 1)

It's this way or that way and I don't know what those two ways are and it's up to them to tell me what they what they think, but certainly in terms of just being included in that process and, and being informed and um having your say, you know having an opportunity to ask your questions or to just even express what your fears. (Mother # 8)

Witnessing a team approach provided primary caregivers with reassurance that their child was getting care from multiple health care professionals rather than just one individual who made the decisions around the child's care. As participants of the care giving discussions, primary caregivers ensured that thoughtful and collaborative decisions were being made and, consequently, allowed them to *be present* for their child.

We didn't miss out on those key opportunities, and I mean we didn't have any input really into what was happening in the conversation cause you know it's all kind of happening

and they're making.....not decisions but they're discussing the situation but we could, we could see the um the, the team environment and the fact that it's not just one person making the decision, there's a lot of like care and thought and consideration being put into what's going to happen. (Mother # 1)

And so if you're, and to not expect to necessarily be sort of shunted down to the bottom of that hierarchy where you're sort of told what's going to happen but, but to allow yourself to be involved as a team player or a team member without having to feel like you have to be aggressive about it. So it's not a sort of the typical patriarchal sort of hierarchy where the doctor is the person who makes all the decisions and you are then left to follow that path that's given to you, it's the family being active within those treatment um considerations and then following the path, like having options set before them and choosing the one that sort of fits with their philosophy and, and um and their belief structure and you know what they feel is the best fit for them. And I guess as a child obviously they're not really given those decisions to make. (Mother # 9)

One participant commented on their negative experience upon being transferred to a different unit after being in the PICU. She felt as though the doctor was the one making decisions and that she was not invited to have any input around her child's care. This lack of involvement was difficult.

As much as I think, the residents still came in and whoever the Chief was, or the resident in charge or whatever during that time, he was excellent um in terms of you know coming in and talking about what the team thought and um but I would say that coming from an environment where you're so well looked after, to an environment where you're once again shunted to being the person who receives the information and doesn't have any sort of not much in the way of giving back information and not as much in terms of the decision process, that transition was really hard. (Mother # 8)

Participants did not welcome being told what was going to happen in relation to their child's care without having any input, reinforcing the need for collaboration.

Being Updated

Being updated referred to by participants as ongoing and timely communication from health care providers about their child's health status. Being updated allowed primary caregivers

to *be present* and be there for the child by having a better understanding around the child's plan of care eliminating the fear of the unknown. Being updated was especially important when primary caregivers were asked to leave the unit for periods of time as frequent updates reassured participants that their child was still alive.

Well, I do believe it [family-centred care] means that and that the type of stuff that's going on during the care would be explained to either the guardians or whoever is there for the person that's in, uh in the hospital (Father # 2).

And that's the other piece into the family-centred care, is that if anything would have gone wrong or, they would have phoned me and I would have, you know they were really good about that, keeping me, keeping me you know on par about things. (Mother # 3)

Yeah, so it was, it was a great environment, I thought that they did an excellent job in terms of keeping, keeping us well-informed and, and making us feel like, get the updates, know what was going on, know what their thought process was in terms of why they were treating him the way they were treating him. And so um you know and what the next step would be if, if that wasn't going well or why they were doing this next test. (Mother # 8)

Furthermore, being updated helped primary caregivers cope with the stress from uncertainty. However, at times primary caregivers felt that health care providers were not always open about giving information on the child's status.

Yeah. And the feedback that we got, I mean it really helped compared to like begging for information in the other ward some time and I mean neurology was very good to us I mean I can't speak badly to them at all, Dr. "B" and her team were very, very good but you kind of fluked into seeing them and getting information. (Father # 2)

Yeah and I, I mean it helped us understand what was going on and it helped us deal with the situation by knowing what, what was happening and I mean we were pretty fortunate because I'd say like ninety percent of the people that were caring for "L" were very um very open. And talked to us about a lot of stuff, but there were a few where you'd have to like pull answers. (Mother # 1)

Upon not knowing what was happening with their child, primary caregivers often thought the worst. Participants were concerned that the reason they were not allowed on the unit was because their child was dying or had passed away.

And that was horrible, we were out there for three or four hours, we didn't know if he was dying, it was No one came to update us; um we kept phoning in like there's a little phone in the wall to see if you can like go in. We kept phoning and they were like no, no, you know not yet, not yet and that was horrible. (Mother # 4)

I don't remember how long we waited. It felt long but it wasn't really that long. Nobody really kind of gave us any update. I can't remember if I phoned or not. I think I was just worried someone was going to come back and tell me that she had passed or something. That was my thought, I guess. (Mother # 7)

That could be done. So I hated waiting out there and like I said not knowing if he's living or dying or what's going on and, and taking so long for anybody to get to us, that was horrible, like I hated every single second of that. (Mother # 4)

Being updated in terms that primary caregivers could understand was also important. At times primary caregivers had difficulty understanding what they were being told with respect to their child's condition. This difficulty was often due to the medical terminology that was used in the intensive care setting. Clear and concise explanations around the child's status contributed to primary caregivers understanding of their child's status. When clear explanations were lacking primary caregivers did not feel appropriately updated.

Um and yeah just you know spoke English to me during rounds rather you know. Made it so that we knew what was happening. (Mother # 3)

I would think that yeah, the morning meeting that the doctors, uh the doctors and nurses had and then we were able to stand there and listen in and then someone would come over and give us the layman's term of what's going on. (Mother # 2)

Well I mean after the first few days you know not knowing, like you know taking my notes like what does this mean, what does this mean, and then after awhile you get to know the lingo and you get to understand what they're talking about (Mother # 8)

While the information being given by health care providers was not always clear for primary caregivers, the ability to ask questions contributed to primary caregiver's ability to understand and be updated. Participants appreciated when health care providers welcomed them to ask questions and were grateful when their questions were answered.

Right so it's like, don't just sit there silently. Ask your questions, make your demands, um, I mean I'm sure they were quite tired of us asking about her seizure medicine every single time, every twelve hours but we just didn't care. I'd rather be labelled a pain and somebody that you have to be careful around. (Father # 2)

And if you kind of ask the same question again and so I remember them always you know answering the questions and telling us what was going on. (Mother # 1)

Yeah, so really appreciated that. That was really good. And they always at the end asked me if I had any questions or— Yeah, so that was good. So, if I didn't understand some of the medical lingo, or terminology, then I was able to find out. (Mother # 6)

At times, primary caregivers did not know what questions to ask and wondered if the questions they asked were appropriate. However, primary caregivers also felt more at ease when their questions were appropriately addressed.

And we'd call throughout the night and I'd like I'd wake up I'd be like I'm just going to call. They encouraged that and I, regardless of how many times I called a night they were always like, more than happy to tell me how she's doing and. (Mother # 8)

The, the care there was amazing, if you had questions like they, they were just, they were there for you. The doctors were great and they knew, well like I guess all the other kids in the ward or in the ICU were sick as well but they, just this, the, the way they cared and the way they made you feel and they answered your questions and stuff it was just fabulous, it was great. (Mother # 4)

While some participants were hesitant to ask questions, others were more at ease with asking questions to health care professionals. Those who were more at ease with asking questions were more vocal and had a greater knowledge base. These participants' comfort levels were enhanced as a result of being more familiar with the environment from frequent hospital visits. Therefore by feeling comfortable with asking questions, these primary caregivers were able to *be present* for their child and have their needs addressed.

Like not that they were, they were never unwilling to tell me what was happening or explaining, but I think but at the time we were more vocal, so we knew what to ask for,

when to ask for, um what, like when it was okay to question things, that was the only thing like that I found was different in the first experience. (Mother # 9)

Participants whose child was admitted to the hospital for the first time appeared less comfortable with asking questions around their child's care. These feelings of discomfort reinforce the need for health care providers to encourage and welcome primary caregivers to ask questions when needed.

Upon receiving updates and information on their child's status, primary caregivers reinforced the importance of having another person present for support. Primary caregivers felt having another set of ears was essential in the dissemination of bad news. Several participants commented on how difficult it was to remember what was being said about their child a result of extreme emotions. These emotions caused primary caregivers to misinterpret or misunderstand the information they were being given by health care providers and were therefore not appropriately updated and not able to *be present* for their child. Having a support person to listen was helpful in this matter.

Because when we got the news for him, after his second MRI, and it was really bad, I could not tell you what she said. You know, I heard, first thing I heard that it's not good. I'm going to go through that, and after that it was nothing. I just—it could have been the Charlie Brown teacher talking, you know what I mean? Because I didn't hear anything. And my sister took notes. So that once it sets in that, yes, this has happened. Then we sat down and we went through them, you know, because you don't hear it. That's a big one, actually. (Mother # 6)

It is hard to adjust. I could not tell you— Sometimes what they said. And like, for an example, when we would talk to the lawyer and that, we, to go through the time lines and stuff like that, you don't, you don't remember things, and you don't, you think you will you don't. So to have that support system. (Mother # 5)

Being updated on the child's status allowed primary caregivers to be there for their child. Being updated allowed primary caregivers to know what was happening with their child and

understand where their child's needs were. If participants did not know what was happening, they could not anticipate what their child's needs were creating difficulty in *being present* for their child.

Continuity of Care

Finally primary care givers defined family-centred care as having continuity of care. According to primary caregivers, continuity of care encompassed consistency in the health care providers who were caring for their child in the PICU. This consistency fostered the development of a healthy relationship between the primary caregiver and the health care provider. When a relationship was established, participants were able to trust the care providers and felt more at ease knowing the health care provider could *be present* for their child in instances where primary caregivers could not. Participants also felt reassured their child was receiving adequate care upon leaving the unit for the night to sleep when they trusted the care provider.

Yeah, and then at that point, I mean I think that every time we went in they would say, oh they would know. You know, they really knew us well because we spent so much time. So it was nice because we knew the staff and everything. So, the following times that she did end up there it was sort of, we knew that she was in a good place and we felt comfortable having her there, yeah if if you, if it can be, you know, a good experience at least we knew that they knew her. (Mother # 8)

Yeah. Um you know there were a few nurses that really got to know him because they, they would always get him. For me that was important, that, that the nurse coming on knew who he was, knew who we were. And it, it was nice that we didn't have to adjust to a new face or yeah it just helped in the care. But it is, it, you know yeah for continuity of care it's definitely nice to have the same staff on. (Mother # 3)

So, um, I just found that you now, like, our nurse just got to know us a little bit. Asked us about our family. Asked us about, you know, what's been happening in the past-so you can build that short-term—hopefully it's a short-term relationship—that at least you know where they're coming from. And then, I'll go back to establishing that, oh, you have

two other kids at home, and running back and forth. Then you kind of understand, you know, where the parents and the kid's coming from. I think that—so, just basic questions, you know. (Mother # 6)

Furthermore, when trust was present, primary caregivers felt reassured that if there was a change in the child's condition they would be promptly notified by health care providers. If the child's health status was deteriorating primary caregivers could return to the hospital to *be present* for the child.

In the ICU I, we might have once but even then I don't think we did number one cause he was paralyzed, number two it was one on one nursing. And every time I left it's like if anything happens phone me, phone, me, phone, me, phone me. They had my home number, they had my cell phone number, they had everywhere to possibly reach me. Um so and there because like I said its one on one nursing, there's somebody with him all the time, I didn't feel as bad leaving. It was safer to leave him. So you were able to go home and get some rest. We could go home, get rest and feel. Feel like he was actually being taken care of. (Mother # 4)

Without an established relationship certain participants were uncomfortable leaving their child. Some felt they would not be notified of changes that occurred in their child's health status or that the child would not receive adequate care. Without continuity of care, there may be difficulty in establishing a relationship and gaining trust in health care providers. Under such circumstances, primary caregivers were not at ease leaving the child and the need to *be present* was greater.

Continuity of care was also beneficial for health care providers as it allowed them to get to know the child. One primary caregiver commented on how nice it was that she did not have to go through the child's history upon subsequent admissions to the hospital as the health care providers remembered the child from previous admissions.

There was comments from a couple of them like, wow, she's grown so much. And yeah I mean they saw her when she was three months and then they saw her again when she was twelve, fourteen months. So it was nice seeing some of the familiar faces. I mean it was

neat too because a lot of the uh, a lot of the nurses remembered "N" when we came back because when you're in for a three, three-and-a-half week stay, yeah, you get familiar with the child. (Father # 2)

All primary caregivers appreciated having a familiar face when it came to their child's care and did not like adjusting to a new health care provider. Two primary caregivers commented on when they were transferred to a different unit from the PICU how frequently the nurses changed. These primary caregivers felt like health care providers did not know the child's situation as well as they should have. Additionally, it was tiring continuously establishing a relationship with various health care providers in order to develop a sense of trust in their ability to care for the child.

Every shift change you're dealing with somebody that has no idea about her situation and there, you rarely saw a familiar face and that was very, in Intensive Care it was a completely different story. Everybody knew her situation and knew of her risks and of her, kind of her story. (Mother # 2)

Finally, having one nurse to every patient contributed to continuity of care in the PICU. The one nurse to one patient ratio reassured primary caregivers that their child would be well looked after while they were off the unit. Moreover, primary caregivers could feel reassured that health care providers would *be present* with the child; however, when the patient load was heavier such as on the general care ward, health care providers were not able to *be present* with the child as they had to provide care to several other children. In these circumstances, several participants didn't want to leave their child's side and their need to *be present* was greater.

Um so and there because like I said its one on one nursing, there's somebody with him all the time, I didn't feel as bad leaving. It was safer to leave him; we could go home, get rest and feel like he was actually being taken care of. (Mother # 4)

Yeah, it was good. I stayed the first night there and then we just ended up taking turns, then we ended up going home because it was a one-on-one care and we were suggested to get your rest now, till you go up to the next ward. (Mother # 6)

Conditions Needed to Experience Family-Centred Care in the PICU.

The following section addresses research question number three of this research study which is:

3) What conditions need to be in place that will help promote family-centred care for primary caregivers who have a critically ill child in PICU?

Primary caregivers identified four conditions that must be in place and these include 1) being present for rounds, 2) caring behaviours, 3) feeling welcomed, and 4) support. These factors will be discussed in detail in the next section.

Being Present for Rounds

According to participants, presence during rounds consisted of being physically present with the health care team in order to partake in a collaborative effort around discussions on their child's plan of care. Being there during rounds gave primary caregivers the opportunity to *be present* by being physically present to collaborate with the health care team. Furthermore, being present during rounds satisfied primary caregivers' need to know and be updated on their child's status and provided the opportunity to ask questions around the child's plan of care. Finally, presence during rounds fostered continuity of care by facilitating the maintenance and development of relationships between primary caregivers and health care professionals.

*I was always there for rounds in the morning, I always made sure I was there for the uh cardiac rounds in the morning, like I would be at the hospital at seven in the morning and everything just because I wanted to know what was going on and I had questions.
(Mother # 4)*

Um, I think being as involved as you can. Like, with the morning rounds, that was very helpful for me. Just sort of understand and I thought they were really good about like letting me know that I could participate or I could be there, it was important. So I always made sure I was there for when they were doing them. (Mother # 7)

It was more family oriented. Cause you could have everyone in there and they, they did rounds with everybody in there. They didn't do shift change with everybody but rounds everybody was there, yeah. (Mother # 6)

While presence during rounds was beneficial for primary care givers, barriers existed such as having health care providers who were not supportive of this practice. In fact one participant was asked to leave during rounds and this participant felt alienated during a time when she needed to hear information about her child. She did not appreciate having to leave and felt this did not encompass family-centred care. All other participants however were invited to stay. Presence during rounds was an essential component to experiencing family-centred care in the PICU for primary caregivers.

So when they're divulging all the information about..... "R" and you want to be there. Even though I might not understand it I still take notes. , I was just feeling alienated during what I would say would be the most important thing that I needed to hear. (Mother # 5)

Caring Behaviours

Another condition that was essential in experiencing family-centred care in the PICU was having health care providers who demonstrated a caring behaviour. Primary caregivers defined caring as health care providers whose heart was in it. Primary caregivers appreciated feeling like the health care professionals truly cared for their child and that the care being given to their child was not just a job, rather something meaningful. When health care providers demonstrated caring behaviours, primary caregivers felt reassured health care providers would be there for their child and with the child when primary caregivers could not. There were several ways in which health care providers demonstrated caring behaviours such as being friendly and protective of the child.

They become very protective of what's happening to your child as well. So, I think that above all I knew that like after that incident I thought, you know what, if anything

happened, I knew that it would be taken care of You know, they would care for her the way that I would want her to be cared for. (Mother # 8)

There can't be—it's a job, right? And it's a caring—it's a typical job because it's a caring job, you need to care for your patients. (Mother # 6)

And uh yeah so it was funny that, and that's one thing that as much as we need to be advocates for our children like the nurses and the uh attendings are even almost more so protective of what happens. (Mother # 9)

Moreover, caring was experienced when health care providers considered primary caregiver's needs in addition to the child's needs. Participants appreciated being reminded to get some rest and sleep. When primary caregivers were rested they were better able to *be present* for their child. Without rest it was difficult to be there with and for the child due to exhaustion.

Or, or if they just told us to just go home and get some rest. Because by this time it was five in the morning or something silly like that. (Mother # 4)

And yeah I remember just, and, and the nurses informed us of that, you know they said, actually the last night that "L" was in PICU, one of the nurses said to me, you know you really should go home and sleep tonight, like I know you were here the whole time, but once they're up on the ward it's going to be different and you're going to have to be a lot more um, not involved but. (Mother # 1)

However, primary caregivers were not always given the opportunity to sleep at the child's bedside overnight. Primary caregivers could remain awake at the bed side however this was not ideal as many participants became exhausted from the emotions of having their child admitted to the PICU. Primary caregivers needed their sleep.

I guess the one thing I didn't like is you couldn't stay there. And everyone is very nice and, you know, helpful, but I didn't like that you couldn't stay there. If you wanted to stay there, you couldn't sleep there, I guess, so—can't be in the room with her all the time, right? I mean, you could if you wanted to stay awake around the clock, stay up all night, and so forth. And then having kids at home, which is understandable too, but they wouldn't allow anybody to come in, so, which is understandable too, but still, that was sort of the separation. (Mother # 7)

One participant had experienced a caring gesture from a member of the housekeeping team who came to offer some help. This helping gesture contributed to a caring environment from all members who worked on the unit, and not only those team members involved in direct patient care.

You know what I can't say enough about the place, it was really, except for the part that my son was sick on a ventilator. The staff were just amazing. You know and, and I, I really just, you know I remember even the people who came in and cleaned the floors being just gentle and kind and helpful. You know and not to say every person certainly, like but I just remember one person in there cleaning the floors saying oh can I get you something, maybe it was the remote control for the TV, oh, oh that's right cause I think the remote was outside the room. And I couldn't change the channel, like you could sort of do it through the window, and he said well I'll go wrap it up for you and I'll get it for you. Yeah, no I thought everybody was really, was really great that way. (Mother # 9)

While caring behaviours were always appreciated, participants felt that some health care providers were more caring than others. For many participants the level of care the child received was dependent on who was looking after their child. Participants felt some health care professionals portrayed being a nurse as just a job and felt these care providers did not always demonstrate a caring behaviour.

When you're there or even just like the, and like I said I think it almost seemed like it was dependent upon who the nurse was, like do you, do you need a cracker (chuckle) I've got some crackers, you know but. (Mother # 1)

It did. Some of them were a little bit more um, not welcoming, I shouldn't say it like that but some of them more definitely more encouraging like. Because at the time I mean after the second or third stay I knew kind of what I was allowed to do and I felt more comfortable approaching her. Whereas uh during that first day I kind of just waited and to see like If the nurse would ask me if I wanted to take part in because I didn't, I didn't want to make them feel uncomfortable either. You know? That I'm hovering because uh Really you're sitting, staring, watching them do their job and I'm sure that can be intimidating. (Mother # 8)

Not even just the familiarity, the, the level of care that they were giving. Like it was plainly clear that some of them took their job to their heart. And others it seemed to be just a job. As opposed to people that are just like when's my shift done. Whereas

someone that's just doing it for a job. Or you know it's a, it's just a way of getting by. You can tell that the care level changes. (Father # 2)

While varying personalities cannot be changed, the level of care being given to the child must always be at heart. Participants felt that demonstrating a caring behaviour was the nature of the job in the PICU and that health care providers should always be aware of their behaviours while caring for their patients. When caring behaviours were lacking, participants were less comfortable leaving their child as they felt that health care providers would not *be present* for their child upon leaving the unit. Participants also appreciated those health care providers who went above and beyond to meet their child's needs by doing extra little things. These extras included taking the time to do things health care providers thought would make the child and the family happy.

Um they would start to get me to like "S", oh she was cute, she did footprints of "J" and casted his feet and stuff like that. Which was really sweet, you know, you know that those are things that they do for parents when things are not going well, I know that. But the fact, I mean I knew that, we were going for surgery the next day and she, it, it became like a, the whole, everybody got involved in it, cause everybody knew "J". (Mother # 3)

And then the nurse asking me what kind of music does "W" like and, and he's eighteen months old you know, but we've been listening to Coldplay and I said well "W" and his sisters kind of like Coldplay, he said oh I got some Coldplay, so he put some Coldplay on for, for him to listen to. And so um everybody was awesome. (Mother # 9)

Finally, health care providers demonstrated a caring behaviour through having a good bedside manner. Participants appreciated when health care providers were professional at the bedside, sensitive, and respectful to the child and family's needs. Some primary caregivers felt care providers' assessments when the child was sleeping could have been done in a more respectful and quiet manner. While primary caregivers understood that assessments on the child were necessary, the way care providers went about their assessment was impactful.

Um I mean it doesn't have anything to do with the nursing, but we did have a neurologist who came in who had a horrible bedside manner cause "L" wasn't uh, wasn't responding. And so we had uh two neurologists, one was a lady I can't remember her name but she was really good, and then we had this other man and he would come in and you know shine the flashlight in "L's" eyes and (chuckle) he was like "L", "L" can you hear me, and I was just like oh my god if that was me and someone was yelling at me like that (chuckle) I wouldn't answer either. And so like the room was usually dark and pretty peaceful right and, and whatever a soothing environment and then all of a sudden he would just come in and flick the lights on and "L" with a flashlight, and he says, I think maybe the lights are bothering him and I said, maybe try turning off the lights and he did, and then "L" ended up opening his eyes for the first time. (Mother # 1)

And we noticed like there was some nurses who would come in and be very respectful of the fact that um you know he's sleeping or it's, like I know vitals and all these things need to be taken regularly and all the time, but there literally would be people would like flick on the light, wheel in and do everything and then there were others who would you know quietly open the door. (Mother # 1)

Support

Support was another condition identified by primary caregiver's that contributed to family-centred care in the PICU. Support was defined by primary caregivers as having someone they cared about by their side during their child's stay in PICU. Support enhanced participants' ability to cope with the devastation of having their child in the PICU. Coping allowed primary caregivers to *be present* for their child by being strong. If primary caregivers were not able to cope, they may not have been strong enough to *be present* and be there for and with their child. There were several ways by which primary caregivers experienced support during their stay in the PICU. Several participants had support from family members including spouses, parents and siblings. It was helpful when these family members could be at the hospital with primary caregivers; however, visitor restrictions in the PICU were a barrier to having other family members be there for them.

I know normally they um in PICU they don't really like having especially cause he was query H1N1 they don't like having um other people, outside people other than immediate family there. They did end up making an exception for my mom to come. (Mother # 9)

Another way by which primary caregivers had support was by having family available to look after the siblings of the critically ill child. This allowed primary caregivers to focus on their sick child and spend more time at the hospital while feeling reassured their other children were being looked after. Not all participants however had support and one participant needed to bring her other children with her to the hospital as she did not have the support at home. Another participant did not initially take help that was being offered which contributed to feelings of stress and anxiety. This participant thought she could cope on her own and felt overwhelmed upon experiencing difficulty with coping. This reinforces the importance of taking help when it is offered. While most primary caregivers were grateful for the help they received some participants found it difficult having family members as a support. Several primary caregivers felt their family members did not truly understand what they were going through because these family members had never experienced what primary caregivers were going through.

When "C" was in the ICU one time I ran into a friend of mine in the hospital, I says oh yeah you know "C" he's having a bit of a rough time right now and he's uh, he's in the ICU, she's like oh yeah I know what that's like, we had to spend a night on the ward when my daughter had ear tubes put in, I'm just like yeah that's the same. So it's kind of like you need somebody, like nobody really ever fully understands. (Mother # 4)

Just you know I had nobody, like nobody, our families, nobody in our family has a special needs child, nobody knew what we were going through. (Mother # 5)

Furthermore, some participants were offered a support group to help assist with coping. These participants appreciated having support from someone who had previously experienced being in the PICU and could empathise with them and truly understand what primary caregivers were going through.

They don't get it, somebody who's been there. Been, done, been there and done that, it's like yes, I can tell you, I know what you're going through. I know those feelings are real. I can validate those feelings. Almost like it would be like a grandmother talking to the first time mother, yes it's going to be okay, you're going to get through this. (Mother # 5)

Um I guess if, for caregivers if they could be put in touch with other people who have gone through like the same kind of thing. Just for, just for that support and just for um like I said because then they both know and they both get it. And you know this is what I did and did you find this and but you know you say that to your parents and it's just like oh well I'm sure they're doing the best they can. And its, it's just, it's different. (Mother # 4)

While many participants felt the support from other primary caregivers who previously had a child in the PICU helpful, the engagement in support was difficult initially. This difficulty was experienced by those participants who did not feel ready to talk about what was happening with their child. However, once primary caregivers had a better idea of their child's prognosis and had developed a relationship and trust with health care professionals, primary caregivers felt more at ease talking about their experience with others.

I kept thinking how am I going to go to a support group and talk about my baby that has a heart defect when they don't even know what's wrong with him. I couldn't wrap my head around, how am I supposed to talk about something I don't know anything about. (Mother # 4)

At first, at first honestly I didn't want to see anybody extra, I didn't want to talk to anybody, I didn't want to, like they even have I know between the PI and the NI or especially I guess the NI and the T1 that they have the family support group meetings and stuff like that, I wanted nothing to do with anybody. Like um so the first time, no I didn't want anything to do with them, but after that I sort of relied on them to say you know like is okay if you want to just step out or if you know to go to the...you know that kind of thing. (Mother # 8)

it's just my personality, like they kept saying, you should, you should partake in the support group and I was like no, no, you don't know me, that's not my style, I'm not going to, yeah I just was, I think I was really hard on him (chuckle) um in the beginning especially, once I got to develop a relationship with him it was a bit different but . You know it's one more admission that something's wrong. And that's hard to do that. (Mother # 3)

One participant also mentioned how being offered support after the child's discharge from hospital would have been helpful. The whole PICU experience can significantly impact primary caregivers after being discharged.

Um, and I mean, it's very emotional. Like, I still kind of carry it with me a little bit too. So I mean I think, um, it's good to just make sure, I guess, that you're, um, supported as well, you know, afterwards, because it's very, like, make you fatigued when you only have two people that can kind of go in and out of there with her all the time. (Mother # 5)

Having support after discharge could assist primary caregivers in coping with feelings of anxiety and feeling overwhelmed from their PICU experience.

Feeling Welcomed

Finally, feeling welcomed on the unit was another factor necessary for primary caregivers to experience family-centred care in the PICU. Feeling welcomed was defined by participants as feeling comfortable while on the unit. Being comfortable made primary caregivers feel like they wanted to be on the unit thus they could *be present* and be there with and for their child. When primary caregivers did not feel welcomed, *being present* was more difficult. Primary caregivers felt welcomed on the unit by knowing where they could go and what their boundaries were. Participants also felt that having their basic needs met was also important in making them feel welcomed. Participants wanted to know where they could shower, wash up, eat and go on line to check e mails. Clarifying where primary caregivers could go would have contributed to feeling welcome on the unit.

Then I think I would have almost felt a little bit more comfortable where, where the boundaries are. Yeah, like you don't even know okay so can I be here for rounds, can I not be here for rounds, am I allowed to use that phone, can I not, like am I allowed to ask to care for her, am I stepping on someone's toes or you know can I request for any number of things. (Mother # 7)

And no one kind of coming up to you and saying, hey you know what there's a place for you to come and shower. Or there's a place for you to come and do this. Those first few days and so I think um looking back it probably would have been helpful to know what options there are for us, where to go, where to be. You know where can I go to get online to email, send out an email about what's happening or where do I go to...Or to eat or.
(Mother # 1)

It was, and the bathroom because that's the only bathroom there, it would be nice if there was a bathroom on the other side that parents could use. Yeah cause you'd have to leave to go into the waiting room, then you have to be buzzed back in, like that was a bit, you felt like, I felt like a nuisance sometimes to the desk if I would do that and I would always leave to go grab some lunch or stuff like that. So you don't want to become a nuisance, so it would be nice if there was a facility that a parent could use, but I know, I mean.
(Mother # 3)

Moreover, primary caregivers would have felt more welcomed by having better sleeping accommodations. Participants were not encouraged by health care providers to remain in the room with their child overnight despite wanting to *be present*. Several participants did not know where they could stay for the night and did not want to go home or be too far from their child. Having the option to stay on the unit overnight would have allowed participants to *be present* for their child and make them feel more welcomed.

Um oh gosh that was probably the biggest one in PI at the time, because the fact that you that we couldn't sleep there right because they don't have a bed. I mean you could stay and sit in a chair all night, but really. A tired mom doesn't help right. So that would have been nice had they had like a cot just like you have in the wards. (Mother # 3)

Participants also felt more welcomed on the unit by having privacy. Privacy included having single rooms with adequate space to place personal belongings. However, not all primary caregivers felt they had enough space. In fact, one participant commented on how the limited space made her feel like she was sharing her experience with other families on the unit. Primary caregivers wanted space to grieve and let out their emotions especially when times were critical; however, this was not always possible.

According to participants, the PICU waiting room was not welcoming and the room felt cold and plastic. Several participants commented on how dirty the PICU waiting room was from so many people coming and going. Many participants felt the waiting room lacked comfort and privacy. Furthermore, primary caregivers commented on the lack of comfortable chairs to sit in while in the waiting room.

It wasn't a big room either, like there was a couple of people in there. We kind of found the room small for multiple families if they were there at the same time. (Mother # 5)

Its, it's very plastic, it's very uncomfortable, it's um, it's um, it can get dirty because some other parents come in there. And they don't care about leaving their garbage and everything all around and it's, yeah sometimes you just kind of go okay let's go to the cafeteria instead. (Mother # 4)

Finally, participants would have felt more welcomed on the unit by having somewhere to relax and escape from what was going on, while still being close to the child. Perhaps a room within the hospital that was comfortable and offered some privacy for families could have been beneficial.

Its just, it's not a, a comforting place, like if your child's in the ICU it's not a comforting place to go and just like, something like this would be nice, you could kind of go uh okay, let's just kind of sit and regroup and whatever. (Mother # 4)

Chapter Summary

Chapter five presents the reader with a description of the research findings. A demographic profile of the research participants and children who were admitted to the PICU was presented. This was followed by a discussion on the essence of the lived experience of primary caregivers in the PICU which was *being present*. Themes that communicated the substance of the essence were described as physical presence, participation in care, and advocating. Primary caregiver's definition of family-centred care in the PICU was presented.

Themes that defined family-centred care included collaboration, knowing, and continuity of care. Many primary caregivers had learned from their experience in the PICU and had input into how their experience could have been better. Factors that primary caregivers felt needed to be in place to experience family-centred care included being present for rounds, caring behaviours, feeling welcomed, and support. The following chapter will be a discussion of these findings.

Chapter Six: Discussion of Findings

Chapter six presents a discussion of the findings from this study. The purpose of this phenomenological study was to arrive at an understanding of the lived experience of family-centred care of primary caregivers who have had a child admitted to the PICU. The essence and themes supporting the essence are presented followed by p
rimary caregiver's definition of family-centred care. Factors that need to be in place to experience family-centred care in the PICU are discussed and compared to past and current literature. The methodological strengths and limitations of this study are presented with recommendations for nursing practice, education, and research.

Being Present

The essence of the lived experience of primary caregivers who have had a child admitted to the PICU is described as *being present*. The concept of presence has been in the nursing literature for decades; however, difficulty remains in defining the concept. This difficulty may stem from the concepts intuitive and subjective nature or its multiple meanings within the nursing literature. For the purpose of this study, *being present* was adopted from Woodgate who has conducted a great deal of research around presence in nursing. Woodgate and Degner (2003) conducted a study on children with cancer and discussed how families were able to “keep their spirit alive” through being present with their child. This was especially important in helping families and their children get through difficult times. Similarly, in a study on sibling's experiences of childhood cancer, siblings expressed a greater desire to be present with their family to maintain a connection and a sense of belonging in the world. This presence was achieved by being with their parents and their siblings who had cancer (Woodgate, 2006). Furthermore, in a study on social support by adolescents with cancer, being there was a

component of being present. Being there was more than a physical experience consisting of a psychosocial and emotional component in addition to a physical component (Woodgate, 2006). Similar to Woodgate, participants from this study defined *being present* as being there for their child and being there with their child. Being there with their child included a physical presence which allowed primary caregivers to see firsthand what was happening with their child. However, primary caregivers felt that *being present* had a deeper meaning than just a physical presence. This was evident when participants talked about the need to be there for their child. Participants were there for their child by participating in the child's care activities, being a part of decision making and advocating for their child. Experiencing *being present* as more than a physical presence is consistent with the findings from several other authors including Paterson and Zderdard (1988) who contend *being present* includes a humanistic component and encompasses devotion to another. Similarly, Easter (200) states that presence consists of something physical, psychological, and spiritual. The physical component includes a body-to-body presence, the psychological component consists of being present in mind, and the spiritual component encompasses holism and spirituality. Primary caregivers did not specifically refer to psychological and spiritual presence; however, it was implied through being there with their child and being there for their child. Primary caregivers' definition of presence is also consistent with Avery (1986) who states an essential component of presence is being there. Common characteristics of being present that were noted by Avery (1986) included touching, intimacy, caring and recognition which were all common characteristics seen from the primary caregivers who were interviewed in this study. Additionally, Osterman describes four ways of being present as measurable constructs and separates the characteristics of presence as being partial presence and full presence (1996). There was no mention from primary caregivers about levels of

presence, rather being present was considered two separate entities; primary caregivers were either present or they were not present.

Being there for the child reassured primary caregivers and allowed them to cope with the devastation of their child's admission to the PICU. According to Pettigrew (1996), one of the outcomes of presence is an enhanced coping ability for primary caregivers. Similarly, Olsen, Dysvik and Hansen's study on family member's presence in the ICU revealed that *being present* reassured family members that their loved one was getting good care and it allowed them to be updated on the patient's health status (1998). Maxton (2008) also commented on parental experiences in the PICU and how *being present* provided comfort, support and reassurance for parents. This reinforces primary caregiver's need to be present at all times during their child's admission to the PICU and demonstrates the positive impact being present has for primary caregivers.

Participants had a greater need to *be present* when their child was more acute and their child's prognosis was uncertain. This is congruent with studies on presence during resuscitation where parents wanted to be with their child under all circumstances. A child undergoing resuscitation has a very uncertain prognosis, thus the need to be present with their child was greater for parents in these studies (Dingeman et al., 2009; Duran, et al., 2007; Guzetta et al., 2006; Maxton, 2008; McGahey-Oakland et al., 2007; Tinsley, 2010; Vander Wonning et al., 1999). Additionally, when the admission to the PICU is unexpected and the child is in critical condition parents experience greater feelings of stress, uncertainty, fear, and helplessness (Eberley et al., 1985; Myer et al., 1998; Stanik, 2005). Primary caregivers who had a child in the PICU did not want to leave their child's side until the child's prognosis was known. The only

exception was leaving the room during invasive procedures and when primary caregivers were asked to leave for the night.

Presence was also defined in the literature as a reciprocal process (Paterson & Zderdad, 1988); however, reciprocation was not always evident in this study. While some participants felt the child could sense their presence, there were no concrete signs from the child to acknowledge this perception. The children were often sedated, unconscious or sleeping, reducing awareness of their surroundings. Despite the lack of reciprocation, *being present* was still therapeutic for primary caregivers.

The literature consistently states that parents want to *be present* with their child at all times (Beckman et al., 2002; Boie et al., 1996; Maxton, 2008; McGahey-Oakland et al., 2007; Tomlisson et al., 1999); however, this was not always true for primary caregivers in this study. Some participants chose to leave their child's room during invasive procedures from feeling overwhelmed by witnessing procedures done on their child. When procedures were more invasive, primary caregivers were less likely to stay with the child and wanted the freedom to come and go from the unit.

Although a great deal of studies on presence within the nursing literature focus on the nurse patient relationship, (Easter, 2000; Godkin, 2001; Hessel, 2009; Hines, 2001), information and knowledge gleaned from these studies can be transferred to the parent-child relationship. However, there is a need for more research on the meaning of *being present* in the PICU setting and the effect presence has on primary caregivers. If parents are to recover from the crisis they experience when their child is admitted to PICU, they must be able to understand the child's health status and become involved in care (Farrell, 1989) which is accomplished by *being*

present. Health care providers are in a position to encourage presence to enhance primary caregivers' coping mechanisms and increase their satisfaction with care. Primary caregivers from this study experienced presence by having a physical presence, participating in the child's care and advocating for their child. These methods of being present will be discussed in further detail and compared to the literature next.

Physical presence

Physical presence fulfilled primary caregivers' need to *be present* and be there with their child. According to primary caregivers, physical presence was experienced by being in the same proximity as the child including visual contact to see what was happening with their child. Recent literature also recognizes physical presence as an essential part of *being present* (Dingeman et al., 2007; Easter, 2000; Mangureten et al., 2005; Shandor & Miles, 1982). For primary caregivers, physical presence decreased feelings of loneliness and isolation and provided a sense of encouragement and reassurance. Physical presence also fostered the connection primary caregivers shared with their child, especially in circumstances where they are not in control. The unique connection experienced between the parent and the child must not be interrupted especially in situations of uncertainty (Dingeman et al., 2007; Giganti, 1998). A connection is maintained when primary caregivers can physically hold, touch or talk to their child and is defined as the sharing of personal space with a relative (Van der Woning, 1999). Meert's study on parent's experiences in the PICU demonstrates how breaking the unique parent-child connection can exacerbate feelings of emotional distress and anxiety as parents feel like they are abandoning their child upon being asked to leave (2009).

Primary caregivers felt that being there for their child was beneficial for both themselves and their child. Primary caregivers felt their child could sense their presence despite the inability

to communicate. Participants also felt that they were contributing to their child's well being. This is consistent with a study by Tinsley et al. (2010) on families experience during CPR in the PICU where parents felt that being present gave their child strength to survive (2008). Similarly, Ditcher (2008) conducted a prospective observational study looking at toddler's responses to the separation from their parents upon admission to the PICU. The child's heart rate was continuously monitored and increased upon separation from the parent reinforcing the need to maintain a connection with the child with physical presence.

According to primary caregivers, physical presence also included touch. The ability to touch and hold their child was beneficial for them and fostered the connection primary caregivers experienced with their child. This is consistent with a study by Tinsley, et al., (2010) on parent's perceptions of presence during resuscitation where it was noted that 67% of participants felt comforted by touching their child. Similarly, a study by Rennick et al., (2011) on a talk and touch intervention in the PICU revealed that parents who were able to talk with and touch their child felt more reassured than parents who could not have any contact with their child. Furthermore, a major theme in a study on family needs in the ICU by Mitchel and Chaboyer (2010) included the ability to have physical contact with a loved one creating a positive experience for both the family member and the patient. The information gleaned from these studies is congruent with primary caregivers' experience in the PICU. While touch was a positive experience, it was not always possible due to the constraints of the PICU environment. Some primary caregivers were required to wear gowns, gloves, and masks for isolation purposes preventing participants from getting close to their child. Increasing health care providers' awareness around the benefits of physical presence is essential. Primary caregivers must be encouraged by health care providers to remain present with their child in the PICU.

Participation in Care

Participation in care allowed primary caregivers to *be present* to be there with and be there for their child. Participation in care was described by participants as being actively involved in care activities related to the wellbeing of the child. It was noted however that there must be consensus with health care providers on which care activities the family would like to be a part of. Participation in care has various meanings within the profession of nursing including sitting passively by the child's side while care is delivered by health care providers or being actively involved in the child's care activities with minimal assistance (Frank & Callery, 1991). The latter is consistent with participants' definition where an active role in their child's care was preferred. Participation in care significantly decreases parental stress levels and promotes coping (Frazier, 2010; Just 2005; Mitchel & Chaboyer, 2009; Seidman et al., 1997).

Despite participant's need to be a part of their child's care, the technology of the PICU may pose barriers in the provision of care. Parents may struggle with how to best help take care of their sick child in an unfamiliar environment (Haines et al., 1995; Just, 2005). Primary caregivers from this study did not know what their boundaries were on the unit and were consequently reluctant to participate in their child's care for fear of overstepping their boundaries. This concern is congruent with the findings from a study by Seidman et al., (1997) on parental stressors and coping strategies in the PICU where parents struggled with how they could best participate in their child's care in such a foreign environment. However, guidance from health care professionals will enable primary caregivers to feel welcome on the unit and to know how they can best care for their sick child. When primary caregivers cannot be a part of their child's care, feeling of helplessness and powerlessness develop as primary caregivers are used to being the protector of their child. Previous to the child's admission to the PICU, primary

caregivers provide the child with care and guidance; however, this role changes upon admission to the PICU. The highly technological environment of the PICU creates an interruption in primary caregivers' responsibilities and they must give up a piece of their role to machines and hospital staff causing distress. This change in primary caregivers' roles is referred to as role alteration. This role alteration may lead to role conflict whereby conflict occurs over the development of a new role in relation to the child's care (Lewandowski, 1980). In fact, several studies on parental stressors in the PICU claim that one of the major stressors for parents upon the admission of their child to the PICU is the alteration in their role as caregiver to their child (Carter & Miles, 1989; Ferrell, 1989; Jay, 1987; Johnson, 1990; Miles et al., 1989; Rennick, 1986; Seidman et al., 1997; Tommilson et al., 1999; Woodfield, 1997). However, involvement in the child's daily care regime allowed primary caregivers to maintain their role as caregiver to their child.

Jay (2005) refers to role revision whereby parents give up their role of being a parent to a healthy child and take on a new role to an acutely ill child. One primary caregiver who was interviewed found it difficult caring for her critically ill child and wanted to be caring for her son the way other mom's were caring for their healthy child. Mitchel & Chaboyer, 2010 contend health care providers can assist with this role transition by empowering parents to take on the challenging new role. Similarly, in a study on maternal self efficacy on participation in the care of the critically ill child, it was noted that mothers were more satisfied when they were empowered to be a part of the child's care. According to Algrean (1985), not all health care providers support parental participation in care which is consistent with what primary caregivers experienced at times from health care providers in the PICU. Health care providers and primary

caregivers must work as a team to establish a regime in the provision of care to the critically ill child offering primary caregivers a sense of belonging in the PICU.

Advocating

Another component of *being present* identified by primary caregivers included the ability to advocate for their child. Primary caregivers in this study wanted to be the voice of their child. Children in the PICU are often too sick and too young to make decisions around their own care. Furthermore, many children are sedated, unconscious and are unable to make appropriate care decisions. Participants felt strongly about making decisions on their child's behalf. Advocating allowed primary caregivers to be there for their child as they felt they knew their child best and knew what their child's needs were. Primary caregivers' desire to advocate for their child is consistent with Myer's (2010) study on parental experiences in the intensive care unit where parents had a need to remain the primary advocate for their child. However, as the child became increasingly ill, their ability to be decision makers decreased. Thus there was greater difficulty in being there for their child under such circumstances. When parents are no longer the primary authority figure in their child's life, they grieve the loss of this role and place trust in the health care providers who are looking after their child. It is these professionals who become temporary decision makers until the child becomes more stable (Vandal-Walker et al., 2010).

Participants also felt advocating included having their concerns addressed. This is similar to a study on parental needs in the PICU by Farrell (1998) where parent's ability to advocate and have their concerns addressed was a major theme. Primary caregivers from this study felt they knew their child best and knew what their child needs were. These primary caregivers experienced frustration when they felt they were not being listened to. Vandell-Walker et al. (2010) study on nursing support for family members of critically ill patients demonstrated that

some parents experienced difficulty voicing their concerns. Family members were apprehensive about reporting errors and voicing their concerns and did not want to be seen as complainers. These family members also feared their loved one's care may be compromised if they complained. Contrary to Vandell-Walker et al., primary caregivers did not appear afraid to voice their concerns and opinions. Furthermore, when concerns were not addressed primary caregivers felt like they were not being listened to. If concerns were appropriately addressed however, primary caregivers felt more reassured contributing to a more positive hospital experience.

Family-Centred Care

Three themes emerged from the interview data on how primary caregivers of this study define family-centred care. These themes include: 1) collaboration, 2) being updated, and 3) continuity of care. These themes are discussed and compared to the literature in the next section.

Collaboration

Collaboration was an essential component of family-centred care identified by participants which is consistent with Shields and Tanner's study on family-centred care in the PICU (2004). Primary caregivers experienced collaboration by working as a team with health care providers and being treated in a non-hierarchical manner where there was mutual respect for all members of the team. Team work included participating in decisions around the child's plan of care which allowed primary caregivers to *be present* and be there for their child. The American Academy of Pediatrics (2003) states that collaboration among patients, families, and the health care team improves decision making capacity around the child's care and improves patient outcomes. While healthcare professionals possess clinical knowledge, primary caregivers are able to meet their child's emotional needs contributing to a more holistic approach to care.

Thus, it is essential health care providers work collaboratively with families in the decision making process in addressing the child's needs.

When primary caregivers were not included in decisions being made around their child's care feelings of distress were experienced. One participant talked about how she felt alienated during a time when she needed to be there for her child the most. This is consistent with Henderson and Knapp (2006) who also claim that parents want to be a part of the decision making process around their child's care and become distressed if they are not.

Presence during rounds also enhanced primary caregivers' ability to be a part of decisions being made around their child's care. Presence during rounds assured primary caregivers that they were getting the information they needed and allowed them to collaborate with all health care team members. Jacobowski's study reinforced how family presence during rounds in the ICU contributed to families' ability to be adequately updated by receiving the most up to date and comprehensible information on their loved ones health status (2010). In fact rounds is the most common method of information delivery in the intensive care setting (Aronson, Yau & Morrison, 2009; Jacobowski, 2010). Presence during rounds was an opportunity for primary caregivers to be introduced to the health care team and set the basis for the development of a relationship with health care providers. When a relationship was established with health care providers, primary caregivers felt more at ease asking questions and providing input about their child. Primary care givers in this study were not always comfortable asking questions; however, being present during rounds was helpful in this matter. Rounds were also an opportunity for the team to discover new information about the child and for primary caregivers to learn the unit's daily routines and culture. According to Aronson and colleagues (2009), primary caregivers feel

more supported and informed upon collaboration and presence during rounds as compared to those who were not a part of rounds.

Furthermore, Aronson et al. discuss barriers to collaboration such as a lack of support from health care providers. It was noted that health care professionals expressed concern that rounds would be lengthened if family was present. Moreover, the dissemination of bad news among a large group of people was another concern of health care providers (2009). Despite these barriers health care providers must encourage presence during rounds fostering collaboration and offering an exchange of information benefiting both primary caregivers and health care professionals.

Similar to being present, collaboration should be a reciprocal process whereby health care providers and primary caregivers equally benefit (Frazier, & Warren, 2010; Tughan, 1992; Woodfield, 1997). It was not possible in this study to witness reciprocation as health care provider's perceptions on collaboration were not explored; however, collaboration was important to primary caregivers in receiving quality care and having their needs addressed.

Being Updated

Another way by which primary caregivers defined family-centred care was by being updated, which was described by participants as having the information they needed about their child's condition. Primary caregivers wanted to be updated as frequently as possible and in terms they could understand to *be present* and be there for their child and. Myers et al., (1998) noted that being updated allowed parents to ascribe meaning to their child's illness and was especially important when the child was most critical and prognosis was uncertain. This is consistent with Seidman et al. (1997), and Farrell (1989) who contend that the need to know in the ICU is

especially important in times of uncertainty. When primary caregivers did not know what was happening with their child feelings of stress and anxiety was experienced. However, frequent updates from health care providers on the child's status provided has been noted to offer reassurance to parents that their child is still alive enhance caregivers' ability to cope with having a child in the PICU (Haines, 1995; Hickman et al., 2010; Sinjari et al., 2009).

Attention to communication is essential upon updating primary caregivers on their child's condition and plan of care. Effective communication enhances primary caregiver's ability to understand the child's condition especially with the use of complex medical terminology which can lead to confusion. Additionally, encouraging primary caregivers to ask questions is essential and will contribute to a better understanding of their child's illness. However, primary caregivers commented on how they did not always feel welcome to ask questions. Holmes (2004) discusses her personal experience as a parent in the PICU and recalls how she felt reluctant to ask questions for fear of upsetting the health care providers. Travertine's study on communication in the ICU reinforces how parental anxiety was decreased upon being encouraged to ask questions about the patient's status (2002). Interestingly, while many primary caregivers from this study were reluctant to ask questions, one participant with a chronic child who was frequently admitted to the hospital was more comfortable with asking questions. In fact, research has shown that parents of children who have frequent hospital admissions are more at ease asking questions about their child's status in comparison to those parents of children experiencing their first hospital admission (Myers et al., 1998). The enhanced comfort level may be a result of parents' familiarity, comfort, and confidence in communicating and interacting with hospital personnel.

Upon being updated several primary caregivers from this study felt overwhelmed upon receiving information about their child's condition and health status. Several participants

benefited from having support from another family member. This support was helpful to assure important information was not missed during the dissemination of bad news. Several participants commented on how they could not process information being given as a result of emotional distress. Although having a support person to listen upon being updated is helpful, visitor restrictions may pose a barrier to having other family members involved in the dissemination of information. A more open visitation policy would be helpful in addressing this issue.

Primary caregivers also expressed a need for frequent and honest updates on the child's health status and to be informed promptly of any changes. This is consistent with Gavin (2000) who reinforces the importance of giving honest and frequent updates to parents on their child's status to enhance parental coping. While health care providers may be reluctant to update families, the literature reinforces that parents want to be informed under all circumstances including the dissemination of bad news (Farrell, 1989; Holmes, 2004; Meert et al., 2009; Tomlinson, 1999). Primary caregivers felt at times that information was being held back. Health care providers may have held back information for fear of upsetting primary caregivers; however, primary caregivers wanted to be updated under all circumstances.

In communicating effectively, information must be relayed in a timely manner and must be given in terms that primary caregivers can understand. While several professionals may be involved in updating the family, attention must be given to assure consistency in information delivery to avoid confusion (Miles and Carter 1982). Updating families about tests and treatments as well as the extent of the child's illness are also essential (Petersen, Cohen and Parsons, 2004; Traveline, 2002), however, it has been noted that health care provider often do not update families frequently enough and the communication used in practice needs great improvement (Nolan et al., 2007).

Continuity of Care

Family-centred care was also defined as continuity of care which was described by primary caregivers as consistency in care. This consistency entailed having the same health care provider looking after the child as much as possible. Continuity of care was important for the development of relationships with health care providers. A relationship allowed primary caregivers to gain trust in health care providers and when trust was established, participants felt more at ease leaving their child upon taking a break or leaving the child's side. Continuity of care provided primary caregivers with confidence that the health care provider would *be present* for the child when primary caregivers were not there providing them with comfort and reassurance. This is consistent with Stanik (2005) and Myer et al. (1998) who state that consistency of staff is important for the development of a healthy relationship and trust in health care providers.

Continuity of care could be enhanced by assigning the same nurse to the same patient. However, this consistency is not always an option as nurses work shifts, have earned days off and may be assigned to other patients on the unit to accommodate work flow (Frazier & Warren, 2010). Furthermore, in a study by Graham, Dvora, Pemstein & Curley (2009) one parent commented on how frequently nurses and attending physicians in the PICU changed creating difficulty in maintaining a relationship with these health care providers. Primary caregivers felt that adjusting to a new nurse was difficult and often stressful. Some participants felt like they were starting over again by getting to know the person looking after their child which can be a daunting task.

Additionally, when continuity of care was lacking, the information being given to the family could be misunderstood (Vandell-Walker et al., 2010). It has been suggested limiting the number of health care providers who interact with the child and family to prevent confusion and to more effectively meet the needs of the child (Ebrerly et al., 1985; Pointin & Lewis, 2008;). However, this is not consistent with what primary caregivers defined as collaboration where multiple individuals partake in the care of the child. Additionally, children who are critically ill in the PICU often have complex medical needs due to the acuity of their illness and require care from multiple health care professionals (Gill, 2005); therefore, limiting the number of health care professionals that interact with and care for the child is not an option. In fact primary caregivers appreciated having a multitude of professionals involved in their child's care providing reassurance their child was getting the best possible care.

Continuity of care was enhanced by having one nurse for every patient which provided primary caregivers with reassurance their child would be well looked after. One primary caregiver from this study realized how much she appreciated having one nurse to every patient since the regular care ward was drastically different. Upon being transferred to a non intensive care ward the nurses had a larger patient assignment which was less reassuring for primary caregivers as every shift there was a different health care provider looking after their child. Additionally, on the regular care unit the nurses had more than one patient to look after which took away from nurses ability to have close contact with the child. Thus primary caregivers were more reluctant to leave their child's side which contributed to feelings of exhaustion.

While continuity of care can be difficult to attain in an environment such as the PICU where there is a high turnover of patients and high acuity, health care provider must be aware of

the benefits continuity of care provides for primary caregivers and their children and attempt to maintain consistency in care providers.

Factors Needed to Experience Family-Centred Care in the PICU

The following section describes factor that need to be in place for primary caregivers to experience family-centred care in the PICU. These factors include: 1) feeling welcomed, 2) caring behaviours, and 3) support. These factors are discussed and compared to the literature in the next section.

Feeling Welcomed

Feeling welcomed on the unit allowed primary caregivers to experience family-centred care in the PICU and was defined as feeling comfortable to *be present* on the unit. There were several ways by which primary caregivers could have felt more welcomed on the unit. Participants suggested having an orientation to the unit upon their child's admission to the PICU to establish boundaries and open lines of communication with health care providers contributing to a more family-centred approach to care. According to primary caregivers, an orientation could include a tour of the unit with an introduction to other health care professionals involved in the child's care. Additionally, primary caregivers should be made aware of the resources available to them such as support from other disciplines, the unit's phone number and where they can go to get sleep and meet their basic needs. This is consistent with Amico and Davidhizar (1994) whose study on parental needs in the PICU revealed parents wanted an orientation to make them feel more welcomed on the unit. Primary caregivers wanted to meet their basic needs and know where they could shower, sleep and eat. While an orientation to the unit is beneficial, it can be

difficult to provide as health care providers are busy with direct patient care when the child is initially admitted; however, an orientation can be helpful once the child is stabilized.

Privacy also enhanced comfort on the unit and made primary caregivers feel welcomed. However, primary caregivers commented on how there was a lack of privacy on the unit and in the waiting room and reinforced the need for a private space to let out their emotions, grieve and have somewhere to escape. Privacy is often difficult to provide for families due to the nature of the PICU environment. Privacy is frequently lacking in the hospital waiting rooms and sharing an environment with unfamiliar people, who are upset and crying can create additional distress for parents (Hickey & Lewandowski, 1988; Neal et al., 2007). Primary caregivers also commented on the lack of space in the PICU. More space was needed to put their personal belongings and to remain with their child. In some cases, curtains were used for privacy instead of walls. When space was limited, primary caregivers felt like they were in the way and did not want to remain on the unit.

Furthermore, primary caregivers may have felt more welcomed by having better sleeping arrangements. None of the participants from this study were invited to sleep at their child's bedside which did not allow them to *be present* at all times. Primary caregivers did not want to leave their child's side but needed to sleep. The inability to remain at the child's bedside at night created a feeling of distress especially when there was nowhere close to the unit to sleep. Several participants stayed awake at the child's bedside or slept in the waiting room to remain close to their child. However, poor sleeping arrangements led to feelings of exhaustion and may have affected primary caregivers' ability to *be present* for their child.

Despite not being able to accommodate primary caregivers at all times to feel welcome on the unit, suggestions have been made. Snacks and meals could be provided to those who need

(Frazier & Warren, 2010); however, this may not be realistic in a time when finances are limited in health care. Frost et al. (2010) also suggest the use of curtains for more privacy. This would be helpful as a visual block however curtains do not block sound and were not effective for primary caregivers. Finally, inviting primary caregivers to sleep with the child at the bedside especially when there are no other sleeping arrangements close to the unit would help decrease primary caregivers' stress level and allow them to *be present* and be there with and for their child.

Caring Behaviours

Caring behaviours were experienced when health care providers demonstrated a sincere interest in being there for their child. This desire to be there gave primary caregivers reassurance that their child would be well looked after when they could not *be present*. According to Authier (2004), *being present* is the true gift of caring. Primary caregivers need reassurance that when they cannot *be present* with their child, healthcare providers will take on this role. For the participants of this study, caring meant more than *being present* and included health care providers who would go out of their way to do things that would make the child and family happy. This is consistent a study by Vincent, Alexander, Money & Patterson (1996) on parental descriptions of caring behaviour in the PICU where a father considered a nurse to be caring as the parent felt the nurse had gone a step beyond the normal to meet the child's needs.

Primary caregivers also felt cared for when health care providers demonstrated professional behaviours. Professionalism consisted of health care providers who had a strong knowledge base and competence in care delivery offering reassurance to primary caregivers that their child was in good hands. Similarly, Godkin (2001) contends that a nurse who is caring appears confident and is knowledgeable. Furthermore, primary caregivers felt those health care providers who demonstrated a good bedside manner were caring. A good bedside manner

included being polite and sensitive to the child's needs. Caring behaviours contributed to the development of a healthy relationship between primary caregivers and health care providers fostering trust. This is consistent with Stanik (2005) who reinforces how empathetic and caring behaviours facilitate the development of a relationship between the nurse and the family over time.

Primary caregivers appreciated when health care providers assisted them in meeting their basic needs which contributed to a sense of well being and enhanced coping mechanisms. In a study by Axelsson et al. (2005), a parent commented on how being offered a glass of water or being asked if they were hungry by health care providers contributed to feelings of being cared for.

Caring is a therapeutic intervention for all families (Godkin, 2001). When health care providers demonstrated caring behaviours, primary caregivers felt more reassured and were better able to cope with their child's admission to the PICU. Therefore health care providers must demonstrate caring behaviours towards the family and the child at all times.

Support

Support was another factor that contributed to primary caregivers' experience of family-centred care in the PICU. Support was defined by primary caregivers as having someone to help them cope with the devastation from the child's admission to the PICU. By having support, primary caregivers could be strong enough to *be present* and be there with their child and for their child. This is consistent with Amico & Davidhizar (1994) who noted that parents who received support and intervention were better able to nurture their child and experienced less stress. One form of support in which primary caregivers found beneficial was the presence of

another family member to be there for them such as a spouse or an extended family member. Seidman's study on parental coping in the PICU (1997) suggests that the greatest source of support for parents during the child's hospitalization in the ICU was one another. Only two of the nine interviews conducted for this study consisted of both primary caregivers therefore it is difficult to know how much support the other seven primary caregivers had from their spouses.

Primary caregivers also found it helpful having support to look after their other children at home. This support facilitated primary caregivers' ability to be there for their hospitalized child. Parents often worry about their other children at home while they are at the hospital and having the additional support at home was helpful (Hickey & Lewandowski, 1988). Although primary caregivers appreciated having someone with them at the hospital, visitor restrictions can pose a challenge (Flint & Walsch, 1988; Tughan, 1992). Primary caregivers' need for support reinforces the importance of an open visitation policy for parents and families in the PICU.

Primary caregivers also discussed how participating in a support group enhanced their coping abilities by having others families who could understand what they were going through. Nolbris, Abrahamsson, Hellsrom, Olofsson and Enskar (2010) recognize the benefits of a support group for family members as a means of being able to talk about and deal with their situation. Primary caregivers felt that initially a support group was not helpful because they were trying to grasp what was happening to their child. However, once their child's prognosis was known primary caregivers were more open to accepting help and support from other families and health care providers. The benefits of support were also evident in Maxton's study on presence in the PICU where the use of a support nurse was beneficial in reassuring parents (2008). Health care providers must assess primary caregivers' willingness to accept support. If primary caregivers are not open to support, feelings of pressure and distress may arise. Offering support

to primary caregivers is essential as they experience a great deal of stress and are overwhelmed with the admission of their child to the PICU.

Conceptual Model

The framework used to guide this study was the Synergy Model which was used to enlighten, rather than predict the way in which a synergy between families, health care providers and the technology of the PICU could be attained. This model could be appropriately used as a guide to understand certain components of this study; however, the model did not hold true to all the aspects that this study brought insight to. Discrepancies and similarities between the Synergy Model and this study are discussed next.

A synergy consists of the collaboration between health care providers, families, and the use of technology which come together as a whole for improving patient outcomes and increasing satisfaction with care (Johnson & Gordin, 1999). The Synergy Model suggests that through the collaboration among health care providers, primary caregivers, and the use of technology in the PICU, a synergy can be created contributing to a greater satisfaction in care. The Synergy Model held true to this study to the extent that when primary caregivers experienced what they defined as family-centred care, they experienced greater satisfaction with the care their child received. Family-centred care was experienced by primary caregivers when their needs were adequately met by health care providers. For the purpose of this study, health care providers' competencies as defined by the primary caregivers included having the knowledge to assess and address each family's unique needs. When health care providers were able to successfully address primary caregivers' needs, a synergy could be attained. Therefore, it could be concluded that when health care providers' competencies were in synch with the primary caregivers' needs a synergy was created, leading to greater satisfaction with care.

Furthermore, in meeting the needs of primary caregivers in the PICU, a collaborating approach among health care providers and primary caregivers was essential in assessing where the gaps existed.

This study also brings further insight on the way in which a synergy affects primary caregivers who had a child admitted to the PICU. A synergy may assist primary caregivers cope with having a child admitted to the PICU, providing them with reassurance, and facilitating their ability to remain present with their child.

One component of the Synergy Model that was not addressed in depth by primary caregivers in this study was the way in which a synergy with technology could be attained. Primary caregivers focused mostly on collaboration with the health care team and did not address how technology affected this process. However, participants recognized there were certain aspects within the PICU environment that prevented them from getting close to their child such as isolation equipment used for infection control including the need to wear masks, gowns, and gloves. When primary caregivers could not be close to their child, a sense of distress was experienced and a synergy was not attained.

While the Synergy Model focuses on health care providers' behaviours and competencies, in addition to collaboration between the health care provider and the family, this study brings further insight to aspects of family-centred care that were important to primary caregivers. These aspects include presence, advocacy, and being updated on the child's status. It is these factors in addition to health care provider's competencies which contributed to primary caregivers' satisfaction with care. For the purpose of this study, satisfaction with care was attained when primary caregivers experienced what they defined as family-centred care.

Methodological Strengths and Limitations

This section discusses the strengths and limitations with respect to the research design and method used in this study. These strengths and limitation were considered in interpreting the findings of this study.

Strengths

Hermeneutic phenomenology as interpreted by Van Manen (1990) was an appropriate methodology for this particular study. Hermeneutic phenomenology offered a mode of inquiry that assisted the student in finding a more in depth meaning of the human experience (Speziale & Carpenter, 2007). By understanding the philosophic underpinnings of hermeneutic phenomenology and using Van Manen (1990) as a guide, the student was able to arrive at a deeper understanding of primary caregiver's lived experience of family-centred care in the PICU.

A purposive sample method was used for this study with a small sample size of nine. The smaller sample size that was used for this study does not allow for the results to be generalized to a larger population; however, this is not the goal of qualitative research. Rather the purpose of qualitative research it is to understand the essence of participant's experience by in-depth analysis and interpretation of the data (Patton, 1990).

Limitations

This study design was retrospective in nature and the data was collected from what primary caregivers could remember from their experience in PICU. The student did not interview primary caregivers who had a child in the PICU at the current time of the interview as this could

have been too distressing for primary caregivers and many participants would have opted not to participate in the study.

This study was cross-sectional in nature where information was collected at one point in time. Longitudinal research provides insight on changes of behaviour over a period of time. Results from this study could have differed upon considering data collection directly after the child's discharge and again at a later date. Similarly, if this cross-sectional study consisted of interviewing families directly after their discharge from hospital, rather than a period of three months passed, data may have been different from the current results.

Upon conducting interviews, only two out of the nine interviews included both primary caregivers. Results may have been different had there been more spouses involved in the interview process to provide further insight into their experience in the PICU.

Furthermore, the student works in the PICU environment which may have contributed to certain bias in interpreting data during and after the interview process. In qualitative research the researcher must put all knowledge on a topic aside to truly understand the essence of participants experience (Speziale & Carpenter, 2003).

Recommendations

The findings and information gleaned from this study have provided important recommendations for the implementation of family-centred care in the PICU. These recommendations are presented in the areas of nursing practice, education, and research.

Nursing Practice

The findings from this study revealed that primary caregivers with a child admitted to the PICU have a need to *be present* with their child. By integrating an intervention plan that focuses on the promotion of presence in the PICU, primary caregivers' coping mechanisms are enhanced. A healthy relationship between health care providers and primary caregivers can contribute to the development of an appropriate intervention plan that is targeted at addressing the needs of primary caregivers who have a child admitted to the PICU. By engaging in a relationship, knowledge is gained around the unique needs of the family allowing health care providers to develop a plan of care which appropriately meets the unique needs of each child and their family.

To enhance primary caregivers' ability to *be present* and be there for their child, health care providers must encourage and empower primary caregivers to participate in their child's care. An appropriate intervention plan can be devised through the collaboration with primary caregivers and health care professional. Furthermore, health care providers must listen to what primary caregivers are saying about their child and appropriately address primary caregivers' concerns when they arise.

Participants in this study also reinforced the need to advocate for their critically ill child. Primary caregivers must be invited to be a part of a collaborative effort with the health care team around decisions that are made in relation to the child's care. Collaboration is enhanced by allowing primary caregivers to be present during rounds.

Primary caregiver in this study also wanted to the freedom to come and go from the unit, thus an open visitation policy would facilitate this need. Moreover, primary caregivers wanted to

be able to sleep on the unit to *be present* with their child at night. Primary caregivers could feel welcome to stay the night by being offered a comfortable chair or cot to sleep on with a blanket and a pillow.

Support was also beneficial for primary caregivers. Participants reinforced the need to have another family member present. Health care providers can encourage other family members to be present by creating a welcoming environment on the unit for the entire family. An assessment of the type and extent of support needed for primary caregivers is also important. It may also be beneficial for primary caregivers to have other support mechanisms such as other hospital services or local support groups.

Primary caregivers must also be updated frequently and honestly on the child's status and have explanations in terms they can understand. Effective communication will enhance primary caregivers' ability to remain updated on their child's status. Furthermore, health care providers must make a conscious effort to assure primary caregivers are being updated by asking if they have questions around the child's plan of care. Health care providers must also be willing to clarify any uncertainties.

This study also reinforces the need for consistency in health care providers who look after the child and who interact with the family. While this consistency is not always possible, every attempt should be made to facilitate continuity of care by assigning the same nurse to the same patient. Consistency in care will also enhance the development of a strong partnership between primary caregivers and health care providers.

Despite the stress incurred from the child's admission to the PICU, primary caregivers felt reassured when health care providers demonstrated caring behaviours towards the family and

the child. Thus, health care professionals must be sensitive to the family's unique needs and assure a caring attitude towards the family. All nursing interventions in the PICU must facilitate primary caregivers' ability to *be present* with their child. This presence will promote a family-centred approach to care and enhance primary caregivers' ability to cope with the devastation from the admission of their child to the PICU.

Education

This study adds to the existing body of knowledge on family-centred care in the PICU by helping health care providers who work in the PICU understand primary caregivers' lived experience of what it is like having a child in intensive care. With the realization that the findings from this study cannot be generalized to every family as each family unit has their individual needs, the findings can serve as a starting point for conversations about how to meet the needs of families in the PICU setting. Health care providers must be taught that by assessing each families needs on an individual basis, it will be possible to more effectively understand the needs of each family and develop interventions accordingly.

Further development of communication techniques will assist health care providers in effectively interacting with primary caregivers and keeping primary caregivers appropriately updated. Moreover, health care providers can further their education on family-centred care and their ability to address the needs of primary caregivers in the PICU by attending conferences and seminars. Reading research articles that focus on family-centred care can also contribute to health care providers' knowledge base.

Research

Although the findings from this study support themes previously mentioned in the literature around family-centred care, this study further highlighted the essence of family-centred care experienced by primary caregivers who had a child admitted to the PICU. Further research is warranted however, which focuses specifically on the themes identified that support the essence of primary caregivers' lived experience.

Primary caregivers in this study wanted the option to be present with their child; however, this opportunity was not always provided. Further research is needed around interventions that will facilitate primary caregivers' ability to remain present with their child and address current barriers around presence in the PICU. This will contribute to health care providers' knowledge around the benefits that being present offers to primary caregivers.

Furthermore, primary caregivers who wanted to be present and were asked to leave by health care providers experienced great distress. More research on the effects of separation from the child in the PICU will enhance health care providers' understanding of the effects separation from the child has on primary caregivers during a time when they need to be there the most.

All participants for this study were Caucasian. This study did not explore cultural influences on the lived experience of family-centred care. While family dynamics between cultures vary, further research is warranted around exploring how the varying cultures define and experience family centred-care.

The admission of a child to the PICU affects not only primary caregivers, but the family as a whole and equally affects aunts, uncles and grandparents and other extended family members. While primary caregivers appreciated when health care providers asked about other

family members, this study only considered the primary caregivers' perspectives. Further research on siblings experience around family centred-care would be beneficial for health care providers in addressing the needs of the family as a whole. Perspectives of siblings and other family members may offer further insight around family- centred care.

While some health care providers remain reluctant to include the family in the care of the child despite the benefits participation in care offers for families, further research around health care provider's perceptions of family-centred care in the PICU will help overcome barriers to its implementation into practice.

Research provides concrete evidence around primary caregivers' experiences and perceptions of family-centred care. A more in depth understanding of family-centred care will assist health care providers with its successful implementation in the PICU.

Chapter Summary

This chapter presented a summary of the findings from this study. The essence of primary caregivers' lived experience and themes supporting the essence were discussed. The discussion of the research findings reveal that participants from this study had both similar and different experiences compared to other research studies. The Synergy Model was compared to the findings of this study. Methodological strengths and limitation of the study were presented. Recommendations for nursing practice, research, and education were suggested.

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Appendix A: Letter of Invitation

Dear Parent

My name is Devon Brown and I am a pediatric nurse in the intensive care unit and a student in the Master's of Nursing Program at the University of Manitoba. This letter is being sent to you on my behalf by _____. I do not know your name or have any information about you.

To complete my nursing program, I am doing a study entitled: The Lived Experience of Family-Centred Care by Primary Care Givers of Critically Ill Children in the Pediatric Intensive Care Unit. The purpose of the study is to learn about the experience of family-centred care by parents or primary givers who had a critically ill child admitted to the PICU. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study.

I am inviting parents who had a child admitted to PICU to take part in the study. Parents who agree to be in the study would be asked to take part in one individual audiotape-recorded interview and a brief follow-up telephone interview.

The interviews would be arranged at a time and place convenient for participants. Each interview should take between 1 to 2 hours to complete. Sample interview questions are included at the end of this letter. The study specifics are explained in greater detail in the consent form also included with this letter.

Once all interviews are completed, I will compile all gathered information from your interview and the interviews of other parents and compose a paper highlighting the findings. All identities of the families will remain confidential throughout the entire study and will never be revealed or discussed with anyone. This paper will be shared with other health care professionals so that they may further learn from your experiences. If you wish, you will have the opportunity to receive a summary of the study.

If you are interested in participating in this study please contact me at 510-6870 at which point I can answer any questions you may have around this study. If you decide to participate, I will set up an interview time and place convenient for you. If you decide not to participate, you can say no without any consequences. Participation throughout this study is completely voluntarily and you may stop at any time.

Thank you for your time and consideration

Sincerely,

Devon Brown

Master of Nursing Student

University of Manitoba

SAMPLE QUESTIONS FOR PARENT INTERVIEWS:

- Could you please tell me about your child's stay in the PICU?
- Do you feel you experienced what you believe is family-centred care during your child's stay in PICU? Please explain.
- From your perspective could you please tell me what conditions helped support your understanding of family-centred care during your child's stay in PICU?
- What advice would you give to health care professionals about how they can best support family-centred care in PICU?

Appendix B: Interview Guide

Introduction to the Interview

Thank you for agreeing to meet with me. I would like to learn more about what your experience of family-centred care when your child was in the PICU. I would like you to share your experience from the time from the admission to the PICU to the transfer to the ward or discharge home. I also want to inform you that you do not have to answer a question if it makes you uncomfortable. I understand that it may be difficult for you to discuss your experiences with having a child in PICU. At anytime, we can turn the tape recorder off to “take a break,” if you would like to. No specific information from the interview will be shared with your child’s healthcare providers. All information will be kept confidential and you may withdraw from the study at any time.

Note: Probes will used as necessary to elicit discussion

- 1) Could you please tell me about your child’s stay in the PICU?
 - Probes: Time of admission
 - Why was your child admitted to the PICU
 - History of illness
 - How long were they admitted for?

- 2) During your child’s stay in PICU what was the experience like for you?
 - Probes: What did you do day to day
 - Communication with staff
 - Supports
 - Positive and negative experiences

- 3) Currently at Children’s Hospital there exists a policy around family-centred care. What is your definition of family centred-care?

- 4) Do you feel you experienced what you believe is family-centred care during your child’s stay in PICU? Please explain.
 - Probes: What were some of the positive family-centred care encounters that you experienced as a primary caregiver during your child’s stay in the PICU?

 - What were some of the negative family-centred care encounters that you experienced as a primary caregiver during your child’s stay in the PICU?

- 5) From your perspective what conditions helped support your understanding of family-

centred care during your child's stay in PICU?

- 6) From your perspective what conditions did not help to support your understanding of family-centred care during your child's stay in PICU?
- 7) a) If you could change anything about your experience in the PICU what would it be?
b) If you could change anything about your experience in the PICU with respect to how family-centred care is practiced, what would it be?
- 8) a) What advice would you give to parents or primary caregivers of critically ill children in relation to having a child in PICU?
b) What advice specific to family-centred care would you give to parents or primary caregivers of critically ill children?
- 9) What advice would you give to health care professionals about how they can best support family-centred care in PICU?
- 10) What advice would you give to administrators about how they can best support family-centred care in PICU?
- 11) Is there anything else you would like to address that we did not talk about today?

Appendix C: Demographic Form

ID#: _____

Date: _____

Information gathered in this form will help us get to know you and your family better. All information will be kept confidential.

1. What date was your child admitted to the PICU? _____

2. What was your child admitted with? _____

3. How long was your stay in PICU? _____

4. How old was your child upon admission? _____

5. How old is your child now? _____

What is your child's current grade in school? _____

Do you have other children? _____

If yes, what are their ages? _____

What is your age? _____

6. What is your relationship with the child?

Mother _____

Father _____

Grandmother _____

Grandfather _____

Aunt _____

Uncle _____

Other _____

7. How old are you? _____

8. Male or Female? _____

9. What is your occupation? _____

Circle: Full Time Part Time Casual

10. What is your partner's occupation (if relevant)? _____

11. Who else lives in your home with you?

- Mother
- Father
- Pets
- Someone else _____

12. Do you live inside or outside the city? _____

Appendix D: Consent Form

Research Study Title: *The Lived Experience of Family- Centred Care by Primary Care Givers of Critically Ill Children in the Pediatric Intensive Care Unit*

Study's Investigators:

Devon Brown, RN, Graduate Student, Faculty of Nursing, University of Manitoba

Dr. Roberta Woodgate, Faculty of Nursing, University of Manitoba, Advisor

Dr. Susan McClement, Faculty of Nursing, University of Manitoba, Internal Committee member

Dr. Stasa Veroukis, Pediatric Intensivist, Pediatric Intensive Care Unit, Health Sciences Centre, external committee member

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involved. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, agree to participate in the above study. I have been told that the purpose of this study is to arrive at an understanding of the experience of family centered by parents or primary givers who had a critically ill child admitted to the PICU. I understand what is learned from this study will be used to improve family centered care in the PICU.

I understand that if I agree to participate in the study, I will be asked to participate in an open-ended audio tape-recorded interview. I understand that the Master of Nursing student, Devon Brown under the supervision of Dr. Woodgate, will be doing the interviewing for the interviews. I understand that I will be asked questions related to my perspectives and experience with family-centred care during the time my child was admitted to the PICU. I understand that

the interview will take one to two hours and will be tape recorded for further analysis and interpretation. 1 to 2 weeks after the interview I will be contacted by the interviewer to follow-up. I understand that I may be asked to complete a Demographic Form prior to being interviewed. This form should take approximately 5 minutes to complete. During the interview, the interviewer will be taking field notes to describe her observations, reflections and potential arising themes. These notes will be kept confidential except to be shared with her supervisor to aid in analysis of the data.

I understand that my participation in this study is completely voluntary. I understand that even if I decided to participate, I may withdraw at any time and refrain from answering any questions, without prejudice or consequence.

I understand that findings from this study may be presented at a health or educational conference or published in a professional journal. In all instances, my or my child's identity would not be discussed or revealed to anyone. Only Devon Brown, the study's researcher will have access to our names. As well, I understand that in all instances, our names and identities would not be discussed or revealed to anyone. I am aware that my name will be replaced with a code number so that no one will be able to identify me. I understand that only Dr. Woodgate and Devon Brown will have access to the interviews. I understand that all data including the audiotapes, interviews, transcripts, field notes, and demographic information will be stored in a locked filing cabinet and computer protected by a password known only to Devon Brown. I understand that all data will be destroyed following completion of the study. I understand that if I decide to participate in the study, a summary of the study will be provided to me if requested.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive my legal rights nor release the researchers, or involved institutions from their legal and professional responsibilities. I understand that my participation should be as informed as my initial consent, so I should feel free to ask for clarification of new information throughout my participation. I understand this research has been approved by access committee at Health Sciences Centre and the Education/Nursing Research Ethics Board at the University of Manitoba. If I have any concerns or complaints about this project I may contact Dr. Woodgate at 474-8338 or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to me to keep for my records and reference.

I agree to take part in the interview.

Yes _____ No _____

Signature of Primary Caregiver

Print Name of Primary Caregiver

_____	_____	_____	_____
Signature of Witness	Title	Print Name of Witness	Date

I would like a summary report of the findings:

_____	_____
YES	NO

Please mail a summary of the report findings to:

Name: _____

Address: _____

Postal Code: _____



Health Sciences Centre
Winnipeg

Office of the Director of Research

Dial Direct 204-787-4831
Fax 204-787-4547

December 13, 2010

Ms Devon Brown
Principal Investigator
98 Red Moon Rd, Wpg MB R3X 0C3

Dear Ms Brown

RE: THE LIVED EXPERIENCE OF FAMILY CENTERED CARE BY PRIMARY CAREGIVERS OF CRITICALLY ILL CHILDREN IN THE PEDIATRIC INTENSIVE CARE UNIT.

ETHICS #: E2010:116 RIC #: R12010:188

The above-named protocol, has been evaluated and approved by the HSC Research Impact Committee.

The Department of Research wishes you much success with your study.

Sincerely

A handwritten signature in blue ink, appearing to read "Karen Shaw-Allan".

Karen Shaw-Allan
Research Protocol Officer
Health Sciences Centre

cc: Director of Research
Ancillary Services, Finance Division



Appendix F



UNIVERSITY OF MANITOBA | **Ethics**
Office of the Vice-President (Research)

CTC Building
208 - 194 Dafoe Road
Winnipeg, MB R3T 2N2
Fax (204) 269-7173
www.umanitoba.ca/research

APPROVAL CERTIFICATE

November 9, 2010

TO: Devon Brown (Advisor R. Woodgate)
Principal Investigator

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

Re: Protocol #E2010:116
"The Lived Experience of Family Centered Care by Primary
Caregivers of Critically Ill Children in the Pediatric Intensive Care
Unit"

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

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

Please note:

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

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

Table 1. The Research Process

van Manen's (1990) Methodological Themes	Research Activities for this Study
1. Turning to a phenomenon which seriously interests us and commits us to the world.	- Orientating to the phenomenon by conducting a literature review, formulating the research questions, and determining and describing assumptions. Creating of a proposal and recruitment of participants.
2. Investigating experiences as we live it rather than as we conceptualize it.	- Exploring the phenomenon. Generating data first by determining personal experience, and then through interviews of families that experience the lived knowledge. Consulting phenomenological literature and research done on the chosen phenomenon.
3. Reflecting on the essential themes which characterize the phenomenon.	- Engaging in phenomenon reflection by conducting thematic analysis of the lived descriptions. Determining thematic statements that portray the phenomenon.
4. Describing the phenomenon through the art of writing and rewriting.	- The act of phenomenological writing and rewriting. Creating thick descriptions and interpretations of the lived experience.
5. Maintaining a strong and orientated pedagogical relation to the phenomenon.	- Maintaining the research questions and purpose of the study and its relation to nursing.
6. Balancing the research context by considering parts and whole.	- Movement from themes to the entire transcripts of individual interviews

