

**Parents' Experience of the Transition with their Child from a Pediatric  
Intensive Care Unit (PICU) to the Hospital Ward: Searching for Comfort  
Across Transitions**

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Thesis submitted to the  
Faculty of Graduate and Postdoctoral Studies  
in partial fulfillment of the requirements  
for the degree of Master of Science in Nursing

University of Ottawa

January 2013

### **Abstract**

The pediatric intensive care unit (PICU) has been described as a stressful place for parents of critically ill children. Research to date has examined parents' needs and stressors with a child in PICU. There is a paucity of research examining the experience for parents of a child who is transferred from the PICU to the hospital ward. Open-ended interviews were conducted with 10 parents within 24-48 hours after transfer from a PICU to a hospital ward at a children's hospital in Canada to understand this experience. Parents revealed that the experience involved a search for comfort through transitions as expressed through the themes of: 'being a parent with a critically ill child is exhausting', 'being kept in the know', 'feeling supported by others', and 'being transferred'. The findings from this study can help nurses and other health professionals working with parents to support them through the transition from PICU. Recommendations are made for the inclusion of family-centered care practices to assist parents through transitions.

## Acknowledgements

I first have to thank my thesis committee, starting with my supervisor, Frances Fothergill-Bourbonnais. Your years of wisdom, the guidance and support you have provided, and your calm, organized approach have really helped get me through this project. I cannot thank you enough. To Margot Thomas, who was excited for my project from the beginning (and I hope still is, after multiple editions...), thank you for your support, advice, and guidance. To Denise Moreau, for your advice, efforts, and thoughtful suggestions, thank you.

To the nurse educators from CHEO and to all the nurses I have talked to on the various wards who and have helped me with this project, thank you. From the PICU, I would like to thank the care facilitators and ward clerk for helping me get this project running, reminding nurses to tell the families about my study, and remembering to call me if there was someone who agreed to take part. To all of the PICU nurses for being so positive, supportive, helpful, and interested (!) in the project, thank you.

I would like to thank the following organizations for financial support received: the Canadian Association of Critical Care Nurses (Smiths Medical Canada Ltd. Education Award), The Ottawa Hospital (Johnson and Johnson Nursing Research Award), and The Ottawa Hospital (Gladys Morehead Dominion Chalmers Nursing Bursary).

To my wonderful husband, Joel, who has supported my drive to complete my masters, cheered with me through all the highlights, lifted me up through all the low points, and been the best partner anyone could ask for, thank you and I love you. I would also like to thank my parents, my parents-in-law, and all of my siblings, extended family, and friends for their support and encouragement during my education and this project.

This thesis project has increased my communication skills and has taught me the value of listening (truly listening) to people. To all the parents who have shared their time

and their stories with me, thank you. You will never know how much your stories have affected me and forever changed my thoughts about, and approach to, families.

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## **Chapter 1 – Introduction**

The pediatric intensive care unit (PICU) has been described as a stressful place for patients and family members due to the sudden, unexpected, and life-threatening illness experience, and uncertainty regarding prognosis (Keogh, 2001). In a PICU, the goal is to restore the health of infants and children (up to the age of 18) suffering from acute life-threatening illness or injury, such as respiratory failure, sepsis, neurologic illness or injury, and cardiac conditions (Shanley, Wheeler, & Wong, 2009). Once the child's condition is stabilized, the child is transferred from the PICU to the hospital ward. This transition can be a challenging time for parents.

My interest in the experience of the transition from the PICU to the ward for parents stemmed from a clinical experience in PICU as part of a Masters in Nursing course in March 2009. As a part of this experience, nurses from the PICU at a children's hospital in Canada were informally interviewed about concerns of parents of children admitted to their unit. These nurses suggested that the transfer process in place did not prepare parents for the relocation of their child out of the unit and to the general ward. The nurses also saw the current transfer process as lacking in psychosocial support for the parents. The nurses thought this transition from PICU to the ward was the period where the parents experienced the most uncertainty, anxiety, and stress when compared with the rest of the course of their child's PICU admission. After looking at the transfer process in this PICU and examining the literature around transition from PICU, I realized there were many questions still to be answered. Thus, this qualitative study examining the experience for parents of the transition from PICU to the hospital ward transpired.

### **1.1 Background**

Parents experience multiple transitions when a child is in PICU. Parents can go through the transition from well to critically ill child, from home to hospital, and to a critical care area. Another transition to an unfamiliar area and a new team of hospital care providers takes place for parents when their child is ready to move to the hospital ward. Once the child is on the ward, they are still ill, but no longer critical (thus being in a critical care unit is no longer necessary). However, the parent, after the transfer, may still perceive the child as critically ill.

Bench and Day (2010) conducted a meta-synthesis of the qualitative research on the discharge experience of adult patients and found that the transfer out of an adult intensive care unit (ICU) to the hospital ward was psychologically distressing to patients and family members. Terms such as Relocation Stress Syndrome (Keogh, 2001), Transfer Stress (Leith, 1999), and Transfer Anxiety (Leith) have been coined to describe the phenomenon of psychological distress in patients and family members after discharge or transfer from an ICU. Davydow, Gifford, Desai, Needham, & Bienvenu (2008) found that some adult patients and their family members experienced Post-Traumatic Stress Disorder (PTSD) after ICU. Haines and Childs (2005) reported that the transition of children from PICU to the wards appeared to be a universal concern.

There is, however, little research examining the experience for parents of a child who is transferred from the PICU to the hospital ward. Since the parents' experience of the transition is not yet fully understood, nurses are unsure of what the needs of parents are. Thus, transfer planning is often based on nurses' perceptions of what patients and families need, rather than on evidence of what they actually want or need (Keogh, 2001).

## **1.2 Purpose of Study**

This study was undertaken to describe the lived experience for parents when their child was transferred from the PICU to the ward. The objectives of the study were to describe: the parents' perspective of the transfer process, supports and challenges during hospitalization and the transfer, information received during the hospitalization, and the differences between the PICU and the hospital ward.

### **1.3 Definition of Important Terms**

**Transition.** A transition is described by Meleis (2007) as a change in health status, role relationship, expectations, or abilities. Transitions happen when changes are linked with experienced time, or during periods between stable states of health or illness (Meleis, 2007). For the purpose of this study, the transfer of a child from the PICU to the general ward is considered a transition. A care transition is a hospital discharge or movement from one setting to another (Geary & Schumacher, 2012). Care transitions involve not only the physical movement of patients, but also the transfer from one group of health care providers to another. Deficient care transitions can lead to a lack of continuity, consistency, and coordination with both medical and nursing care resulting in readmissions, communication problems leading to lack of understanding the care plan, unclear expectations, or misunderstanding of medication regimens (Geary & Schumacher).

**Family.** Families are defined as who they say they are, or “a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another’s lives” (Wright & Leahy, 2001, p. 69). Families can be built on more than blood, adoption, or marriage and can take many different forms including friends, neighbours, or others as family rather than just those people living in a household.

**Parent.** A parent, for the purposes of this study, is defined as one who brings up and cares for another which can refer to biological parents (a mother or father) or “social” parents

(foster parents or guardians) (Encyclopaedia Britannica, 2011). As Lewandowski and Tesler (2003) note, children may have other family members or friends as their primary caregiver. They suggest using the word parent as synonymous with “primary caregiver and decision maker” (Lewandowski & Tesler, p. ix) which fits with the operational definition used for this study.

**PICU.** The PICU is a specialized medical unit providing continuous care including intensive monitoring, and frequent assessments and updates by physicians and nurses (Downes, 2009). The term ‘critically ill’ refers to all the children in this study who are hospitalized and in PICU, regardless of their current location (PICU or hospital ward). The term ‘ward’ is used for the inpatient hospital units (medicine, surgery, or other acute care units).

## **Chapter 2 – Literature Review**

This chapter will highlight a review of selected literature pertaining to parents' transition with their child from PICU to the hospital ward as well as general literature on parents in PICU, parental needs, and family-centered care. This chapter will conclude with limitations in the existing literature, followed by a summary of the literature review.

A literature search for articles exploring the transition for parents of a critically ill child from PICU to the ward was performed in July 2011 using the search terms parents, ICU, pediatric, transfer, and transition. The databases CINAHL and Pubmed were used for this search and any articles written after 1995 were included. MEDLINE and PsychInfo databases were also scanned, but revealed no additional papers. Reference lists of articles found using the initial search terms were also checked. Other selected literature pertaining to having a child in pediatric ICU, parental needs, family-centered care, and transitions was also explored to better understand the experience for parents.

### **2.1 Hospitalization of a Child with Critical Illness**

The admission of a child to a PICU is seen as a crisis for parents (Keogh, 2001; Ridling, Hoffman, & Deshler, 2006). Mullen & Pate (2006) noted that “regardless of the anticipated outcome, admission of a child to the PICU is a highly stressful event for families” (p. 1). Reasons for admission to a PICU include sepsis, respiratory infections and acute respiratory failure, and exacerbations of chronic illnesses such as chronic respiratory failure, with subsequent need for mechanical ventilatory support (Shanley, Wheeler, & Wong, 2009). Cardiac surgery or other cardiac and circulatory conditions (arrhythmias, low blood pressure), traumatic injuries, and neurological problems such as seizure disorders or brain tumours are other reasons for admission (Shanley, Wheeler, & Wong).

Parents and children in PICUs are subject to traumatic events related to either the medical condition or the treatment in the PICU (Ward-Begnoche, 2007). When parents bring their child to a PICU, they turn over the care to the personnel of the unit (Goldstein & Todres, 2009). This causes a disruption in parent roles (Ridling et al., 2006) and, for some parents, this may be the first time they have not had total control over the care of their child (Dampier, Campbell, & Watson, 2002). Parents also experience separation from the child, distress concerning the environment, procedures, and uncertain outcomes (Ridling et al.). Ehrlich, Von Rosenstiel, Grootenhuis, Gerrits, and Bos (2005) noted a crisis in a family, such as having a critically ill child, causes significant disruption, which can lead to psychological distress.

## **2.2 Parental Needs and Stressors**

Many studies (Carnevale, 1990; Colville, Darkins, Hesketh, Bennett, Alcock, & Noyes, 2009; Dampier, et al., 2002; Heuer, 1993; Jee, Shepherd, Boyles, Marsh, Thomas, & Ross, 2012; LaMontagne & Pawluk, 1990) have examined parents' needs, stressors, and coping in the PICU. Many of these needs, such as the need for information, environmental needs, and the maintenance of the parents' role have been consistent throughout multiple studies. Research focused on patient and family needs specifically in the ICU setting has established repeatedly that communication with caregivers is highly valued (Johnson, Wilson, Cavanaugh, Bryden, Gudmundson, & Moodley, 1998).

The Critical Care Family Needs Inventory (CCFNI) was developed based on Molter's (1979) examination of family member's needs in adult ICUs which revealed that needs fall under the categories of assurance, support, information, proximity, and comfort. The top ten needs in this study were: to feel there is hope, to feel hospital personnel care about the patient, to have the waiting room near the patient, to be called at home about changes in the

patient's condition, to know the prognosis, to have questions answered honestly, to know specific facts about the prognosis, to receive information about the patient once a day, to have explanations given in understandable terms, and to see the patient frequently (Molter, 1979). The CCFNI is a 45-item Likert scale tool where family members rate each need out of 4 in terms of importance from not important (1) to very important (4) (Molter & Leske, 1983).

Sturdivant and Warrant (2009) conducted a study using the modified CCFNI for PICU parents to understand their 10 most met and 10 least met needs. They found that all of the needs that fell under the categories of assurance and information were the most frequently met, but parents needs under the categories of comfort and support were least met.

Latour et al. (2011) looked at 559 parents' self-rated perceptions and needs related to information, care and cure, organization, parental participation, and professional attitude using a survey constructed by the investigators with 74 items ranked in terms of importance on a scale of one to ten. They compared parents' responses to 264 health professionals' perceptions based on a two-step study that identified and prioritized satisfaction with care items amongst PICU nurses and physicians. The results indicated that parents rated their needs for information and parental participation as more important than the health care professionals' ratings, while health professionals ranked multicultural care as more important than did parents. Interestingly, parents ranked 10 items under the information domain as more important than did health care professionals, including: the need to receive oral and written information, getting daily information about care and treatment, being informed about effects of medications, knowing about the future perspectives, tests and procedures, changes in the child's condition, and that information was easy to get (Latour et al.).

### **2.2.1 Need for information.**

Aldridge (2005), Carnevale (1990), Colville, et al. (2009), and Noyes (1998), affirmed that one of the most common needs for parents in PICU was the need for information. Parents wanted regular and consistent information and their stress was increased when they perceived inappropriate body language, poor timing, a lack of introduction, or poor consistency with getting information (Colville, et al.).

Jee, et al. (2012) used the Compass Questionnaire to measure parental experience (including stressors, needs, and coping strategies) of 182 parents (91 mothers and 91 fathers) whose child was admitted to a ten bed PICU in Southampton, United Kingdom. The authors found parents sought trust and assurance, and wanted to know about outcomes. Thus, the parents stayed at the bedside for long periods in an effort to seek information (Jee et al.). The need for information ranked highest in this study followed by assurance, trust, and proximity to the child. The authors found that parents of emergency patients responded similarly to those with elective admissions in terms of stress, but that some of their needs, stressors, or coping strategies were different. Both mothers and fathers found the emergency nature of the illness more stressful when compared to their counterparts whose children were admitted electively (Jee, et al.).

### **2.2.2 Environmental needs.**

Two studies (Carnevale, 1990; Jee, et al., 2012) reported parental stressors related to the environment of the PICU. Carnevale (1990) looked at the experiences of five parents in a ten bed PICU and found that parents felt stress from the environment including lights, noise, and activity. Carnevale noted that parental stress was reactivated with a change in environment (i.e. moving from the PICU). Jee et al. reported that parents in PICU ranked their environmental needs for personal comforts and facilities lower than their other needs.

However, environmental needs were ranked at over 80% in terms of importance (Jee et al.). Related to parents' environmental needs was that they wanted to be close to their child. Colville et al. (2009) and Jee et al. both called this need for closeness 'proximity to the child'. Parents wanted to be able to be close to their child at all times without visiting restrictions; having a place to rest in the hospital or unit assisted parents in meeting this need (Jee et al.)

### **2.2.3 Need for maintenance of parental role.**

Many authors noted a loss of parental role as one of the main stressors in PICU (Carnevale, 1990; Carter & Miles, 1989; Colville, et al., 2009; Jee et al., 2012; Noyes, 1998). In the study by Jee, et al. this stressor was described as parents feeling they were unable to care for the child as they normally would and having to leave their child in the hospital while they went home. Carnevale (1990) called this 'parental role conflict' where parents were unable to carry out normal parental roles or functions and were therefore uncertain how they should act or what they should do during the PICU admission. Colville, Cream, and Gracey (2003) used the Impact of Events Scale (IES) and found significant differences between mothers and fathers in terms of their parental role experience in PICU. These authors noted that mothers spent more time with the child during the PICU stay, were significantly more distressed at the admission, and reported significantly more intrusive thoughts and levels of avoidance than fathers. Parents needed to feel involved in the care of their child and to feel that their opinions and input, as a parent, were heard.

## **2.3 Family-Centered Care**

When a child is admitted to a PICU with a critical illness, this challenges the normal equilibrium of the family unit (Norton, 2005). When the family unit is disrupted, the well-being of the parents is also disturbed (Dampier et al., 2002). Davidson, Jones, and Bienvenu

(2012) suggest that anxiety, post-traumatic stress disorder (PTSD), and depression in parents during the PICU stay may affect their ability to care for their child after PICU and can cause issues with bonding. Therefore, it is important that nurses and other health professionals are assessing the family as a system, taking into account parents' feelings, coping, needs, and stressors, and providing support where necessary.

To assist parents through this experience of hospitalization and their child's illness, family-centered care was developed. Family-centered care has become a core value for most pediatric hospitals (Keogh, 2001). In family-centered care, families are viewed as a whole, recognizing that family functioning encompasses the well-being of each individual and families are recognized as the constant for the child (Dampier et al., 2002; McCubbin, & McCubbin, 1987). Children are affected by and affect those with whom they have relationships, thus family-centered care can help achieve consistency for the child by including families in the child's care (e.g. physical care or rounds) during hospitalization (Harrison, 2010).

Lewandowski and Tesler (2003) published a document in collaboration with the Society of Pediatric Nurses and the American Nurses Association outlining the basic goals and elements of Family-Centered Care for all pediatric settings. These guidelines include 8 elements: 1) family at the center (recognizing that the family is the constant in a child's life and that illness and injury of the child affect all family members); 2) family-professional collaboration (unlimited parental access, parental presence during procedures and tests, comfort and hygiene facilities); 3) family-professional communication (exchanging complete and unbiased information at all times); 4) cultural diversity of families (providing culturally competent care incorporating the family's religion, beliefs, and practices); 5) coping differences and supports (recognizing and respecting different coping mechanisms, providing

developmental, educational, emotional, spiritual, environmental, and financial supports); 6) family-centered peer support (encouraging and facilitating family to family support and networking); 7) specialized services and support systems (ensuring flexible, accessible, and comprehensive coordination of care between hospital, community, and home through case management or care coordination); 8) holistic perspective of family-centered care (paying attention to development needs, life beyond illness, and normalization for the child and family) (Lewandowski & Tesler, p. 1-6). The elements of family-centered care are echoed by other authors (Harrison, 2010; Rushton, 1990) and are used to create programs and policies in various institutions and settings. Family-centered care is differentiated from other approaches such as family-allied or family-focused care in that the family is treated as the unit of care in family-centered care (Lewandowski & Tesler; Wright & Leahy, 2001). Assessments and interventions in family-centered care are based on the family unit rather than the individuals and there is a true partnership between health professionals and families.

Some of the important aspects of family-centered care include that parents: have unlimited access to their child with comfortable facilities (chairs, beds, and food); are encouraged to participate in care and decision making; may be present during procedures, rounds, and reports; and should be involved on advisory and program development committees at the institution (Harrison, 2010; Lewandowski & Tesler, 2003). For health care professionals, some important expectations in a family-centered care facility are: comprehensive family assessments including siblings and extended family and ensuring there is good communication between the family and health care team (seeking out and respecting family input, ensuring there is two-way dialogue) (Lewandowski & Tesler). In the PICU, implementing family-centered care may mean having an open-door visitation policy with a parent able to stay overnight, and being present for clinical rounds, resuscitation, and

invasive procedures (Goldstein & Todres, 2009). Another important role for health care professionals in family-centered care is family support ensuring that families are assessed as to how they are coping and their need for support (Lewandowski & Tesler). Health care professionals should assist families by supporting and augmenting positive coping mechanisms, and providing support where needed through available resources (Lewandowski & Tesler).

The Registered Nurses of Ontario (RNAO) has developed general guidelines for nurses who are working with families whose loved one is ill (Registered Nurses' Association of Ontario, 2002). These guidelines, which focus on supporting families by assessing the patient in the context of his/her family and helping families to identify supports, may provide some guidance to nurses who work with families.

Historically, there have been some barriers to the implementation of family-centered care, specifically in intensive care settings (Smith, Hefley, & Anand, 2007). Some of these identified barriers for nurses include the inability to stop viewing family as visitors, concerns about allowing parents to take on aspects of care from a legal perspective, and having limited communication skills, difficulty with role negotiation, difficulty developing relationships, lack of time, a negative attitude, and/or lack of support from the system and other health professionals (Harrison, 2010). Harrison, in a literature review on the development of family-centered pediatric nursing care, identified that hospital systems most supportive of family-centered care included those whose culture supported inclusion of families, had educational programs for staff, and had mandated competencies related to family-centered care.

## **2.4 Transitions**

Meleis (2007) identified that transitional states can be a life phase (developmental transition), condition (health/illness transition), or situation (situational transition), and that

transitions are embedded in the context of a particular situation. Transitions have a beginning and an end. Situational transitions have been defined as “geographical changes, discharge from hospitals, and relocation to rehab” (Meleis, 2010, p. 4). Parents of critically ill children go through multiple transitions: from well to critically ill, home to another city, hands-on parent to observer, and between physical locations (emergency department, intensive care unit, operating room, hospital ward). While parents and children are undergoing situational transitions (from one unit to another) they may be experiencing other transitions as well. As Geary and Schumacher (2012) note, “multiple transitions can occur within the same individual or family simultaneously” (p. 237). For example, children may be undergoing developmental transitions, parents of new babies may be undergoing the developmental transition to parenthood, and most children have experienced a health/illness transition from healthy to ill.

During transitions, people suffer multiple losses which contribute to uncertainty and necessitate expert care for families and individuals to achieve healthy outcomes (Meleis, 2010). Healthy outcomes of transitions may include well-being, more energy, increased quality of life, role mastery or increased functional ability, and personal growth or transformation (Meleis & Trangenstein, 1994). However, some of the less desirable outcomes of transitions can include physical debilitation, lowered immune system, a period of grief, or the experience of traumatic stress symptoms (Meleis, 2010). Meleis advocates that helping people to achieve healthy transitions should be the goal, and possibly the definition, of nursing (Chick & Meleis, 1986; Meleis & Trangenstein, 1994; Meleis, 2010).

## **2.5 The Impact of Hospital Transitions**

One of the roles of a health care professional is to assist parents and children through transitions by providing transitional care. Transitional ICU care has been defined as the care

before, during, and after transition from the ICU (Chaboyer, James, & Kendall, 2005). Transitional ICU care is important because it has helped with consistency and minimized disruption for the adult patient while inadequate transitional care has been linked to complications such as adverse events, increased morbidity and mortality, and ICU readmissions (Chaboyer, James, & Kendall). Therefore, patient safety is a key goal in assisting patients and their families through transitions. Poor transitions have also been linked to role insufficiency, which is defined as “disparity in fulfilling role obligations or expectations” (Meleis, 2010, p. 2) which could mean parents are not able to fulfill their parental role if they do not have a healthy transition from PICU. To provide expert transitional care, it is important to first understand the transition experience from PICU to the ward.

### **2.5.1 The transition from PICU to the ward.**

Parents of PICU patients can experience transfer anxiety and uncertainty related to the transition from ICU to the ward (Ridling et al., 2006). According to Ridling et al., the transition experience culminates in “families’ experience [of] loss when they leave relationships developed during the crisis” (p. 114), parents not knowing what to expect on the new unit, changes in the nurse to patient ratio, and a loss of monitoring. Some suggestions for interventions to prevent this anxiety and distress are: including parents in the process, providing positive feedback or encouragement, providing information (written and verbal), starting the transfer process early by removing the monitors, offering a tour of the new unit, and introducing a PICU liaison role (critical care outreach) (Ridling, et al.).

When a child is transferred to the hospital ward, the intensive monitoring equipment and familiar personnel from the PICU are lost, and the parents must once again take on aspects of the caregiver role which can be stressful (Dampier et al., 2002; Ward-Begnoche,

2007). As McCubbin and McCubbin (1987) noted, in their resiliency model of family stress, adjustment, and adaptation, these transitions can affect the well-being of the family unit, and the individual parents. According to this model, families develop strengths to protect them during transitions such as problem solving methods, interpersonal and community relationships, and spirituality. Stress can sometimes be viewed as a positive experience that leads to resiliency in the family system (McCubbin & McCubbin). However, the demands on the family system during the transition from the PICU to the ward may be too much to manage for some parents.

### **2.5.2 Parents and psychological issues after PICU.**

Studies have found that many parents suffer psychological complications after transition from PICU. For example, Board and Ryan-Wenger (2002) followed parents in a three-group prospective comparison study from the time in the hospital up to six months after discharge and reported that mothers with a child in PICU experienced more distress than mothers of children in general units and those with ill children who were seen in a clinic or urgent care but not hospitalized. The mothers of the PICU patients also had increased levels of anger, depression, and anxiety compared to their counterparts without critically ill children.

Bronner, Knoester, Bos, Last, and Grootenhuis (2008) studied parents, who had a previously healthy child admitted to a PICU, at three and nine months post-hospital discharge. Using the post-traumatic stress questionnaire which measures symptoms of PTSD and allows for psychiatric diagnosis of PTSD based on symptom severity, the authors studied 140 mothers and 107 fathers. They found that three-quarters of parents had persistent PTSD symptoms, and one in eight participants were diagnosed with PTSD. Mothers with children

who had ICU-related morbidity had higher levels of PTSD than those who did not, and of all those interviewed, six parent couples had a diagnosis of PTSD (Bronner, et al.).

Ehrlich et al. (2005) studied 192 parents of children who survived severe meningococcal disease and were in PICU. The parents were assessed for psychological distress up to 36 months after their child's discharge from hospital. These authors found that psychological distress in these parents, as measured by the Goldberg General Health Questionnaire, did not decrease over time, and that parents did experience severe psychological distress.

Colville and Gracey (2006) followed 34 mothers of PICU patients up to eight months post hospital discharge using two different tools measuring psychological distress. They found that mothers who talked about their experiences were less likely to display PTSD. They found that between one- and three-quarters of mothers would appreciate a follow-up appointment, and that 18% suffered from PTSD, while another 53% had psychological distress. It was further reported that some particular aspects of PICU predicted future distress. For example, the child's appearance, witnessing medical procedures, the sights and sounds of the PICU, and communication difficulties with staff were all predictive of future psychological distress.

As shown through this review, research has been undertaken with parents in PICU, mainly relating to exploring parental stress during the PICU admission and after hospital discharge. One of the most stressful experiences parents had was the admission of their child to a PICU (Hickey & Rykerson, 1992; Jee, et al., 2012). This presents both a challenge and a privilege and responsibility for nurses working in this area: to provide care to patients, while being attuned to parental needs (Hickey & Rykerson). It is also important for nurses working

in PICU to remember that “parental stress is a normal, inevitable response when a child is seriously ill” (Noyes, 1998, p. 140).

## **2.6 Parents and Transfer from PICU to the Hospital Ward**

There were seven articles located through the literature search that specifically looked at parents and the transition from the PICU to the hospital ward with their child. Two of these studies were conducted in the USA (Bouve, Rozmus, & Giordano, 1999; Van Waning, Kleiber, & Freyenberger, 2005), three in England (Colville et al., 2009; Haines & Childs, 2005; Keogh, 2001), and two in Australia (Caffin, Linton, & Pellegrini, 2006; Linton, Grant, & Pellegrini, 2008). There were no Canadian studies located.

### **2.6.1 Survey and intervention studies.**

Most of the research found was quantitative in nature, employing self-report measures. These studies evaluated parents’ needs before transfer (Linton, Grant, & Pellegrini, 2008), parent satisfaction with PICU (Haines & Childs, 2005), parental response to interventions such as the creation of an ICU liaison nurse (Caffin, Linton, & Pellegrini, 2006) and implementation of a transfer protocol (Bouve, Rozmus, & Giordano 1999; Van Waning, Kleiber, & Freyenberger, 2005).

As an example of an intervention study, Linton et al. (2008) surveyed 35 parents about their needs prior to the transfer of their child, developed and implemented a discharge brochure based on suggestions from the literature, and evaluated whether this protocol better met parents’ needs related to the transfer to the ward. The researchers found that the changes in the staffing and monitoring were of high stress for the parents, and that the most important aspects were to know the name and location of the ward and to be informed and involved in discharge planning. The discharge brochure developed increased the parents’ understanding of what to expect on the ward (Linton et al.). A limitation of this study was that it looked at

the preparation for the transfer and did not evaluate the actual transfer process to see if the preparation made a difference in terms of adverse psychological responses such as stress or anxiety.

Haines and Childs (2005) explored parental satisfaction with PICU care, including discharge planning, using a questionnaire they developed. The authors not only looked at the transfer, but rather at a multitude of other aspects, such as issues around admission, information and communication, parental support, PICU environment and facilities, and perception of standards of care (Haines & Childs). In this study, a survey was mailed to parents four days after transfer from PICU, but there was no specification as to when parents filled it out. The findings of this study revealed parental dissatisfaction regarding: the supervision and safety on the wards, lack of preparation for transfer from PICU, concerns about inadequate staffing, reduction of nursing presence causing anxiety, and lack of preparation for changes in staffing levels (Haines & Childs). Some limitations of this study included that the authors claimed to do a quantitative study, but provided only descriptive statistics. The tool used was also based on previous satisfaction surveys and was not validated. The authors admitted that their tool might not have covered all of the areas of patient satisfaction or dissatisfaction. The timing of data collection was also not specified.

Bouve et al. (1999) implemented an intervention (a transfer preparation letter with ten minutes spent with the nurse reviewing the information) before transfer and tested it against 50 parents' self-reported anxiety scores (using the State-Trait Anxiety Inventory) pre- (24-48 hours before transfer) and post-intervention (one to two hours after transfer). The authors concluded that regardless of levels of anxiety pre-intervention, parents who received the intervention had significantly lower scores on the post-intervention measurement than those who received usual care. In addition, the intervention group's anxiety levels decreased more.

There were multiple limitations in this study including spillover of the intervention information to the control group and a possible influence of using the same tool (the State-Trait Anxiety Inventory) pre- and post-intervention in such a short amount of time (Bouve et al.) Additional limitations included the inability to tell whether talking with the nurse or the letter decreased the anxiety, since it was a combined intervention (Bouve et al.). Therefore, what in particular was causing parents' stress or anxiety about the transfer remained unknown.

A third intervention study by Caffin et al. (2006) aimed to evaluate the implementation of a liaison nurse on readmission rates. Feedback about the liaison nurse role was obtained from 86 parents who moved from PICU as well as from 65 ward nurses caring for them using a survey (Caffin et al.). The liaison nurses' role was to follow patients who were discharged in the previous 48 hours, support the child and family through the transition, provide nursing education on the wards, facilitate timely nursing interventions, improve communication between PICU and ward staff, and reduce readmissions to PICU (Caffin et al.). Parents were asked questions about their anxiety related to leaving the PICU and their perception of the support provided by the liaison nurse (Caffin et al.). Nurses were asked to identify what they saw as the liaison nurse role, how their role affected the transfer, and whether it should continue (Caffin et al.). Caffin et al. found that 53% of parents were anxious about leaving the PICU, but 87% of parents felt the liaison nurse decreased this anxiety. After the implementation of the liaison nurse, there was not a significant difference in PICU readmission rates but parents and nurses were both pleased with the liaison nurse's role and their support with transfers (Caffin et al.). Some of this study's limitations included that they had low response rates (57% for the staff survey and 43% for the parent survey), developed their own survey, and asked only yes or no questions.

VanWaning, et al. (2005) undertook another intervention study for parents transferring from PICU to the ward where family participants filled out a questionnaire to determine their satisfaction with transfer. The items in the questionnaire were based on nurses' observations of and thoughts about transfers from the PICU. The questionnaire was given to a cohort of families and 30 families returned the questionnaire over the course of one month. Based on the results, the authors developed a transfer protocol, which included a transfer letter, transfer sticker, and a tour of the ward designed to reduce anxiety and improve satisfaction around transfers. After the transfer protocol was implemented for two months, 26 families completed the post-intervention questionnaire. The authors concluded that before the intervention, nurses thought parents lacked awareness of the child's improving health status. Parents were not given a tour, did not understand differences in routine care between units, were not prepared to be involved in their child's care, and were unprepared to do daily activities with the child because they had not done them in PICU (VanWaning et al.). After the implementation of the protocol, parents better understood the increased number of patients, the decreased frequency that the nurse would check on their child, and the parents' role regarding care on the wards (VanWaning et al.). Parents thought the tour aspect of the intervention was helpful and rated the transfer as prompt and efficient (VanWaning et al.). However, there were some limitations to this study. For example, the authors developed their own questionnaire and based their interventions on results from this questionnaire, as well as nurses' thoughts about the transfer, and suggestions in the literature, rather than on an understanding of parents' experience. A second limitation was the low response rates (57% returned the pre-intervention questionnaire and 43% returned the post-intervention one). Another limitation was that this was more of a quality assurance study, in that the authors did not seek ethical approval or report any of the demographic data.

### **2.6.2 Studies of parental experience.**

Authors agree that qualitative methodology allows for better understanding of parents' transfer experiences (Dampier, Campbell, & Watson, 2002; Keogh, 2001; Noyes, 1998). Keogh (2001) used hermeneutic phenomenology in a study to describe the parents' transition experience from the PICU. Keogh found that, for parents, the transfer from PICU was seen as a crisis, eliciting distress similar to that caused by the admission. Keogh interviewed six parents (two fathers and four mothers) and found their responses fell under two theme clusters: emotional responses and organizational issues. The themes related to emotional responses included: 1) positive feelings, 2) negative feelings, and 3) dependency on the PICU staff (Keogh). Themes related to organizational issues were: 1) care management, where parents perceived poor communication, lack of preparation and continuity of care, and 2) intermediate care facility, where parents expressed the potential benefit of a unit, such as a step-down, between PICU and the ward (Keogh). A limitation of this study was the timing of the interviews, which were done before hospital discharge, but the precise timing was not stated. Keogh also stated that she did not reach theoretical saturation during data collection. These two limitations could decrease the study's transferability. In addition, Keogh recommended the results be corroborated with further studies in similar settings.

Colville et al. (2009) did a second qualitative study with the aim of understanding psychological distress in parents of children who were in PICU. Parents were interviewed eight months after hospital discharge. The authors did not intend to look at the transition from PICU to the ward, but the transition process revealed itself in the findings. The researchers asked parents four open-ended questions about memories in PICU, coping in PICU, whether or not the parent thought they had been changed by their PICU experience,

and what the worst thing that happened in PICU was or whether any incidents came to mind (Colville et al.). Parents' responses fell into four themes of vivid memories, transitions, communication with staff, and long-term impacts (Colville et al.). With respect to parents' responses on transition, they knew the child was ready to go but found themselves unprepared, found the transition stressful, and reported that the transfer renewed their anxiety about the child's safety (Colville et al). The additional findings of this study included that parents found the child's admission very stressful, that the transition to and from the PICU were the most stressful periods, and that other patient outcomes during their PICU admission served as a constant reminder of what could happen to their child. Parents had post-traumatic stress symptoms and retained vivid memories of the PICU when interviewed at eight months after discharge (Colville et al). One limitation of this study was that the authors decided to do a secondary analysis of another study where they asked open-ended questions during the data collection, instead of carrying out a full qualitative research study. It was particularly remarkable to note that although the authors did not aim to study transitions from PICU, it came through that many parents rated this as the worst event about PICU.

### **2.6.3 Limitations of current literature on parental transitions.**

Most of the studies reviewed did not look exclusively at transitions, making it more difficult to evaluate the data and draw conclusions. For example, Haines and Childs (2005) looked at discharge planning, Caffin et al. (2006) evaluated the liaison nurse role and readmissions as well as transfer, and Linton et al. (2008) and Bouve et al. (1999) did not study the actual transfer, but only looked at pre-transfer. Additionally, VanWaning et al. (2005) looked at satisfaction with a transfer protocol and Colville et al. (2009) examined psychological distress.

A few studies explored the experience of the transfer from PICU to the ward for parents. Chaboyer, Kendall, Kendall, and Foster (2005) noted that despite the large body of literature on transfer anxiety, there have been gaps in understanding of the experience of the transfer, “which fosters prescriptive rather than individualized transitional care” (p.138), meaning that transfer protocols do not necessarily fit each individual family and need to be flexible and individualized. Some authors suggested that qualitative methods would be better employed to understand the phenomenon of the experience of the transfer from the ICU. For example, Dampier, et al., (2002) stated, “the study of families’ experiences in PICU does not lend itself easily to classic quantitative research strategies” (p. 185). Keogh (2001) agreed, stating “quantitative studies can only reveal a part of the picture that represents the whole experience of have a child transferred from an ICU to the ward” (p. 8).

Another limitation of most studies was that there were mostly female participants (mothers), while fathers’ experiences and views were rarely captured. In a review of parents experiences and needs in PICU, Noyes (1998) noted that most articles were missing fathers’ perspective. Getting the perspective from the whole family is very important in family-centered care, because mothers and fathers may experience stress differently and have different needs while in PICU. For example, Jee et al. (2012) found that mothers needed to participate in care, be informed about the transfer, and be informed of changes in their child’s condition significantly more often than fathers. Jee et al. also noted statistically significant differences between mothers and fathers in terms of the emphasis placed on the ability to care for the child, the child’s looks, and reactions to the procedures or leaving the child. Bronner et al. (2008), Choi, Donahoe, Zullo, and Hoffman (2011), and Colville et al. (2009) suggested the importance of including mothers and fathers in studies of this nature because most research has focused on mothers. A few of the studies reviewed did include

mothers and fathers' perspectives (Colville et al., 2009; Keogh, 2001), but perhaps more limiting is that the majority of the studies reviewed (Bouve et al., 1999; Caffin et al., 2006; Haines & Childs, 2005; Linton et al., 2008; VanWaning et al., 2005) did not report the demographic data.

The studies presented assessed the experiences of parents retrospectively instead of looking at the experience as it was occurring. Not only may retrospective research fail to describe the experience of the transfer, findings may also be susceptible to changes in memories. In the psychological construct known as the memory-experience gap, experienced emotions, in retrospect, are evaluated as more intense than they actually were (Miron-Shatz, Stone, & Kahneman, 2009). The same recall problems exist in retrospective evaluation of traumatic or potentially traumatic events (Lalande & Bonanno, 2011). Retrospective memory deficits can occur due to repression, dissociation, or even simple forgetting or lack of interest or willingness to disclose. As was shown, there have been negative psychological reactions of parents following PICU, however, the understanding of the parents' experience as they are going through the transition from the PICU to the hospital ward has not been well described in current research, so it is difficult to pinpoint the onset of these symptoms. This in-the-moment experience of the transition is the gap to be filled by the proposed study.

The timing of the data collection varied in the literature. Some of the data collection occurred prior to the transfer (Bouve, et al., 1999; Linton, et al., 2008; VanWaning, et al., 2005) and one study did not specify the timing (Keogh, 2001). One study collected data using a letter mailed out 4 days after discharge from PICU, but responses were not received until up to three weeks later (Haines & Childs, 2005). In another study, the data was collected eight months after discharge home from hospital (Colville et al., 2009). Only one study seemed to evaluate the actual transition from PICU, with the data collection done 48

hours after the transfer (Caffin, et al., 2008). To capture the actual experience of the transition, and fill this gap in the literature, the proposed study will involve interviewing parents 24-48 hours after their transfer from the PICU.

## **2.7 Summary of Literature**

In conclusion, this literature review has examined the impact on parents of having a child in PICU including parental needs, family-centered care, transitions, and finally, the transition for parents from the PICU to the hospital ward. There have been difficulties identified for parents in the transition from PICU to the ward. Developing an understanding of what this experience is like for parents is important before planning any further interventions. A singular focus on the experience of the transition from PICU to the ward for parents will allow for an in-depth understanding of this experience. The results may facilitate the ability to better plan or guide interventions based on what parents actually feel, think, want, and/or need.

## Chapter 3 – Methods

This chapter contains a description of the study design, methodological assumptions, the sample, setting, procedure for participant selection, procedure for data collection, data analysis, and methods used to ensure rigour and ethical standards.

### 3.1 Study Design

The research design that captures an understanding of the lived experience for parents of the transition from the PICU to the hospital ward is the hermeneutic phenomenologic method. This research method (also called interpretive phenomenology) aims at describing the meaning of human phenomena and, further, understanding the lived structure of the meaning (VanManen, 1990). The transition theory, as explicated by Meleis, complements a phenomenologic research approach, because it adheres to a perceived worldview, “knowing through a more subjective view of those who are experiencing the situation and those agents who are uncovering the situation” (Meleis, 2007, p. 491). Hermeneutic (or interpretive) phenomenologists acknowledge that each person experiences the phenomena differently. An understanding of the transition experience will hopefully provide nurses and other health professionals with knowledge to enhance the care of parents during the transition.

Hermeneutic phenomenology contains four aspects: lived spaces, lived body, lived human relationships, and lived time (Polit & Beck, 2008). VanManen (1990) calls these four elements ‘lifeworld existentials’ and states that they can be used to guide reflection during the research process, including question posing, reflecting, and writing. Lived space is felt space, which can be thought of as physical space and how the space affects the way people feel (VanManen). The lived space in this study refers to the setting where the parent experienced the transition, therefore the hospital setting will be described in detail. Lived body refers to a person’s physical body and to the fact that every person is bodily in the

world (VanManen). Lived human relationships (or lived other) refers to the relationships maintained with others in the space shared with them (VanManen). VanManen states that this relationality can be physical (a handshake or hug), conversational, or existential (one's relationship with religion or spirituality). Lived body and lived human relationships in this study refer to the people who participated in the research, what they shared about their experience with others (lived relationships), and how the experience affected them physically, mentally, or emotionally (lived body). The processes of recruiting parents and the characteristics of these participants will be explicated. Lived time refers to the temporality experienced by people, and relates to subjective time, rather than objective or clock time (VanManen). Lived time for this study refers to the transition experience that parents have undergone. Van Manen states that lived experiences must be already lived through in order for people to reflect on them. Thus, the timing of interviews in this method is important.

Hermeneutic phenomenology achieves rigour through “interpretive descriptions that exact fullness and completeness of detail, and that explore to a degree of perfection the fundamental nature of the notion being addressed in the text” (VanManen, 1990, p. 17). Bracketing of one's own worldviews is not necessary in hermeneutic phenomenology and, although the researcher tries not to have presuppositions about the phenomenon of interest, prior understanding on the part of the researcher is expected (Polit & Beck, 2008; VanManen, 1990). It is acknowledged that the researcher, through the course of the interviews, will share the parents' experience. During data collection and analysis, the researcher must be cognisant of his/her presuppositions to reduce bias, but biases cannot be eliminated in hermeneutic phenomenology (Polit & Beck, 2008). Instead, reflection is seen by VanManen (2006) as the process of writing. Keeping a journal of the researcher's

experiences during the process of data collection and analysis will be used to reflect on personal notions of the findings in order to be aware of potential bias.

### **3.1.1 Researchers assumptions.**

Having completed a rotation in the PICU as a part of a Masters in Nursing course prior to initiating the study, the researcher thought that the parents' experience of the transition from the PICU to the ward would involve some element of stress and anxiety at leaving a familiar unit with one-to-one nursing care, intensive monitoring, frequent updates on their child's condition by physicians and nurses, and support from the nurses and social workers. The researcher also thought that the parents would be concerned about moving from a unit with so many resources (e.g. a parent room with television, bedrooms, showers) to one with less facilities.

## **3.2 Participants**

At the outset, a purposive sample of ten parent participants was the aim for the study, since most phenomenologic studies have six to ten participants (Polit & Beck, 2008). All efforts were made to include both mothers and fathers (or both parents of a child) whenever possible. Sample size was re-evaluated while data collection was ongoing. Interviews continued until the thesis committee agreed that rich descriptions of the phenomenon had been achieved by the tenth interview.

Inclusion criteria for parents were: (1) age greater than 18 years, (2) English speaking, (3) the parent (biological mother and/or father, or legal guardian) of a child being transferred from the PICU to the hospital ward, and (4) the transfer had occurred less than 48 hours prior to the interview. For the parent to be included, the child needed to be: (a) no more than 18 years of age, (b) admitted to the PICU for more than 24 hours for an acute, life-threatening illness, requiring ventilator support or blood pressure support, or any child

admitted for a trauma, surgery, or an infectious process such as respiratory syncytial virus (RSV) or sepsis.

Exclusion criteria included: (1) the parents of a child readmitted to the PICU on the same hospital admission and (2) involvement in a Child & Family Services case (i.e. admitted for suspicions of child abuse or neglect).

The reason parents had to speak English was that the researcher was not bilingual. The reason for the child having to be in ICU more than 24 hours with a life threatening illness was to allow for relative homogeneity of the sample, as it was felt that after 24 hours parents would have experienced the environment of PICU. The inclusion and exclusion criteria were developed in collaboration with the PICU Advanced Practice Nurse, and were intended to ensure the homogeneity of the sample, and prevent further distress or burden for parents.

### **3.3 Setting**

Participants were recruited from a Pediatric Intensive Care Unit of an academic children's hospital in a large Canadian city with a population of over 900,000. The following description of the setting is based on information gleaned from the hospital website, the PICU Advanced Practice Nurse, the Social Workers from the PICU and cardiac program, and from personal experience while doing a practicum and collecting data for this study.

This hospital treats children with trauma and medical or surgical needs, including respiratory, cardiovascular or cardiac surgery, neurologic or neurosurgical, gastrointestinal or general surgery, psychiatric, nephrology, metabolic, hematologic, burns or plastic surgery, genitourinary, orthopedic, otolaryngology, septic, toxic ingestion, and oncologic conditions. The hospital is a referral center for children in need of surgical and medical services not available in their home hospital, including neurosurgery, cardiac surgery, and oncology,

among others. The hospital receives a large number of patients referred from surrounding cities, from throughout the province, and from neighbouring provinces.

### **3.3.1 Pediatric Intensive Care Unit.**

The PICU is a ten-bed unit where patients are cared for by an interdisciplinary team including pediatric intensivists (physician specialists in pediatric intensive care), resident and fellow physicians, nurses, and other health professionals (e.g. respiratory therapists, social workers). Inside the PICU, each child has a private room with an area for parents, with a cot and chairs, and a locker for personal belongings. The rooms are located around the unit periphery with the central nursing desk, a unit pharmacy, and xray viewing room in the center of the unit. Patients predominantly receive one-to-one care provided by a Registered Nurse which includes continuous cardio-respiratory monitoring. This unit had 2397 patient days in 2009/2010 (Children's Hospital of Eastern Ontario, 2010), with the most common admissions for respiratory issues (bronchiolitis, pneumonia, asthma), cardiac disease (post-operative cardiac surgery, cardiac arrhythmias), and trauma (M. Thomas, personal communication, March 24, 2011). Patients who are admitted to the PICU require more intensive monitoring (nursing supervision and electronic monitoring) and advanced life support (invasive ventilation, blood pressure or heart rate support, continuous intravenous medications, and complex or complicated nursing procedures) than can be managed in other areas of the hospital.

The hospital has a care philosophy of family-centered care (Children's Hospital of Eastern Ontario, 2009b) which is enacted in the PICU by ensuring an open-door visiting policy (with restrictions based on number of visitors and relation to patient), the ability of parents to stay overnight, and for parents to participate in all aspects of patient care as appropriate to situation and patient or family willingness. These aspects of care include

interdisciplinary patient care rounds and supporting the patient during procedures or other components of care (M. Thomas, personal communication, March 24, 2011).

Attached to the PICU is a family lounge with sleep rooms, a kitchen, computers, television, couches, and bathrooms with showers. As the PICU is a locked unit, parents of PICU patients gain access to the family area and the PICU with a swipe card that is given to them when their child is admitted. The parents may stay overnight and have access to the unit and their child at all times through their swipe cards. Patient care rounds take place each morning in the PICU with the interdisciplinary care team of the staff physicians, residents, fellows, nurses, pharmacists, care facilitators, dietician and respiratory therapists. This team discusses each patient in the unit, and decides the plan of care for the day. Often, the other consult teams (palliative care, cardiology or cardiac surgery, hematology or oncology, etc.) also participate in these rounds. Parents in the PICU are welcome to listen in and participate in these daily rounds if they wish.

The process in place for transfers from the PICU to the ward at the time of data collection was a transfer form with areas to document psychosocial needs, follow up, and palliative care (Children's Hospital of Eastern Ontario, 1993; Children's Hospital of Eastern Ontario, 2009b). Two of the nurses interviewed during the researcher's clinical experience in PICU mentioned that these report sheets are a systematic, concise way to give report to the floor, and that the floor nurses like it.

### **3.3.2 SPOT team (critical care outreach).**

In addition to the interdisciplinary team in the PICU, there is a critical care outreach team called the SPOT team. The researcher received the following information on the SPOT team from C. Ramsay, SPOT respiratory therapist and educator, on October 25, 2012. SPOT stands for Speed, Proactive, Outreach, and Teaching. Speed means the team will arrive

within 10 minutes of being called, proactive means they provide proactive care hoping to prevent further deterioration or (re)admission to the PICU as well as follow-up on high risk patients, outreach means the team goes from the critical care unit to provide resources to the wards and the patient's primary care team, and teaching represents the bedside teaching and formal education sessions provided by the team. The SPOT team consists of a registered nurse, a respiratory therapist, and a physician (either the staff intensivist during daytime hours or the PICU resident on the evenings and weekends). This team responds to critical events or patients who are becoming unstable on the wards as well as provide follow-up for 48 hours after PICU discharge or a SPOT team activation.

Someone calling the number and asking for an assessment of the child because the child/patient is perceived to be deteriorating activates the SPOT team. Guidelines for calling the SPOT team include airway threat (stridor or secretions), breathing (apnea, tachypnea, hypoxemia, or respiratory distress), circulation (worrisome heart rate, blood pressure, or changes in perfusion), disability (changes in level of consciousness or seizure), or if the healthcare provider or parent is worried about the patient. Any health care team member can call the SPOT team. Parents, if worried, can also ask their primary care team to call for the SPOT team. The SPOT team response to calls and follow-up includes patient assessment and making recommendations for the care of the child.

Parents whose child is admitted to the PICU are provided with a pamphlet outlining who the SPOT team is, why it was created, how the SPOT team is activated, and what the SPOT team does (immediate response, clinical support, education, and follow-up). Prior to the patient leaving the PICU, the goal is that the SPOT RN talks with families who are being discharged to tell them about the SPOT team and that they will follow the patient for 48 hours after discharge. When a patient has a SPOT team activation, the team provides

information to the parents about who they are and what they are doing when they respond. There are also posters and parent pamphlets throughout the hospital providing information on who the SPOT team is, what their role is, and what are the criteria for activating the SPOT team.

### **3.3.3 Hospital inpatient wards.**

The inpatient wards to which patients in this study were transferred from PICU include two medicine, one hematology/oncology, and one surgery unit. These wards are split over two floors of the hospital. There are 110 beds in total on the pediatric medicine, oncology, and surgery wards (Children's Hospital of Eastern Ontario, 2009b). The inpatient wards have a central nursing station and private or double patient rooms around the outer hallway. The wards are set up in a U-shape with the desk in the middle and the patient rooms around the outside. The wards are small, without a lot of storage, consequently, wheelchairs, blood pressure machines, computers on wheels, and other patient equipment is often in the hall, making the hallways crowded. The rooms on the medicine and surgery wards are smaller than those in the PICU and have room for one chair or cot per patient for parents to sleep on. The resources for children on the medicine and surgery wards include a playroom on each floor and a library located on one floor. There is also one parent lounge on one floor shared by all the parents with children in the medical and surgical inpatient wards. There are kitchens on each of the wards for parent use. There are also telephones either in the room or on the ward and the hospital provides a service where parents can order meals for their child at any time (which is free), as well as food for themselves (at a cost).

The nurse to patient ratio on the medicine and surgery wards is different from the PICU in that ward nurses usually have two to four patients assigned to their care. In some situations, such as when patients need closer monitoring, nurses will be assigned to a room

with only two patients. Otherwise, the care is divided among the nurses according to the patient's needs, which are matched with the nurse's experience, skills, and scope of practice, rather than according to placement on the ward. Consequently, a nurse may have patients on opposite ends of the ward.

### **3.3.4 Monitoring of children.**

Monitoring can refer to either nursing presence or observation (having a nurse physically or visually monitoring a child), or to electronic monitoring. Most of the children who are monitored on the inpatient wards require closer surveillance due to their medical conditions or needs such as psychiatric patients requiring supervision if they are at risk of harm to themselves or others (Children's Hospital of Eastern Ontario, 2009a, 2011). In this hospital, the use of electronic monitoring, patient observation (the ratio of nurse to patient and level of nursing presence), and vital sign frequency need to be ordered by the physician with input from nursing staff. Some of the rooms on the medicine and surgery wards have monitoring capabilities with electronic bedside monitors, which can continuously monitor heart rate and rhythm, respiratory rate, and oxygen saturation, and send this data to a central monitoring station at the nursing desk. When the child requires more than an electronic monitor, based on the nurses' and physicians' assessment, continuous nursing observation can be ordered by the physician. There are various levels of observation, but the two pertinent to this study are constant observation and constant attendance. Constant observation means the nurse to patient ratio is 1:1 and the nurse must be within an arm's length (6 feet or three steps) of the patient and have direct vision of the patient (Children's Hospital of Eastern Ontario, 2009a; 2011). Constant attendance means the nurse to patient ratio is 2:1 and the nurse must be within the line of vision and direct sight of the patient at all times (Children's Hospital of Eastern Ontario, 2009a; 2011). In this study, when the child

was considered monitored by hospital standards on the inpatient floors, it meant constant attendance and the use of a continuous electronic monitor.

### **3.3.5 Resources for families.**

The provision of additional information about resources for families was felt to be important in this study given that the hospital was a referral center and parents, often from out of town, were staying with their child at or near the hospital. The social workers from the PICU and cardiac program provided the following information on family resources.

There are two residences outside of the hospital: a motel, and a charity-sponsored residence, where parents can stay while their child is admitted to the hospital. Both of these facilities are across the street from the hospital and there is a charge per night for the rooms. The charity-sponsored residence is generally booked well in advance for long-term stays and runs at 100% occupancy, so it is difficult for parents, whose child is unexpectedly admitted, to get a room. Parents of oncology patients usually occupy the charity-sponsored residence. Either parents or a social worker can book the motel rooms.

There are other resources available for parents which can be accessed by the social work team through a consultation from the physician or nurse. The social worker can help parents with booking accommodation, assess them for financial support, and provide funds for meals, lodging, or parking when parents qualify (based on a specific assessment by the social worker which includes financial need among other factors). The social worker can also assist parents with applying for Northern Health Travel Grants (to recuperate some of the costs associated with travelling from certain areas in Northern Ontario), and other assistance where necessary. There are also other resources specifically for cardiac surgery patients including a social worker, who automatically follows all parents of children admitted under this program. Parents receive a tour of the PICU prior to the cardiac surgical procedure and

on the day of the child's surgery, parents wait in a private waiting room and receive frequent updates during the surgery from the cardiac liaison nurse or social worker.

### **3.4 Data Collection**

#### **3.4.1 Recruitment.**

Approval of the project was received from the hospital's Director of Nursing Research and Practice, Inpatient Medicine and Surgery, and Critical Care, as these were requirements of the hospital's ethics process. After ethical approval was received from the hospital and from the University of Ottawa, contact was made with educators and managers of the PICU, surgery, medicine, and oncology wards via email. The researcher met with the educator of the medicine and surgery wards, and posters about the study were displayed in both wards for parents (Appendix C) and nurses (Appendix E). The parent posters were put on parent information boards in each ward, and the nurse posters were put in the report/staff room and the staff washrooms. An email was sent to all nurses on the medicine and surgery wards (via the educators) where information about the study was provided. It was expected that few patients would be transferred to the oncology ward, and so the researcher would explain the study to the staff if and when this occurred.

Over the course of three visits to the ICU, the researcher met with and shared the study information and expectations of nursing staff. The plan was to have the care facilitator or staff nurses identify patients that would be transferred, and present the information sheet (Appendix A) to the parents, then ask if they would consent to being approached by the researcher about the study. This method was chosen because the care facilitators and staff nurses would find out about the potential transfers on morning rounds, and then could talk to the parents about the study in the afternoon. The ward clerk was also aware of the study and

would try to remind the care facilitator and staff nurses to hand out the sheets or ask parents about the study when the child was being transferred.

In the PICU, posters (Appendix E) were displayed in several areas for the nurses. An email was sent to all the ICU nurses reminding them about the study and how they could facilitate recruitment. Information about the inclusion and exclusion criteria, the purpose of the study, design of the study, and how to present the information to parents were provided. A box labelled 'parent study' with the information sheets attached to nursing fact sheets was left at the main desk in the unit. The researcher's contact information was on the posters, emailed to nurses, on the information sheets and nursing fact sheets, and on the box containing the information sheets. To remind nurses of the study and ensure all potential participants had the opportunity to be approached, the researcher visited the PICU most weekdays during data collection. The Advanced Practice Nurse and care facilitators in the PICU also checked for potential participants (i.e. children who would soon be discharged whose parents met the inclusion criteria of the study).

After the parents had been contacted by the ICU nurse and agreed to participate, the researcher met with them usually before the child was transferred. At this point, they were provided with the information sheet (Appendix A). Usually the nurse and parent knew which ward and room the child would be transferred to and the approximate time of transfer. The researcher would set up a time with the parent for a visit on the new ward 24-48 hours after the planned transfer time.

#### **3.4.2 Contacting the parents.**

Seven out of ten parents were referred to the study by the PICU nurse. The other three parents' had children transferred on the weekends, and their information was obtained from the ward clerk or critical care outreach (SPOT) nurse. When recruitment happened in

this way, the researcher went to the floor where the child was transferred, explained a bit about the study to the child's primary nurse, and that nurse approached the parent in the same way the PICU nurses did.

Once the parent agreed to the interview, the researcher kept close contact with the ward clerks in the PICU to find out the timing of the transfers and the rooms to which the patients transferred. Once the child was transferred, the researcher would check in with the parent on the ward the following afternoon. Sometimes, this timing would work for parents but other times, parents would ask the researcher to come at another time.

### **3.4.3 The process of data collection.**

Seven out of ten interviews were conducted in a small private conference room, which was on the same floor as some of the inpatient wards in the hospital. Sometimes the parent would not want to leave their child, so when there was no other child in the patient's room, the interview was done there (two out of ten interviews). One interview was done in the children's library area with the child and other parent there as well. While this was recognized as a less than ideal spot for quiet, confidentiality, and ease of interview, it was the parent's choice of a comfortable location.

The researcher and the interviewee, in hermeneutic phenomenology, are seen as co-investigators (VanManen, 1990). The researcher's job is to "keep the question (of the meaning of the phenomenon) open, to keep himself or herself and the interviewee oriented to the substance of the thing being questioned" (VanManen, p. 98).

Upon meeting the parent, before the initiation of the interview, the purpose of the study was reiterated and the parent was reminded that the interview would be audiotaped. The parent was asked if they had any questions about the study, and the consent form (Appendix B) was reviewed and signed.

The interview was then started with the parents being asked for some demographic data (i.e. age of the child, admission diagnosis, previous ICU admissions) (see Table 1 for findings). These demographics were for description of the sample and to allow for transferability, so that researchers in other areas may more easily apply the findings to their settings (Polit & Beck, 2008). The parents were asked about why their child was admitted to the PICU, which was used as a grand-tour question to open the interview (Polit & Beck, 2008). Open-ended questions were asked to explore the experience of the child being transferred from the PICU to the ward (see Appendix D for sample interview questions). Besides understanding the experience of leaving the PICU, the researcher wanted to find out about parents' feelings related to being in and subsequently leaving the PICU and the parent's knowledge and feelings about going to the regular ward. Prompts such as, "Can you tell me more about that?" or, "How did you feel about that?" were used to encourage conversation and clarify parent's thoughts. At the end of the interview, parents were asked if the interview was helpful for them.

Field notes were written immediately after the interview. A reflective journal was also kept as suggested by Polit and Beck (2008) and VanManen (1990). This journal, used to record insights and patterns of the work in progress, was kept during the transcription and data analysis as well. The journal helped to keep records of the researcher's thoughts and ideas related to each interview and the processes involved in the study, and served to assist with confirmability of the data.

The interviews lasted an average of 23.5 minutes (range 13-41 minutes). The entire interview was audio recorded, and the data transcribed verbatim by the researcher starting as soon as possible after the interview. These transcripts were double-checked with the tapes to ensure rigour (Polit & Beck, 2008). Notations were added regarding changes in voice,

pauses, laughter, and what was going on in the room (i.e. if someone came in). In the transcripts, certain words were bolded, which was reflective of the participants' emphasis on those words or terms. Some parents were mumbling or speaking quietly, which required the researcher listening to the audio tape multiple times, but all words were able to be comprehended and transcribed eventually. These transcripts were reviewed with the thesis supervisor and thesis committee to help with thematic development. The process of data collection occurred over a period of 40 days (from November 7-December 16, 2011).

#### **3.4.4 Pilot interview.**

A pilot interview was conducted at the onset of the study with one parent who met the study inclusion criteria. This interview was done to ensure that the questions asked yielded data that reflected the objectives of the study. No changes were made to wording of the questions, and the data from this pilot interview were included in the data analysis.

#### **3.4.5 Participant description.**

There were 15 information sheets handed out by PICU nurses or floor nurses, meaning 15 parents were approached to be in the study. Eleven parents agreed, and ten were interviewed (one was discharged before the researcher had the chance to do the interview). The characteristics of participants and their children are listed in Table 1. Although in many cases both parents were with the child when they were approached about, and agreed to be a part of the study, when it came time to do the interview, the mothers were more often available and willing to do the interview. Seven out of ten participants were from out of town (defined as more than 100km from the hospital, and the inability to drive home in the evening). Five parents stayed in the child's room the whole time they were in the hospital, three did not stay in the child's room at all, and two parents stayed part of the time with the child and part of the time in another location.

The children were 70% male with an average age of 8.8 years (range 23 months-18 years). This was the first ICU admission in the child's lifetime for eight out of ten patients and the first overnight hospital admission for six out of ten patients. Two patients were admitted for asthma, three for cardiac surgery, and one each for ENT surgery, neurosurgery, a potential lymphoma, spinal surgery, and general surgery. For six out of ten children this was a planned admission, and three out of ten were transferred to monitored rooms (the child was on a continuous electronic monitoring device, such as heart rate, electrocardiogram, or oxygen saturation monitor) with constant nurse supervision (the nurse was in the room with maximum two patients per nurse). The patients spent an average of 2.4 days in the ICU (range 23 hours-7 days). Every effort was made to interview parents within the 48 hours after the transfer and the participants were on the ward for an average of 36.3 hours before the interview. Only one interview occurred outside of the 48 hours and was done at 60 hours post-PICU transfer.

**Table 1: Description of Participants**

Interview number	1	2	3	4	5	6	7	8	9	10
Relationship to child	Mother	Mother	Mother	Father	Mother	Mother	Mother	Mother	Mother	Father
Child's sex (M=male, F=female)	F	F	M	M	M	M	M	M	F	M
Child's age	2 years	3 years	18 years	13 years	3.5 years	15 years	23 months	16 years	6 years	10 years
Reason for ICU admission	asthma	cardiac surgery	neurosurgery	asthma	cardiac surgery	lymphoma, cardiac effusion, increased WOB	ENT surgery	cardiac surgery	spinal surgery	bowel surgery
ICU length of stay	2.5 days	36 hours	24 hours	3 days	23 hours	48 hours	7 days	24 hours	24 hours	7 days
Geographic area (in town/out of town)	in town	in town	out of town	out of town	out of town	out of town	in town	out of town	out of town	out of town

### 3.5 Ethics

Ethical approval for this study was obtained from the Children's Hospital of Eastern Ontario and from the University of Ottawa. Upon meeting the participants, the researcher explained the potential risks, benefits, and confidentiality. Written and informed consent was obtained from each participant before starting the interview, and the participant was given a copy of the consent (Appendix B). The option for the parents to receive the results of the study was mentioned in the consent and information sheets.

Confidentiality was maintained by giving participants a number to identify them at the onset of the study, and no personal information was accessed from patient charts. Only the researcher and thesis committee members had access to any identifying information which was kept in a locked cabinet.

### **3.6 Data Analysis**

Data from the transcribed interviews were analysed guided by the thematic analysis approach outlined by VanManen (1990). There are three parts to VanManen's approach: the wholistic approach, the selective or highlighting approach, and the detailed or line by line approach (Polit & Beck, 2008; VanManen, 1990).

The first part, the wholistic approach, involved reading over the entire transcript to understand the meaning, which was done with the thesis supervisor after each interview was transcribed. To become immersed in the data, and to continually evaluate the researcher's thoughts about the data with the original transcripts, the researcher and thesis supervisor read over the transcripts multiple times throughout the process.

Next, the researcher highlighted statements that were essential to the lived experience (in this case the transition), which was done during subsequent readings of the transcripts. These highlighted statements were colour-coded during the reading of every interview. Significant statements were then compiled from each of the participants' stories. These statements formed the subthemes. Themes began to emerge, and notes and paragraphs were written to "capture these thematic statements in more phenomenologically sensitive paragraphs" (VanManen, 1990, p. 95-96). This step involved constant re-reading of the transcripts to ensure that the themes were reflecting what participants were saying. The relationships between the themes were examined within and between each of the interviews.

The findings were then integrated into an exhaustive description of parents' experience of the transition of their child from the PICU to the ward.

### **3.7 Methods to Ensure Rigour**

The five criteria essential for a rigorous study include: 1) credibility, 2) dependability, 3) confirmability, 4) transferability, and 5) authenticity (Guba & Lincoln, 1994; Lincoln & Guba, 1985). Following these criteria ensures that the study is of high quality and that the analysis and results are trustworthy.

#### **3.7.1 Credibility.**

Credibility can be described as the confidence in the truth of the data and involves the way the study is carried out and how the results are demonstrated (Polit & Beck, 2008). One aspect of credibility often involves member-checking to confirm the validity of the findings with the participants. VanManen (1990) recommends follow-up interviews to discuss the themes with participants. The themes in this study were checked with the researcher's thesis committee who were experts in the areas of critical care, qualitative methodology, family-centered care, and pediatrics (in lieu of member checking). This was done to ensure credibility, and to reduce the amount of burden on parents since most were from out of town and it would have been difficult to arrange the follow-up interviews.

#### **3.7.2 Dependability.**

Dependability is defined as the stability or reliability of the data over time and conditions (Polit & Beck, 2008). To ensure the dependability of the data, a detailed description of the research site and participants is provided. The methodology and analysis are also described in detail to allow for the reader's understanding of how the study was undertaken. Throughout the process of data collection and analysis, a decision trail was kept

to provide credibility of the data. Theoretical, methodological, and analytic choices are clearly laid out in the above sections for the reader.

### **3.7.3 Confirmability.**

Confirmability refers to the objectivity of the data (Polit & Beck, 2008). Although phenomenologists do not strive for the elimination of bias, the researcher's assumptions prior to the study were acknowledged. Bracketing was not done in keeping with a phenomenologic design, but a journal was used to note the researcher's thoughts and impressions about the data.

Through the process of transcribing, reading, and re-reading the interviews multiple times, the researcher became intimately familiar with each parent's story, which assisted with confirmability of the data. Confirmability was also ensured in this study by having the thesis supervisor read all of the transcripts and assist in the development and confirmation of themes. The thesis committee members also read multiple transcripts and provided their opinion on whether or not the data reflected the proposed themes. The data analysis process involved multiple meetings with the researcher's thesis supervisor and members of the thesis committee, which served as checks and balances, to enhance confirmability. Finally, quotes from the participants were used to explicate each theme, thus providing the reader with an understanding of how the themes match with the participants' experiences.

### **3.7.4 Transferability.**

Transferability is the generalizability of a study, or how the findings may be applicable to other settings or group (Polit & Beck, 2008). The aim of a phenomenologic study is not generalizability, rather it is understood that the findings refer to a particular cohort of people at a specific time. The findings may be useful for readers in similar settings with a similar group of patients and parents. To increase the potential applicability to other

settings or groups, the setting was thoroughly described and a description of participants was provided.

### **3.7.5 Authenticity.**

Authenticity is the ability of the text to depict the lives being portrayed so the reader can understand the experience, context, mood, or feeling of those lives (Polit & Beck, 2008). This assertion is in fitting with VanManen's view of qualitative writing. Phenomenological writing, according to VanManen (1997) has lived thoroughness, evocation, intensification, and epiphany meaning the reader can picture this phenomenon in the real world in real time, is able to understand the significance of key phrases, and suddenly grasps the meaning and importance of the phenomenon. By reading and re-reading the transcripts, having done the interviews personally, and getting advice and insight on the ability of the text to tell the participants' stories, the researcher hoped to achieve authenticity. The thesis supervisor and committee members read the findings and confirmed that the participants' stories were understandable through the text. By providing participant quotes in the findings, authenticity is enhanced.

## Chapter 4 – Findings

This chapter contains the findings of this phenomenological study including the overarching theme, main themes, and categories to explicate parents' experience of the transition of their child from the PICU to the hospital ward. The findings are supported by direct quotations from the 10 participants who are referred to using a numerical code. Embedded within the themes are the parents' perception of the transfer process, perceived supports and challenges during the transfer and hospitalization, perception of information received during the hospitalization, and the perceived differences between the PICU and the hospital ward.

### 4.1 Overview of Findings

The overarching theme from the interpretive analysis of the interview data was *'Searching for comfort across transitions'*. This comfort could be physical (comfort with the environment), and/or mental (emotional or psychological comfort). Parents sought comfort by trying to rely on and trust the hospital staff to care for their child throughout the illness experience, which encompassed many transitions. In parents' search for comfort, four main themes were revealed: 'being a parent with a critically ill child is exhausting', 'being kept in the know', 'feeling supported by others', and 'being transferred'. Parents' comfort was affected by their level of exhaustion at having a critically ill child, the way parents received information, the kind of information provided, the support received from health care teams and family and friends, whether or not they felt their child was ready to transfer to the ward, what they were told about the ward, and their perception of the care on the ward following the transfer.

The theme 'being a parent with a critically ill child is exhausting' reflected that parents were physically and mentally exhausted when being interviewed. This theme was

explored through three categories: 'watching over my child', 'searching for a plan of care', and 'organizing home and work'. Parents exhibited behaviours of watching their child by physically being present and checking on the care provided by health care staff, needing to know the plan for their child's care, and working to ensure things were organized in the rest of their lives. These behaviours were parents' attempts to increase their comfort, but these behaviours could also make parents more exhausted.

The theme 'being kept in the know' reflected that parents needed to be advised of what was going on with their child and the plan for their child's care. This theme was described through the categories: 'receiving information' and 'seeking information'. Being in the know helped parents to develop the cognitive framework or compass so they could better understand what was happening and anticipate potential next steps for their child.

As parents were so exhausted, they relied on others to help. This was captured in the theme 'feeling supported by others' in which parents talked about the things that both hospital staff and their friends and family did to support them and their child while in the hospital. Under this theme, two categories emerged: 'support from health care teams', and 'support from family and friends'. Support increased parents' mental and physical comfort. It helped them to have a comfortable place to stay and sleep, be able to talk to someone about their worries, know someone cared about them and their child, and was willing to help them at home and in the hospital.

Parents needed to be informed of the plan and information about the ward when it came time to be transferred. The theme 'being transferred' encompassed everything about the transition from the PICU to the ward: from finding out about the transfer and deciding if their child was ready or not, undergoing the transfer which included transfer planning, and getting settled on the ward where parents assessed the new unit and compared it to their

experiences in the PICU. Three categories within this theme captured parents' experiences of the transition: 'pre-transfer', 'the transfer' (getting to the ward), and 'post-transfer' (getting settled on the ward).

It was noted in parents' experiences that there were more than these intra-hospital transitions being experienced. While the aim of the interview was to explore the transition from PICU to the ward, parents needed to tell their story of the experience from start to finish. Parents revealed many transitions: getting a diagnosis and treatment, getting to the hospital and the PICU, going from a healthy to critically ill child, going from home to the hospital, going through changes in work and home life, going from being a parent of a critically ill child to one who was recovering, and going from watching someone else care for their child to resuming some of the care themselves. Parents did not go through the transitions on their own, but relied on others for advice, information, support, and help. Most parents stayed with their child throughout hospitalization and continued to be watchful, worried, and continually searching for comfort.

Table 2 provides the overarching theme as well as outlines the themes and categories resulting from analysis of the interview data.

**Table 2: Overarching Theme and Outline of Themes**

<b>OVERARCHING THEME: Searching for comfort across transitions</b>	
<b>Themes</b>	<b>Categories</b>
<b>1. Being a parent with a critically ill child is exhausting</b>	I) Watching over my child
	II) Searching for a plan of care
	III) Organizing home and work
<b>2. Being kept in the know</b>	I) Receiving information
	II) Seeking information
<b>3. Feeling supported by others</b>	I) Support from health care teams
	a. Practical
	b. Emotional
	II) Support from family and friends
	a. Practical
	b. Emotional
<b>4. Being transferred</b>	I) Pre-transfer (from the PICU)
	a. Your child is ready.
	b. Is my child ready?
	II) The transfer (getting to the ward)
	a. Setting the expectations for the ward
	b. Making the move
	III) Post-transfer (getting settled on the ward)
	a. It's different here:
	– The physical space
	– The level of care
	– The information and communication

#### 4.2 Being a Parent with a Critically Ill Child is Exhausting

Being a parent of a critically ill child seemed to be exhausting, whether the child was still critically ill or recovering. Parents felt that having a critically ill child required constant physical and mental presence on their part. When being interviewed, it was noted by the researcher that most parents had not had a shower, let alone taken the time to do their hair, and it was clear there were more important things than their physical appearance for parents. The audiotape of parents speaking revealed audible sighs and parents' voices sounded emotionally and physically drained. In the audiotapes, parents sometimes laughed at unusual times, such as when talking about something worrisome or scary. On the audiotapes, parents were sometimes mumbling or speaking very quietly. Some parents had difficulty focusing on the interview questions, which could indicate that their thoughts were elsewhere, perhaps with their child and not necessarily on the interview.

Parents, in particular participant 6, talked about *"the worry of wondering"* – wondering what was next. She noted that she would sit in the room

*"just wondering what he's going to, ah...what they're going to say next, you know? That's the hard part of it is sitting there wondering what's gonna come up, and come out of all of this. And there's a big huge worry in the back of my mind, I'm not gonna lie."*

The worry was not only during one specific time, but was pervasive across the entire hospital experience. The worry may have been about diagnosis or the future, but many parents were concerned about whether their child would survive. This was revealed in the statement that participant 6 felt she was thrown *"for more than a loop. (laughs) Feels like a kick in the face sometimes...That's one thing I don't want to see is my children die before myself, you know?"* Parents' minds were constantly thinking about the situation, but because they could

not know with certainty what the outcome would be or how things would proceed, they remained worried. The constant worry left parents exhausted and searching for mental comfort.

Some parents also found the entire hospital experience to be “scary” for them. One participant (6) stated the experience of being admitted to PICU was “...*probably the scariest moments of our lives. But, ah....we’re dealing with it one day at a time, right? That’s all we can do ... It does scare me because it’s my child.*” All parents experienced some level of fear of the unknown situation, an indefinite timeline, and an unknown outcome. Parents were scared their child might die, that they might end up disabled, or that they would be ill for a long period. Parents were sometimes scared because of previous traumatic hospital experiences. When the child was transferred, these fears of the unknown were renewed for parents, and so the transition was often scary and left parents searching for mental comfort.

Parents expressed that their child’s illness had been a long, emotionally and physically exhausting process. One participant (3) noted the need to take a break from staying in the hospital with her child because she was so tired:

*“this time I haven’t really slept in the room as much as I have before, so... His father slept a couple of nights, and his brother slept here last night, (laughs) so... But, I was, like, exhausted yesterday, I wasn’t feeling good, so I told his brother it’s – yeah – it’ll be good if you can sleep in there ... it wears on you, so...yeah...”*

This exhaustion sometimes was related to the child having multiple hospital admissions, or being from out of town, thus farther away from their support systems. Parents were also tired because they were not physically comfortable in the beds in their child’s room, or were woken up at night by nurses checking on the child. However, despite this exhaustion, parents stayed with their child at all times.

Another marker of parents' exhaustion was that they had difficulty remembering the entire process of events. Participant 10 stated, *"there's a family room, I guess, that we stayed at the first night or two, I can't remember – it's been a real fog."* Another parent (participant 9) talked about being so tired she was forgetful: *"mostly because I've been staying, and I'm tired, and they can tell me something but I tend to forget it."* She recommended to other parents *"pay close attention to what they're telling you. And maybe write it down, (laughs) 'cause you'll forget as soon as they leave the room."*

The exhaustion at having a critically ill child was reflected in the three categories of 'watching over my child', 'searching for a plan', and 'organizing home and work'.

#### **4.2.1 Watching over my child.**

The sense of watching over the child was prevalent from the interviews – both through the parents watching over the child themselves, and the parents receiving mental comfort from the sense that a professional was also watching their child. Parents watched over their child to seek comfort, but also continued this behaviour because they lacked comfort. This sense of always having to watch contributed to parents' exhaustion.

Some parents felt more mentally comfortable in the PICU because someone was always watching their child. One parent (10) noted when his child was intubated, *"there was always somebody in the room. They said that's their policy, not even for a washroom break, nothing; someone has to be there all the time, and that was good."* Some parents referred to this constant nursing presence as monitoring, rather than the medical reference to bedside cardiac or respiratory monitors. Participant 3 explained "monitoring" as, *"just kind of keeping, I guess, watch over him more closely. I guess, you know, watching his vitals more. ... And actually seeing him more, and being more familiar with his information. (laughing)"*

To parents, monitoring was the same as watching. They felt more mentally comfortable

knowing that in the PICU there was always someone right there watching their child. This one-to-one nursing and “level of care” in PICU helped parents to begin to feel mentally comfortable. As participant 7 said,

*“not that it was a positive experience, in the sense that what’s going on isn’t positive, but the level of care has been so great, and that’s really reassuring and encouraging, and you know, although, you know, no one wants their kid to be in ICU, we were also happy that he was being in a place where he was well looked-after, and he was safe, and, you know, that if anything happened they could respond immediately, that sort of thing. So, those were all very encouraging things, so, yeah, so, in the sense that it has been reassuring to us that he’s gotten such good care.”*

For some parents, the level of care did not take away the worry, the sense of vigilance, or the need to watch their child. Often someone from the family or a parent was constantly with the child (both on the ward and in the PICU):

*“when [patient] was in ICU, I spent all day with him, and work was great about giving me time off. And [husband] spent all night with him, that’s how we divided it up. So, there’s still someone with him 24 hours, like, either a grandparent, one of his parents, or his caregiver with him all the time, so...”* (Participant 7)

Participant 9, talked about staying in the hospital the whole time, while her husband only stayed during the PICU stay: *“I haven’t left, just briefly (laughs).”* This showed that parents felt the need to watch over their child despite acknowledging they were being closely watched in the PICU. Some parents were not mentally comfortable leaving the hospital or leaving their child and felt the need to physically be there watching over their child to make sure everything was going well.

When describing the transfer from PICU, some parents noted this loss of nursing presence (“monitoring”) and it made them feel more vigilant, worried, and anxious, which left them searching for mental comfort. Participant 1 explained how her level of comfort was different because she felt her child was being watched more closely in PICU than on the ward. She stated,

*“we don’t leave her at all, when we’re on the ward. Either myself or my husband are always here 24/7. I would just never leave her. There [PICU], I never left her either, just because that’s the type of parent I am, but I would have felt comfortable if I had to ... But, yeah, I wouldn’t do that on the ward.”*

Participant 8 also felt that she needed to be more watchful on the ward, and the patient needed to have the call bell available since she felt there was not someone watching her child as closely any longer. This constant worrying was exhausting for parents, as parents continued to watch because they were not mentally comfortable just leaving their child.

One parent (participant 3) talked of a past experience where she had to advocate for and watch after her child and how that affected her current perception of things and feeling of needing to still be very watchful. She said,

*“He was in the ICU and then [the brain tumor] was...it was hemorrhaging then, and so... he stopped breathing, his heart stopped, and then they did emergency surgery right away. He was in the room, actually, the nurse had called them, because I had told her that the school nurse thought she might have seen one eye dilated, and so I kept on telling everybody that, like, “He had one eye dilated.” So, um, because it’s like, we’ve learned that, like, communication’s not that great when you go between places, so I tried to, like, tell everybody as much as I could about him. And, um, the nurse in the ICU... checked his eyes, like, every hour after I had told her that, and she*

*said she started noticing that one was starting to dilate again. So she called up, like, everybody – the surgeons, and...(sigh) the neurosurgeon doctors, and everybody. So when he actually did stop breathing, everything was in his room, which was like, good (laughing). Yeah, so that, for us that's, like, a big, you know, a big thing.”*

This mother said that the staff on the ward and in the PICU did not know this previous story. However, this past experience affected her perception of hospitals and hospital staff. Perhaps because of this previous experience, participant 3 was always searching for mental comfort with staff and the care her son was receiving, as she was constantly checking on things and watching over her child. As she explained,

*“I... kind of keep track of what is going on, what medications they're on..., because that's another thing that we've kind of gotten in to. It's like, anytime they come in with a medication, I always ask, “What is it?” you know, “When did we give it last?” you know and all that kinda stuff.(laughs) You know I taught him too, before you take anything, ask what it is. Yeah, cause mistakes happen (laughing). So, just kind of keep track of all the stuff because you might have to tell the other people... what's going on.”*

Participant 3 went on to say:

*“what I... always try to do is, like, “He was getting that medication, he's doing this, he's doing this,” and I try to tell them, like, as much as I know. Then when the other ones come in, I try to see, are they doing it right and (laughs), you know, kinda trying to bridge the communication.(laughs)”*

She was worried because of what had previously happened, and this worry was increased because her son had undergone the same type of surgery as in the past. It seemed that this

mother might never be totally comfortable and would always be watchful after having gone through such a traumatic experience.

One parent (participant 6) talked about getting mental comfort from reassuring physical symptoms in their child, which decreased her need to be watchful: *“well, him breathing better is just a good sign to me. And that’s a relief, knowing that he can breathe. And I can feel comfortable going to sleep at night knowing that he’s ok. You know?”* Parents’ mental comfort was influenced by the perception that their child was being watched over closely by the nursing staff and the perception that they were getting good care. Parents could feel more comfortable and feel less need to be watchful if they saw reassuring signs that their child was doing better. Signs of their child improving told parents that the care they were receiving was helping them, which provided some mental comfort and reassurance that they did not need to watch over their child as closely and that they could trust the staff.

#### **4.2.2 Searching for a plan of care.**

One of the factors that parents found most worrisome and stressful was knowing their child was ill and not knowing what would happen next. Parents needed a plan of care. This care involved getting their child diagnosed, getting them the proper treatment, and figuring out what care would be required in the future (whether it be more treatment, a longer hospital stay, etc.). Often, all of their questions could not be answered (i.e. they did not know what to expect for the future or did not have a firm diagnosis), and parents were left without a complete plan of care. This searching for a plan of care left parents feeling exhausted and searching for mental comfort.

For some parents, they really had to advocate for their child to get a plan for proper diagnosis and treatment. Participant 6 talked about her situation after visiting a doctor’s office,

*“the doctor said it was..., like he listened to his chest and it sounded like the flu and that, yeah, it had a gargle, and horrible breathing in his chest, but he never sent him for xrays or anything like that. He, ah, prescribed some prednisone, and new asthma puffers and all this other stuff and...So we walked out of there, and my son was complaining about a pain in his chest. He said, “That’s probably a pulled muscle”...– well a couple of days later, he broke out. And he went to the hospital the first time in [our home city], and they said, “Oh, that’s the measles” .... Well, you know, I don’t think measles clears up in two or three days... Well, this here cleared up in about two or three days and...Then he still just had a horrible, horrible problems breathing. So my dad said, “Well, this is crazy, it’s ludicrous,” right?”*

After this, the child was still getting worse so the child’s grandfather brought him to an emergency department: *“then they done some more xrays, and I guess that’s where they started seeing...the lump over his chest – over his heart, and started seeing all the lymph nodes, they were all swelled out and...”* This mother expressed her concern that despite her best efforts, no one was listening to her.

*“So, thank God, still, I – I think it’s in early stage anyways. You know, early stage of it. And I’m thankful that they caught it enough to send us here and... I believe that a lot of doctors... do not really look over a patient, or whatever... I think they bypass a lot of things, but it actually ticks me off.... Yeah, ‘cause you never know what could be wrong....”*

This participant tried to advocate for her son to receive the care she thought he needed but as a parent, her opinion was not heard. Her trust in the medical system was effectively broken, making it difficult to be mentally comfortable during this current hospital stay. Parents felt like all the pressure was on their shoulders to get their child help while they were ill. This

searching for a plan of care was exhausting for them, and they sometimes felt like their voices and concerns were not heard leaving them also searching for comfort.

Participant 7 also talked about advocating for her son to be seen by a specialist for diagnosis and treatment before coming to the hospital:

*“we had asked for a referral to ENT, um, just because he had a – sort of, he had a hoarse voice, and sort of a high-pitched voice ... He was in speech therapy because of that, and the...speech therapist told us that, you know, “This isn’t just a speech problem, this really sounds like there’s something going on with his vocal cords”. ... So that’s why we had asked for the ENT referral, and then when Dr. [P], his ENT specialist, saw him – she was like, “Well, this is really a breathing issue right now because it’s significantly blocking his breathing airway”. Ah, so, um, that’s why she moved fairly quickly to have the surgery soon after she first saw him.”*

This parent was successful in getting her voice heard, getting her child in to see a specialist, and, as a result, getting a plan for him to go for surgery very quickly. This was reassuring and mentally comforting for her to know she was being listened to. It seemed that the level of comfort for parents was positively influenced by the acknowledgement from medical personnel that the parents’ ideas were valid, and the feeling that they were being heard.

As noted in the previous chapter, six out of ten parents had children who were admitted for pre-planned surgery. Some parents talked about the stress of not knowing exactly when surgery was to take place. This left parents searching for mental comfort because they were not able to plan the rest of their lives around their child’s hospital stay. As participant 3 said,

*“We didn’t really know, exactly, I mean we didn’t know for sure. It wasn’t until Friday that they told us, for sure, that he needed the surgery... Actually, they were*

*going to have it on Monday, and they couldn't schedule it, and then they tried to have it on Wednesday, and they couldn't – or they scheduled it Wednesday, but then there was, like, an emergency. And then he had it on Thursday. But, before that, there was probably a couple weeks that we were thinking maybe he might have to have it, but we weren't sure.”*

Parents who knew the planned date and time of the surgery and who felt the plan was coming together quickly and that their child was getting the care they needed were mentally comforted, even if it meant less time to plan the rest of their lives.

Three participants had to have their child transferred emergently from other hospitals to the research site. Participant 6's child was transferred by air ambulance from another city 6 hours away:

*“my...father and I brought him to the hospital in [our home city], and then they done some xrays on his chest and that, and they, ah, seen that his lymph nodes were pretty huge, and, ah, so they done some more testing I guess (laughs), and then they flew him here and everything, and seen a tumour over the top of his heart.”*

Participant 4 had a child who was also transferred by air ambulance emergently from an outlying hospital:

*“he was having trouble breathing. So... the week before we had him in the hospital in [our home city], and he stayed there for, well three...three days, and then he came home.... All of a sudden it hit him, he had trouble breathing, and so we brought him back to [that hospital], but they looked at him there and they decided to air-lift him down to here.”*

It was scary and distressing for parents to be in a hospital that could not help their child and to know they had to be moved emergently. It seemed to reassure and comfort them once they got to the hospital and their child was then able to receive the care they needed.

Thinking about the future for parents was worrisome and exhausting because of all the uncertainty. Most parents had some timeline for when their child would expect to be well enough to go home, but for some parents this admission was just the beginning of what was to be a very long process. Some parents still did not have a firm diagnosis after moving to the ward. Therefore, they could not know how long her child would be in hospital, whether or not he would survive, what kinds of treatments he would require, or the timeline they would be expecting. Not knowing a plan of care, especially for the future, seemed to be one of the most worry inducing and exhausting facets of the hospital admission for parents. As participant 6 said,

*“Not knowing, and...ah, can something be done? Is it totally cancerous, or is it not? Is it...you know. The thing he has is lymphoma, that’s what they’ve named it too, and that, so... It’s, yeah, it’s the worry of wondering.”*

Other parents did have a plan of care for their child, but this involved treatment not available in their hometown. Participant 8, for example, explained they would have to stay near the research site hospital for a while:

*“we have to stay here for upwards of five to seven days. You know, unless they let us go. But, ah, because there’s no surgeon in, um, [our home city]. There’s a cardiologist, but, um, he needs to have someone there, and, unfortunately, our cardiologist is going on vacation, so. But, they said maybe, ah, first they said Friday we could leave, and now they say maybe next Wednesday we can actually head back*

*to [our home city]. ... We just want him home for Christmas. But, yeah. But, yeah, that's good news."*

For another parent, the long process of care and treatments required proved to be similarly exhausting. Participant 7 said,

*"It's going fine. I mean, it's just a little exhausting. (laughs) I mean, but, it's a long haul, too, it's not like someone who's just in for a week or so. You know, we know that he's definitely going to have to stay [for weeks], at which time he can get the stent out, and then he has to go back to ICU for just probably 24 hours, or overnight – that sort of thing.... And the trach will probably come out two weeks after that. So, there is a possibility of going home for a period of time after that, but there's a question of getting resources, and we'd have to – we have to get the training done, and everything for that so. And also nursing resources over the holiday is a big issue, so. So, it's not – we're not sure what's gonna happen there yet, so ... it's like tiring...we're just happy he's getting good care, and he's doing ok. He just seems a little grumpy. No one wants to stay here (laughing), so."*

All parents experience exhaustion related to the uncertain timeline regarding discharge. All the steps and barriers that might be involved in getting their child well and home left parents searching for comfort with an uncertain timeline.

#### **4.2.3 Organizing home and work.**

Parents spoke at length about organizing their home and work life. Most parents felt the strain of wanting both to be with their critically ill child and still fulfill other roles at home (e.g. mother/father to other children, spouse, career/occupational roles). All parents had other children at home, and most parents were from out of town. They tried to organize everything so that they and their families could be physically and mentally comfortable.

Some parents talked about not having a lot of time to plan these details at home. For example, participant 7 noted,

*“So, it was like, I guess we had a week and a half, or two weeks before – from when we first saw [the surgeon] to when the surgery was scheduled, so .... So, not a lot of planning. Um, (laughs) it was, like, two weeks, then it was like, “Oh, we’re gonna be here for six weeks now. (laughs)”*

Knowing they would be in the hospital for a long period of time caused parents to wonder how things would work with their other children, their spouse, and their jobs.

For most parents staying in or near the hospital was seen as a benefit: one that increased both their physical and mental comfort. It was helpful and comforting for parents to be near their child, to not have to worry about driving back and forth, and to have a place to sleep or rest. As participant 4 explained, it was nice to have the ability to stay in the hospital:

*“That’s the thing, somebody wanted to stay here with [patient], but somebody also had to be at home with our other son. (laughs) And that’s...that’s one thing I found that was great here, that they let you stay with your child.”*

Participant 9 also talked about staying in the hospital the whole time, and her husband coming back and forth for visits:

*“[my husband]’s comfortable going back and forth. I think I’ll probably stay here until [my husband] takes me home. (laughs) ... Um, ‘cause I’m so tired and worried, and I’m – I’m up with her a lot, um, it’s really nice that we’re able to stay here, because, I think if I had to go home every night, I would be a whole lot worse than I am. And I think my mistake yesterday was thinking that I could actually get in to a vehicle by myself and drive, with lack of sleep and her on my mind, and, so...”*

When this participant left for an afternoon the day before her interview, she got into a car accident only blocks from the hospital, showing how exhausting, stressful, and taxing it was for her having a critically ill child.

While staying at or near the hospital was convenient, it caused some difficulties with organizing the home life, balancing parenting duties between two parents or other family or friends, and sleeping in the hospital. The ability for one parent to stay in the hospital did not solve all the problems or worries for parents. As participant 1 explained,

*“We’re fortunate that we can do it..., so, yeah, I mean..., I’d rather be home (laughs). But, yeah, for us, it works. We switch off at around... starting between 7:30 and 9 at night... my son continues his routine. Fortunately he’s in school, so he goes to school and he goes to daycare, and, yeah, fortunately both my kids are easy, so he just kinda rolls with it. So we tell him, you know, who’s gonna pick him up, and who he’ll see in the morning when he wakes up, because who puts him to bed is not who’s at home in the morning..... Yeah, we – we make it work. You know, it’s short-term.”*

Other parents talked about switching off with their spouse so that someone would always be at the hospital with their child. Participant 2 said her husband was at the hospital more than her:

*“he’s been (sighs) here more often than I have, right? We have a three year old at home, so we kind of want to spend time...don’t want to make her feel like we’re... not around anymore, right? So, you just kind of have to find a balance, and he’s more comfortable here than I am, so...we just kind of make it work. It’s been fine.”*

Being apart from their spouse and sleeping in the hospital were not easy for parents, but they thought it was best for their child. Parents lost their normal relationships with their spouse and children, and had to cope with sleeping apart from their family, which may have

contributed to their level of physical and mental comfort. These parents tried to find a balance that worked for them between being at the hospital with their child while still fulfilling their other roles at home or work, but it was difficult, and emotionally and physically exhausting.

Knowing that there were people taking care of things at home or work helped the parents to be more mentally comfortable while in hospital. For example, participant 7 outlined how their family made things work:

*“so [patient] has a twin brother... Both [my husband] and I work....ah, um, so we’ve had our parents – my parents were up for two weeks, and then, um, [my husband]’s mother is up, and then my parents are coming back, and then, so we have, for the whole time period, we’re very lucky that our parents have agreed. And then we also have our nanny... who... is looking after [patient’s brother] or coming here to the hospital, whatever we want, to also help us to give us a little bit of a break.”*

Participant 7 continued to work while her child was hospitalized because she lived in the city. It was still difficult to plan to get to work for her:

*“So sometimes, for a few hours, just so we can go to work for a few hours a day, we either have a grandparent or his nanny come to spend some time with him, so, that’s sort of how we’re organizing it.”*

It was not easy or comfortable for parents to live through these transitions: having their life in upheaval, having to split their time, not seeing their spouses regularly, and going back and forth between home and the hospital. Most parents seemed to find a balance. Although they said the situation was not ideal, parents held on to the fact that they hoped it would be short term (although no one knew for sure), and they were thankful for the ability to make things work for their child.

### 4.3 Being Kept in the Know

Parents relied on health care professionals for information about their child's illness and what to expect regarding recovery. This theme was best explained through the quote from participant 1 "*information is the absolute key to my comfort level*". Parents saw information as a way to be involved in the care of their child and being kept in the know helped parents to be more mentally comfortable with the care, the plan, and the treatment their child was receiving. What parents really wanted to know was what the future would hold for them and their child. When the future could not be predicted, parents were left searching for mental comfort.

Parents described behaviours of both receiving information (where a health care team member included them in rounds or meetings, or gave the parents information voluntarily), and seeking information (where parents actively asked questions, and clarified to ensure they were getting all the information they needed). Parents wanted and relied on the health care providers to be forthcoming with information in order to increase their mental comfort throughout the hospital stay. When staff were not forthcoming parents had to actively seek this information.

#### 4.3.1 Receiving information.

Parents talked about 'receiving information', which was the way they were being kept in the know. Hospital staff offered information without being asked. As participant 10 explained,

*"[the ICU team] were very very proactive at getting information to us. One fellow...a doctor...he was a phenomenal doctor and, not only did he do all of the procedures that needed to be done, but he explained everything – and explained it so that I was*

*comfortable with them. I bombarded him with questions, and, and he made sure that we were comfortable with whatever procedure.”*

Parents wanted to be in the know, and to have things explained to them, which helped to make parents mentally comfortable. Participant 10 went on to explain why this was so important:

*“this one fellow...has gone out of his way many times to hunt us down to say, you know, “Here’s what we’re doing with [patient], if you want, come on over and look at these ultrasounds, I want to explain this,” or, “Look at this x-ray, here’s what I’m doing.” He’s really been proactive, and, ah, that’s, again, you know, that’s very appreciated, it is, because it takes away that wonder.”*

That this member of the health care team went out of his way to locate the parents and give them information was mentally comforting for them.

Participant 6 confirmed the importance of information, saying that everyone gave her information, and *“nobody’s kept us in the dark I don’t think.”* She confirmed, *“Anybody that’s coming into the room – they say exactly what’s going on, and where things are at, and... what they’re doing, yeah...I feel really secure because that’s how they are, they just explain everything here, and that.”* That this parent mentioned feeling secure shows how mentally comforting it was to receive information.

Parents received information in different ways. Most of the time, they were approached by staff and received information through an informal update. Alternatively, parents sometimes received this information through a more formal meeting or during rounds. As participant 6 explained, she took part in a formal meeting about her child’s care:

*“Well, after things started changing, and everything with his chest tube, and that, and it started being dryer and everything. We had a meeting downstairs [in PICU],*

*the doctors, the nurses, and everything, outside the door and they figured that it would be good for him to come up here now, so..."*

This parent appreciated being asked to be involved in a meeting. It was mentally comforting to know that it mattered to staff that the parent was at the meeting. Parents appreciated receiving this information without having to ask.

Participant 1 described some of the information she received, including:

*"keeping me up to date as to when they made the request for the bed, when the request was granted, when the team was going to come down to assess her, um..., I mean, I knew, step-by-step what was going on. I mean, that was the nurses... (hesitant) The nurses were keeping me informed."*

With the receipt of this information, parents had reference points to note their child's improvement.

Parents in general seemed to receive a lot of information in PICU without actively seeking it. It seemed that the hospital staff, specifically nurses and doctors, kept parents in the know in such areas as updates on surgery being performed, day-to-day updates, next steps, and plans for recovery. Parents appreciated receiving information as this made them feel more mentally comfortable with the plan of care.

#### **4.3.2 Seeking information.**

Parents sought information as a way to be involved in their child's care, and to fill in gaps in their understanding of the process or plan of care. Seeking information was used as a supplement to receiving information, and was another way parents were being kept in the know. Some of the ways parents sought information was through participation in rounds or by asking questions of health care providers to either clarify or confirm information they had heard.

Parents chose to participate in rounds because their voice could be included in discussions. As participant 1 said, parents could “*listen in, make corrections, ask questions, I was able...I participated fully in her rounds.*” This participant went on to say that she “*didn’t have to join, but I like to know what’s going on with my daughter,*” and that she “*really appreciated that in PICU..., to be given that opportunity to hear, and know, and... that’s where I get all my information. That’s where I get my information first hand, right?*” Parents saw rounds as their way of seeking first-hand information to ensure they had accurate and current details. This form of being kept in the know helped to increase parents’ mental comfort with the plan and decisions made about their child’s care.

Parents also asked questions to confirm the information they had heard was correct or to check that things had not changed with the plan. Parents sought information mainly from nurses since nurses were the most readily available to answer questions. For example, participant 7 talked about seeking information from nurses as her main resource for being kept in the know. She said nurses were “*patient with questions, they were incredibly knowledgeable and would answer any questions, they were very attentive... from the most serious concerns to more minor things, they were very helpful on all fronts, so.*” Particularly in the PICU, parents appreciated the nurses’ constant presence because it meant they were always there to answer questions.

Parents, when seeking information, went out of their way to find someone to answer their questions, and made sure they understood fully what was being told to them. This sometimes involved double-checking information they heard from one party with another to ensure accuracy or understanding. For example, if the nurse gave the participant information, they would double check with the physician and vice versa.

When parents got to the ward, they found a difference in receiving information because of the decreased visibility and availability of staff to answer questions and get information for them. Thus, parents talked about having to seek information more frequently and actively on the ward. Participant 8 talked about the difficulty in finding out test results on the ward and how this was different from how they got information in the PICU:

*“[patient] went for an xray this morning, and I think we’ve asked three times how that was, assuming it was fine, cause we never heard anything, but, nobody told us. You know, he had already gone for it and come back just as we arrived this morning. And, ah, he told us he went, and, no results. Here we are, you know, 7 hours later, so, I don’t know. (laughs) That’s the difference. You know, that’s the huge difference right there, so.”*

Parents, on the ward, had to seek someone who had the answers they were looking for, instead of receiving information freely as they had in the PICU resulting in a longer wait for information. Having to seek information, instead of being offered it, decreased parents’ mental comfort on the ward.

Seeking information as a form of being kept in the know was parents’ way of staying involved in their child’s care, and helped them to be mentally comfortable during the hospital experience. Parents sought information by being involved in rounds, asking questions, clarifying information, and double-checking. Sometimes on the ward, parents had to seek information more actively as they found information was not offered as readily and it was hard to find someone to answer their questions.

#### **4.4 Feeling Supported by Others**

Parents relied on the hospital physical resources and staff in addition to their friends and family for both practical and emotional support. Practical support was defined as the

actions providing aid which reduced stress (for example, finding parents a place to sleep, food, taking care of other children). Emotional support was defined as the caring, empathetic actions that helped parents to trust and rely on the person providing the support (for example, listening to the parent talk, or caring for the parent through thoughts or actions). The two categories in this theme were support from health care teams and support from family, and friends. This support let parents focus on their child while having others look after home or work and resulted in increased parental comfort.

#### **4.4.1 Support from health care teams.**

Support was provided by the nurses, physicians, and social workers, as well as through physical resources available at the institution. There were two subcategories of support from health care teams: ‘practical’, and ‘emotional’. Practical support included, for example, having a family lounge, kitchens, a place to stay/sleep, and getting information about where to do laundry, or buy groceries. Practical support mainly served to increase parents’ physical comfort. Emotional support was reflected in how health care personnel supported parents and showed parents that staff cared and were genuinely concerned about their child and them, which increased their mental comfort.

##### **4.4.1.1 Practical.**

Staff provided practical support by having family rooms available, organizing somewhere to stay, and seeking monetary resources for parents. Participant 3 talked about *“the family room and all those things, those really are helpful too, and being able to sleep in the rooms...you know? That’s really helpful too, so...”* The social worker helped with *“just getting everything organized, like, making sure that we had places to stay, and making sure that we had the money, and...”* (Participant 5).

There was a charity-sponsored residence and motel across the road from the hospital where many parents stayed. These rooms had to be booked by a social worker. As participant 10 explained, the social worker

*“helped to arrange for alternative housing after, after here. They got us into [charity-sponsored residence] for a couple of nights...And, after that, ah, they ensured that we had a contact at the [motel]. And made sure that we had a room available, and everything, so, we didn’t have to do much on our own. It was really good. They let us just worry about [patient] and I can’t say enough about that – they did an amazing job.”*

Social workers also gave parents advice to assist with practicalities of being away from home. Participant 10 continued,

*“things that we weren’t thinking of that were fairly important, ah, like housing, like, like making sure that, you know – we’re going to be here for a longer term than maybe we’d packed for. So, she said, she pointed out where we could do laundry, she pointed out how close quick shopping were. Without making a deal of it, gave us, you know, “Here’s where some shopping spots are that down the road you might need them, here’s where you can do laundry, at the hospital”, or wherever it happened to be.”*

Parents appreciated the practical support received from hospital staff during their stay because this help increased both physical and mental comfort. Practical support increased their physical comfort because parents had a place to sleep and rest, and it increased their mental comfort to know there was someone looking after these concerns for them, so they could focus on their child. Participant 3 also stated that these resources were necessary: *“you know, those kind of things are good. Because basically, you know, you’re living here for a*

*while, so... (laughs)*” Participant 10 also spoke of how important it was to have this practical support:

*“that was good because we tend to focus on the immediacy of the recovery or what’s going on with our child, and don’t think about all the other things that we’re going to need to do. And we’ve actually had to use all of them, too. We’ve done laundry a couple of times here, and had to shop to get the things that, of course, we didn’t bring.”*

It was clear that the practical supports offered by the health care teams and the services available in and near the hospital helped to increase parents’ physical and mental comfort.

#### **4.4.1.2 Emotional.**

Few parents could recall details about emotional support received from health care teams. It was initially thought that emotional support would be seen as someone asking the parents how they were doing and providing care in the way of listening to their concerns. However, when parents did talk about emotional support from health care teams, it was often in very general terms. As an example, participant 3 stated: *“I mean, the nurses are always very supportive, you know? They really kinda.... reach out, you know? So I think that..., you can notice that they’re doing it – you know, they do good. (laughs)”* Participant 4 talked about health care teams support, saying, *“the thing is...well, they’re also polite...they’re also...like they care, they’re very nice.”* Participant 2 also saw this support in general ways, explaining, *“on the day of the surgery ... there was... a social worker, and she was just, kind of checking in, like, “Do you guys need anything”, or, “Can I do anything?” That kind of a thing...”* Many parents did seem to feel supported and mentally comforted by the health care

team but often could not identify specific examples of emotional support as defined by the researcher.

When parents did provide specific examples of emotional support, it involved someone checking on their child, offering advice, suggestions, and answering questions.

Participant 10 expressed that he saw the emotional support as concern for his child:

*“So, it always seemed that there was somebody coming and checking on him ... with true concern, not just medicinal interest, but true concern. And they made sure that – to express that they wanted to see us before we left ... so, they seem genuinely interested.”*

For this parent, the staff showed they cared about him and his son by checking in and wanting to see him again when he was better. It seemed to be some of the more simple actions that parents remembered most.

Another form of emotional support was when staff cared enough to listen to their concerns and answer their questions. As participant 7 explained,

*“Definitely the nurses, and then ... the doctors ... even the ICU doctors...who are clearly very busy, were always patient with answering questions, and very tuned in to parental concerns, and, making sure that, you know, you understand what’s going on”.*

Being tuned in to parental concerns was different from giving information. It suggested give-and-take in the conversation that parents saw as emotionally supportive and appreciated.

Participant 5 also likened this type of information to emotional support:

*“I guess just that there’s a lot of support, and everybody’s always willing to answer any questions, and... just, them always asking, you know, are you ok, do you have any*

*questions, um..., making sure that you understand, kind of, everything that they're telling you, and..."*

Of note is that only one parent mentioned being asked how she was managing. Participant 6 talked about the experience of being approached by a social worker as an example of emotional support:

*"the social worker – she came to talk to me, or whoever. She was doing rounds around the floor, there, just to talk, and, she was probably the most comforting... She's the one that approached me, and, ah, I was, ah, sitting in ICU, in the waiting room with my sister at the time, and she just came up and she told me who she was and just had a conversation. She asked how I was feeling and that and how's things going and everything..."*

That someone asked how she was doing seemed to mentally comfort this parent. Whether this intervention actually did not happen for other parents, or whether parents just did not remember or think to mention this act is unknown.

Of interest are the limited comments about emotional support from health care teams. Despite stating in generalities that people cared about the child and them, most parents were unable to come up with direct examples of emotional support from health care team members. Instead, parents emphasized the importance of practical support, such as finding them a place to stay.

#### **4.4.2 Support from family and friends.**

Parents also received support from friends and family who helped by taking care of things at home and work. There were two subcategories of 'practical' and 'emotional' support provided by family and friends.

##### **4.4.2.1 Practical.**

Family and friends were seen as offering practical support in various ways. Some by helping out: *“But, yeah, family and friends..., people always rally, right, when... a child’s in the hospital, like, people just kinda like, step up you know, like, “Whatever you need, we’re good.”* (participant 1). Others offered to take care of other children at home:

*“Oh, it’s such a relief! Because you’re kind of like, I don’t really wanna find a babysitter every day, right? That’s not nice, you know...not nice for [3 year old daughter], it’s not, um...it’s just so uprooting and we wanted to keep her life as normal as possible, with her normal activities. And if she’s being shuffled here, there and everywhere ... it’s not good for anybody.”* (participant 2).

Some offered rides in to the hospital: *“My sister helped out, my parents helped out, even our next door neighbour helped out – took my wife in for a visit yesterday.”* (participant 4). It was mentally comforting to parents to know that there were people rallying behind them and willing to do little things to make their time in the hospital easier.

#### **4.4.2.2 Emotional.**

Parents identified receiving emotional support from family and friends who were available for them and listened to their concerns. As participant 6 said,

*“Well, they say talking is good. ... You know, talking, and getting it out. What’s on your mind, say it. And that could be helpful, could be worse. (laughs) But, they’re there for me. I could call my oldest sister that lives here in Ottawa anytime day or night and she’ll be here. If I need anything, she’ll bring it, and that. Same...she’s been saying that to [patient] too. Anything, you need it, call her and she’ll be here...”*

Participant 10 also stated there were a lot of people supporting his family:

*“We’ve been, been almost overwhelmed by all, and like, I mean, from, from... ..  
From friends, family, my – I’m in the military and I’ve had a couple of the, my bosses  
come up and check in on everything and make sure everything’s fine.”*

These examples of practical and emotional support by family and friends served to increase parents’ mental comfort during the transitions they were undergoing with their critically ill child. Knowing that they had someone they could call for a favour, someone who could help at home, or people thinking about them, helped parents be more comfortable.

#### **4.5 Being Transferred**

The theme ‘being transferred’ encompassed moving from the PICU to the hospital ward. It was noted that there were three stages in this transition – the pre-transfer stage, the transfer, and post-transfer. In the pre-transfer stage, when parents were told their child was leaving the PICU, they assessed their child’s readiness for themselves. In the transfer, parents revealed how they were prepared for the transfer and the actual physical move. Finally post-transfer was the point when parents and their child were on the ward. Parents described their physical and mental comfort there, often comparing various aspects of the ward to the PICU.

##### **4.5.1 Pre-transfer (from the PICU).**

When it was time to leave the PICU, parents lost any sense of mental and physical comfort they had developed there. Eight out of ten parents believed that the child was leaving the PICU because they were doing better. Two parents were told that their child’s PICU bed was needed for another patient. Few details about the transfer were given to the parents. However, most parents also assessed the situation for themselves, and decided if their child was ready for transfer based on more practical cues, such as what the child looked like and if they were eating. Four out of ten parents thought it was too early for their child to

be transferred or were unsure of their child's readiness to leave the PICU. The pre-transfer was described through the two sub-categories: 'your child is ready' (in which parents were told by the health care team that it's time to leave the ICU and why), and 'is my child ready?' (where parents evaluated for themselves and came to a conclusion about their child's readiness to leave the PICU).

#### **4.5.1.1 Your child is ready.**

Parents were told their child was ready to leave the PICU in different ways and by different members of the health care team. Nurses or a combination of nurses and physicians told most parents. As participant 8 says, *"I think [the nurse] just told us when we got there that morning, so. Yeah, I mean the doctors told us too."* Participants 3 and 4 were both told by the PICU nurse: *"[a nurse] told us that he was gonna move"* (participant 3), and *"well, the nurses let us know"* (participant 4). Only one parent (participant 1) talked about the plan to move being discussed on rounds: *"it was discussed during rounds that, depending on how she progressed during the day, then they would look to try to get a bed for her just in the regular ward."*

Parents also were given a variety of reasons as to why their child was being moved. These included that their child was "doing well", "doing better", and "stable". As participant 4 explained, he was told *"that he was doing very well, and they didn't need...he didn't need to be in the ICU any longer."* Participant 2 got similar information:

*"she was doing really well in the PICU and they just, um, they told us that she's...that she's ready to...to be moved out if we have a bed and if we have a nurse, then she can go to the floor. She's doing very well."*

Participant 9 also knew her child was doing better, but was told that it would be better for her child on the floor now. As she described, staff informed her

*“that she was stable enough and everything was fine that she could go up. Her pain was under control, and, it was time that she could go up. And it would probably be better for her, seeing other people, and kids, and stuff like that.”*

Most parents received basic details (i.e. your child is doing better), and not specific criteria. A few parents got more information such as with participant 7:

*“we sort of knew, I guess, midway through the week that it was probably definitely a full week’s stay, could be longer depending on how the first trach change went. Ah...so, Monday, Tuesday, we were expecting probably after the trach change, we would be moved, but it really still depended on the trach change. And then, that went very very smoothly, and then they had a room, so we were able to move up on the Tuesday night then. So...”*

There was an acute awareness on the parents’ part that there was a demand for beds in the ICU, and so they had to leave: *“I think he actually probably should have stayed in ICU probably another night or two, but, they did...they didn’t have the beds, (laughs) so...”*

(participant 3) Participant 7 confirmed this understanding: *“we also knew that there was a demand for ICU beds that day, so...”* That parents talked of their child being moved because the PICU needed the bed reflected that this was the message they received and may have left them searching for mental comfort with the transition.

#### **4.5.1.2 Is my child ready?**

Some parents felt they instinctively knew when their child would be ready to move out of PICU. Participant 1 said, *“I knew that she would be moved once she was no longer critical”* which to her meant *“she was really perking up, and, I guess, looking a lot healthier than she had been in the previous 48 hours.”* Others looked at markers such as ability to eat, looking more awake, and the child’s breathing to indicate whether or not their child was

ready to leave the PICU. For example, participant 2 said she knew her child was ready because

*“she was starting to eat...starting just to... be awake a little bit more...just looking a little bit more...healthier...she was just starting to pick up – little by little, right? And..., yeah...by the amount she was eating, pretty much, right, she started to take some solids and just stuff like that. She just started to pick up a little bit.”*

Parents saw their child’s improved breathing or ability to breathe on their own as a good sign of their readiness to leave the PICU. For example, participant 5 felt her son *“was doing quite a bit better...because he was off the breathing tubes, he was breathing by himself with a little bit of help with the oxygen...”* The parents’ ability to see small signs of improvement in their child, particularly ones that were visible and apparent to them (like eating and breathing) helped to increase their mental comfort with the transition from PICU to the hospital ward.

Most parents needed to know and to see for themselves, not simply take the health care professionals word that their child was ready. On the other hand, some parents felt unsure that their child was ready at all. Participant 8 stated,

*“Personally, I didn’t really know for sure. I mean, he hadn’t been up at all, um, but, I mean, yeah, I guess, he was ready. He looked really sad yesterday, when we left last night. But, I think he was just exhausted, so.”*

Participant 3 also was unsure, and wished her son had been kept in PICU longer, stating,

*“I kind of think that they..., like I had said..., that they put him out a little too soon, and I think it’s..., you know, because they don’t have the beds – well, pretty much, they were saying that anyway (laughs). But..., you know, and, he would really have benefited staying another night or two. But other than that..., I mean, it was, you*

*know, nice enough, and everybody was nice enough, and..., you know, helped us move and, you know, so, I mean.... so it's not so bad."*

These parents were not mentally comfortable with messages they had received about the reason for transfer or their child's readiness to be transferred. This made them wish they could stay in the PICU for longer, but they were not given the option or choice of timing of transfer.

Many parents were worried about the transition because of a lack of monitoring on the ward. This monitoring, which referred to nursing presence by parents' perception, was reassuring and mentally comforting for parents when available. As participant 3 stated, *"Well...that's a big part of it, but, I think too, that he could have been... monitored a little bit more closely. So, we've gotten through it, and nothing's happened, but...you know, so?"*

It seemed that parents felt more mentally comfortable leaving the PICU if they knew their child was going to be monitored on the ward. As was discussed in the previous section on watching over my child, parents did not seem to equate monitoring with bedside monitors, but rather with nursing presence (i.e. having the nurse around more often, having the nurse visible and available). Particularly for parents who were unsure of their child's readiness to leave PICU, this presence would have been reassuring and mentally comforting.

Whether or not they felt their child was ready to leave, parents had strong reactions to being told they were leaving the PICU. Some were positive where they saw the transition as a move in the right direction. Participant 2 explained: *"Oh, it was a big relief! ... just to...to hear that she could be moved so quickly out of the PICU was, was amazing! (smiling, laughing) Yeah, she's just a trooper."* For these parents who saw the transition as positive, the move meant progress. As participant 2 said, *"Yeah, yeah – it means progress, right? It means that we're one step closer to home, right? (laughing)"*

Alternatively, when parents felt unsure about the move, they did not see the progress, and were just worried. Participant 3 stated:

*“I think, you know what, when you move from... ICU anyways, you always worry because, you know, because they’ve been so sick, and you know you’re, you know...it’s hard. (laughs) Because you worry that they’re not quite ready, or that they’ve been ok because they’re being watched so closely, and you know (laughs)...so, yeah.”*

Those parents who felt their child was ready to leave the PICU and saw the move as a positive progression towards home seemed to be more mentally comfortable with the transition than those who did not. Parents’ mental comfort also depended on the way they were told of their child’s impending transfer. Those who perceived they were being moved because *“there were no beds”* in PICU may have felt less mental comfort about the transition. Those who were told more details about the criteria for transfer may have been more mentally comfortable about moving. Overall, most parents did not feel comfortable with the transition from PICU to the ward. When the child was moved to the ward, some parents felt the loss of one-to-one nursing care, familiarity with staff and the environment, and a degree of physical and mental comfort.

#### **4.5.2 The transfer (getting to the ward).**

Within the category, the transfer, there were two sub-categories: ‘setting the expectations for the ward’, and ‘making the move’. Setting expectations explored information given to parents about what to expect on the ward. Making the move examined the physical move from the PICU to the inpatient ward, which encompassed what was done in the PICU to physically prepare the child and parent, how the child was moved from one place to another, and getting to the ward including how they were greeted and oriented to the environment. Following the move, parents tried to be comfortable in a new and unfamiliar

area and relied upon the advice and guidance provided by staff in the PICU. Occasionally, this advice made things easier, but sometimes, it served to decrease parents' mental comfort about the move and the ward.

#### ***4.5.2.1 Setting the expectations for the ward.***

Most parents recalled being given little information about the new ward. Parents did not receive standardized information. According to participant 7,

*“there wasn't a **brief** as in what to expect or whatever, but our – everyday we had a nurse assigned to him, and, again, when she said, you know, “Good news, [patient], you're going to the ward, here's what to expect: you just need to pack up, and we'll take you down.””*

Some parents were told about the SPOT team (which was the critical care outreach team in this hospital) and that they would be coming from the PICU to follow up with the child in the coming days after transfer. As participant 3 said,

*“Well, after - well right before he moved here, she told about the program there they have... They're some little program where they have where they follow up with the patient. ... The SPOT team, right. Yeah, she told us about that. ....She didn't say a whole lot.... She told us a lot about the SPOT team and what they would do, and everything...and then if we had a – if I had a concern, that I felt like it wasn't being met, that I could... let the SPOT team know.”*

For two parents, the only information they recalled receiving about leaving the PICU was about the SPOT team follow up. Participant 7 explained what she was told:

*“Well, they told us that the SPOT team would be available for the twenty – I don't know if it was for 24 or 48 hours – I can't remember. And, so that if there's any, any time that we had any concerns ... That if there's – if we had any concerns with*

*respect to what was happening after he left ICU, we could always ask for SPOT to come in, and check, or make sure that, you know, that everything was ok, and that sort of stuff. So, that was sort of, explained how the transition worked, that it wasn't just, like, "See you later." And, ah, and, so there was this, sort of, interim follow up kind of process."*

These parents were under the impression that the transition involved the SPOT team checking up on their child and that it was available to be called if the parents were worried about the care on the ward. They were not told other information about the ward such as how things would differ from the PICU. One parent said that the nurse "didn't say a whole lot" when preparing them for the transfer. Many parents referred to messages from PICU staff about the SPOT team but it was unclear whether these messages increased or decreased parents' comfort.

Most parents were provided few details about the room arrangements, ward location, or the nurse to patient ratio. Participant 4 explained what he was told about the new ward, saying they told him *"a little bit...they...they said the room would be a little bit smaller, but....everything... Everything was fine, everything was great."* It seemed that this participant was either not told much information, or could not recall what he was told. Participant 2 said she was told *"just where – what floor she would be...room, that kind of thing."* Again, a small amount of information was shared and not all parents seemed to know to which ward or room their child was moving.

Some other parents explained that they were told their child was going to a supervised room with monitoring equipment. As participant 5 explained:

*"Yeah, well, they also explained to us that he was going to come up to the ward, and he was still going to be in a supervised room, so it wouldn't be much change from the*

*ICU. And that as he progressed and got better, that they would then move him out of the supervised room into a normal room, and...*"

The explanation of the nature of this particular room seemed to increase her comfort with the transition – *"it wouldn't be much change from the ICU"*, so she thought the only difference would be the physical location. This supervised/monitored room offered parents the mental comfort of knowing their child was receiving similar care and attention to what they had in the PICU. These rooms typically had two patients, both on bedside monitors (for heart rate, blood pressure, respiratory rate, or oxygen saturation), and one nurse in the room at all times. That there was bedside monitoring equipment made the room "monitored", but more significant to parents was that the room was monitored in their sense (i.e. there was a nurse in the room at all times). When parents' children were transferred to these monitored rooms, it increased their mental comfort with the transition. From parents' explanations and understanding, only the sickest children went into these rooms.

A nurse in the PICU warned one parent that it was going to be a big change on the ward. As participant 8 explained,

*"Well, [nurse K] kind of warned me that it was gonna be a big change. So, I guess, no, I couldn't really have been prepared more. Uh, I don't know what I would tell anyone going up there. Just maybe to be prepared that there isn't so much one-on-one and that, you know, be prepared to be a big part of it, you know, if you want your child to have all kinds of attention, it's not gonna happen, so, unless you do it yourself."*

Participant 8 went on to explain what she was told by the PICU nurse:

*"well I think he kind of cracked a joke, like, you should enjoy this now, because everything's gonna change when you go upstairs, you'll, you know, it'll be really*

*loud and noisy, and um, you'll have a smaller room, you'll have to share it, it'll be about the size you're in now, but, with, like, two beds. And it is more crowded, for sure. But, ah, yeah, that's about what he said."*

Information was important to parents to prepare them for the transition. The content of this information and the message provided were not standardized. Some messages conveyed to parents about the ward environment may have decreased parents' comfort with the transfer.

#### **4.5.2.2 *Making the move.***

The actual process of the physical move was relatively smooth and uneventful for parents. The child was prepared with all the required equipment in the PICU, moved in their bed or in a wheelchair to the ward. Handover from PICU to the ward nurse, and/or an orientation to the new ward were usually completed on arrival to the ward.

Some parents had a really good understanding of what was being done to prepare their child and get them physically ready for the transfer. As participant 7 explained,

*"there was a respiratory therapist who came down to say, you know, he was gonna take care of the, that aspect of the move, and he checked everything, and made sure that all the extra trachs were in place, and they had the portable suction kit, and everything, so he sort of got that all lined up. There was the nurse, um..., who was telling me where we were going, and that idea. And we packed up all our stuff, and packed up the stuff for him, and all his files, and there was a porter that came down too. And then, ah, and then, ah, we, he was napping, so they waited until he woke up, and then we just moved upstairs, and, set in place, and...it went very smoothly. It took maybe, I don't know, 20 minutes by the time he was sort of set back into the new room, so."*

Most parents also saw the process as straight forward. Participant 4 agreed that he felt good about the move, saying it was *“just a nice smooth transition. It was...it was easy.”*

Many parents received an orientation to the new ward on arrival. As participant 7 explained,

*“The nurse sort of gave us the run down; she couldn’t actually leave the room, because it’s a monitored room (laughing), but she could tell us where we could find the kitchen, and the phone to call for his food, and so, you know, so we sort of got a run down of where things were and an explanation of how things work and, yeah, so she sort of gave us a little orientation to everything.”*

Parents liked feeling involved in the care of their child, and this included the transfer. Parents were mentally comforted through understanding the process, getting to know the new unit, and being a part of the move.

For a few parents, the timing of the transfer seemed to affect them, and served to decrease their comfort at the initial transition. As participant 8 explained, her son was sent up around shift change and this proved a busy time for the nurses.

*“When we first got there, [the nurse] was kind of in and out. And there was a little bit of craziness, it was like, we didn’t know. But, then she took us on a little tour, and she showed us where everything was, um, for the parents, and, um, like the kitchen, and all that stuff, like, the washrooms, and the daycare center, and all that stuff, so, so that was good. Yeah, it was just, it was about... Actually, when I think about it now, it was about 6 or 6:30, because I know she was leaving. Cause she was probably leaving at 7:30, so. Had we gone up at 4, it might have been a little less – she seemed busy, like harried busy, sort of thing. ... Kind of that time of day, to be finishing up. Yeah.”*

Timing the move correctly was important to parents. When the move was poorly timed, it did serve to decrease parents' mental comfort with the transition.

### **4.5.3 Post-transfer (getting settled on the ward).**

In the post-transfer phase, parents searched for comfort in the new environment of the ward. They made comparisons between the PICU and the ward. All of these comparisons were described through the sub-category of 'it's different here'. The way it was different was highlighted by 'the physical space', 'the level of care', and 'the information and communication'. The physical space was important to parents in that it could increase or decrease their physical comfort. Parents talked about their physical comfort, and their child's, in terms of the noise on the ward and the space available. The level of care referred to parents' perceptions that the level of nursing care was different from the PICU. They talked about the ratios of nurses to children, which lead to the overall busyness of the nurses, and the perception that the care was "not 24/7" on the ward. They seemed to note a decreased nursing presence, "monitoring", and less availability of the nurses for them or their child. This decreased presence could make parents feel that the nurse did not have control over the situation, thereby decreasing parents' mental comfort. Finally, information and communication referred to both the communication between the units and the way parents received information after the transfer.

#### ***4.5.3.1 It's different here.***

##### ***4.5.3.1.1 The physical space.***

When parents were asked about how they were finding the new ward, they talked about the physical space. For the most part, it was felt that the rooms were smaller, wards were noisier, and some parents were worried about a clostridium difficile (c-diff) outbreak on one of the hospital wards at the time.

One of the difficulties parents found with comfort on the ward was that the rooms were small: *“Well, where parents’ sleep isn’t really comfortable. (laughing) And the rooms are very, very tight. But, no everything’s...been ok.”* (participant 9). Parents talked about their child losing their privacy, being in too small a room, and there not being enough space for the parents:

*“I think the beds are not near as comfortable. Maybe that’s to make them get up, I don’t know. You lose your privacy, absolutely. Um...I think they need to put the kids together a little better than they did with this one, and, like, we don’t even have – there’s one chair in there, there’s two parents. You know, we pulled a wheelchair in, and it’s just in the way. It’s just constant, and it’s not comfortable to sit in. You know, we have to be there all day, it’d be nice to have a comfortable chair to sit in, you know, so. And I think there should be two, I really do – I think every bedside should have two chairs. So, I told them as soon as I saw one in the hall, I was scavenging it.”* (participant 8).

When going from the PICU with private rooms and a lot of space to cramped rooms with two patients and their parents, it made the parents less physically comfortable. They also seemed mentally less comfortable because they were more worried about their child not having their own space or being physically comfortable in the rooms. It seemed that the environment of the ward was a surprise to parents, which seemed to indicate they were not necessarily informed of these differences before leaving the PICU. The cramped quarters may have contributed to parents’ physical exhaustion.

Two parents also talked about the amount of noise on the ward as decreasing comfort:

*“it was real noisy here too....I mean the baby [roommate] was noisy too, but, it wasn't always noisy though, but...it was...there was, like, that's kind of...the nursing station, it's quiet now, but a lot of times, it's really noisy.”* (participant 4).

There was also the concern of other parents indiscriminately using their cell phones and disrupting other parents and children. This noise level affected the parents' physical and mental comfort by contributing to the idea that things were not under control on the ward and it made things look and feel very chaotic. While parents cared about the space and the comfort of the beds, the entire feel of the ward was what affected them most, and this was greatly influenced by the noise level.

Participant 8 spoke very expressively about her lack of comfort on the new ward, when talking about the different feeling on the ward:

*“[in the PICU] there was always somebody, almost, if not in the room, like, just right outside. And, I find that we're, now, and you know what, I'm not complaining about this, cause where [patient] is at the end of the hall, he's not by the nursing station, and I'm glad, cause to me, it's pretty chaotic around there. And the phones are ringing, the alarms are going off, and, you know, babies crying. And I'm kind of glad he's up in the corner, but, it wasn't that way in ICU. It was much more subdued, and more... It seems to be a more – more of a sense of calm, does that make sense? ... Um, where up here, it doesn't seem to be so calm. And I don't know why that is, because you would think it would be more extreme down in the ICU, but, I don't know. Maybe parents are getting more of a chance to panic, I don't know, 'cause they don't have somebody standing right beside them all the time. And...”*

This parent found the noise on the ward worse than in the PICU. In the PICU, children were more ill, needed more care, were on more monitors, and there were more personnel around;

so it was surprising that parents found it quieter than the ward. Again, it seemed that parents were not expecting this to be the case and were not told of the difference. The perceived disorganization and chaos left parents searching for physical and mental comfort on the ward.

Some parents saw the new ward in a better light. For example, although participant 2 noticed a change in the size of the room, she saw the transition as positive:

*“Well, the room was larger, so that was great in ICU. (laughing) You kinda have a little bit more room to move and kind of...but, um..., yeah, I mean you need to share your room with another child because your child was getting better, right?”*

Participant 10 was also able to put a positive spin on something he felt was not comfortable:

*“probably the only...downside...something that’s difficult...um...[patient] always has to walk through somebody else’s spot to go to the washroom ... I can’t see it being avoidable unless everyone had their own washroom. ... But, ah, other than that, no, you know, he’s enjoyed where he’s at and everything, and he’s had good care – good food!”*

Two parents talked about the c-difficile outbreak on one of the wards as their primary worry about the physical space. As participant 6, whose child was sent to the ward with the outbreak, explained:

*“Honestly, the only problem I had with the whole leaving the ICU is knowing that there was a restriction of a sickness here and why would they put somebody that has cancer into a unit that’s supposedly, like, sick, you know? There’s a sickness, like, an illness, going around, if his immune system’s weak why is he here right now? Why didn’t they put him in some other unit, like, you know, [Unit B] or [Unit A]? I don’t under – I never asked about it, but it’s been in the back of my mind...”*

This parent was not comfortable on the new ward because she was worried about the impact of additional illness on her child's condition. Participant 7 had similar concerns prior to her child's transfer. For this parent it was reassuring to be sent to a ward without the outbreak, and this increased her physical and mental comfort. It was interesting that parents were aware of this outbreak on a ward.

#### 4.5.3.1.2 *The level of care.*

Parents characterized the ward by what they saw as “*a whole different level of care*” than the PICU. Parents remarked on what they perceived as the busyness of nurses, the ratio of nurse to patient, the nurses' roles, and the attention paid to their child.

As participant 1 explained, she noticed a difference.

*“Then I was in ICU... (laughs), and it's just like a whole different level of care, right, and just so much more one-on-one, and like, every, I mean there was one nurse to my...my daughter, you know? So, the level of care is just, it's a different standard of care. And I just found, yeah..., it's just that difference, right? So the doctors and nurses are just that much more available, and that much more there, all the time. Which they can afford to be, especially because when I was up there, there was only 5...there was only 5 children, in ICU...so..., I totally understand (laughs), you know, I understand the difference. It's just that I really really liked it up in ICU ... But I knew what to expect moving on to the ward because we had just been here, a few weeks ago.”*

This parent, and most other parents, expressed that the nurses and physicians seemed to have more time because there were fewer patients per nurse or physician in the PICU, or that the ratio of staff to patients was greater in the PICU.

Participant 8 remarked that this loss of one-to-one care was extreme:

*“You have all that attention, and you have... It’s, it’s almost too extreme. Like, you go from all kinds of attention to virtually none. I don’t want to say virtually none, but you know, much less, right? And not seeing people right there all the time.”*

She went on to explain:

*“Well, I just find that you go from having like 24/7 to so much less, that it kind of can be a little bit of a shock to the system. Like, leaving last night I was little concerned about [patient], cause he is, um, he is a quieter kid, he won’t, um, I shouldn’t say he’s quieter ... he won’t complain. And, I mean, it would take an awful lot for him to hit that call button. Um, so I was a little concerned that he was gonna try to do too much on his own ... so, I was a little concerned about that ... it’s kind of, you have to work together, right? The parents, and, and stuff, so, yeah.”*

Participant 1 explained why she felt the level of care changed saying, *“the one-to-one care you’re getting here (the PICU) and the feeling of..., you know (laughs), Cadillac luxury service, it can’t be maintained on the ward. There’s just so many more patients, you know, the ratio’s just different.”* Participant 1 continued to describe what this level of care meant to parents and the differences noticed between the units:

*“just the comfort level for the parents is different there too. I guess, they understand that, I mean, kids are in a critical condition and parents need a little bit more ... a few more comforts, you know..., and, reassurances, so they, that’s what I think is why PICU goes the extra mile ... I can’t say anything negative about my experience at [this hospital], you know?... I mean, I just realize there’s two different levels of...of care.”*

That parents perceived two levels of care was noteworthy.

The one-to-one care or nursing presence in the PICU was comforting for parents because the nurse was always available. On the ward, this was not the case and so parents had to become comfortable with not seeing the nurse as frequently because they were busy. Participant 3 explained, saying, *“Well, yeah. I think they know... his medical background a lot... better, yeah - in the ICU. Yeah, definitely. And...., I mean these nurses here are good too..., but they’re just pretty busy too, they say.”* To these parents, their comfort with the transition was decreased because they perceived the nurses on the ward to be too busy to know the child’s information, or to provide the same kind of care. This perceived busyness made some parents worry about their child missing care or attention they needed, and was connected to nurse to patient ratios.

Some parents, conversely, found the change in the level of care to be positive. One parent who found the PICU more stressful, and another who found her child could get more rest because of the decreased level of care, expressed these sentiments. As participant 7 explained, to her the level of care in PICU meant more stress:

*“And I think also ... it was great because there’s such great level of care in ICU, and attention, and, but it’s also, you can just feel the stress of the place, right? Because it’s where all these sick kids are, so it feels a lot more relaxed...on the fifth floor, I think. (laughs) Not in a...like, not in a del – it’s not like the nurses are stressed, or that the people aren’t calm, but you just know that there’s really stressed out people there with really sick kids, so. But, ah, yeah, I think I felt a change in atmosphere, I guess.”*

To this parent, the PICU was positive because of the level of care and attention received, but it was also stressful because the child was so ill.

Participant 6 shared that the decreased level of care on the ward meant more rest for her child. She said, *“They, ah, they don’t come in as often so he gets to rest a little bit more. There’s a difference, and that, um...”* This parent was not worried about the decreased nursing presence. She still felt that her son was well cared for: *“Yeah, they come in. And usually whenever he presses the button, they do come in and check up. They talk all the time.”* In knowing that the nurses were around and would be there if her child needed them, this allowed her to be more mentally comfortable with the transition. A change in level of care on the ward for some parents also meant a decrease in stress and an increase in rest for their child, so they seemed more mentally comfortable with the transition.

Some parents talked about how they were not prepared for the changes they experienced in terms of the level of care on the ward. One parent (participant 1) explained that she knew what to expect from previous experience:

*“Perhaps if I hadn’t had known that, if I didn’t have personal experience (of being on the ward before), I would have been like, “What?! I’m going to see you in, like, two hours from now?” You know, haha ... my experience, um, did me well, to know what to expect, and that’s why I didn’t want to move because I knew (laughing) what I was going to get.”*

It is interesting and important to note that this parent knew what to expect not from what she was told by staff, but from previous experience.

Another parent (participant 1) made a suggestion for transfer planning in the future: *“The only thing, maybe, is they can maybe set the expectation a little more that, you know, you’re going to be one of many there, and, you know, and nurses and doctors work really hard to provide care to everybody, but..., they can’t give the same level that they give downstairs.”*

Parents on the ward ended up providing physical care to their child. Some parents talked about getting food or drinks for their child, helping them with personal care, and getting supplies for them (linen, gowns, etc.). However, parents were not informed of what their role would be on the floor, and therefore these tasks needed to be explained to parents if they were expected to do them.

#### *4.5.3.1.3 The information and communication.*

Parents felt as though they were not as included on the ward as they were in the PICU, due to the way in which communication took place. This was best explained by a quote from participant 1: *“I did feel more involved. And I think the average parent would definitely feel more involved in PICU.”*

Participant 1 explained her experience of trying to be a part of rounds on the first day on the ward:

*“I got here this morning, and rounds hadn’t begun yet. And I asked the nurses, I was like, “Have rounds happened?” She said, “No, not yet.” So I was like, “Cool.” Cuz I want to know...I want to be a part of [the rounds]. And then, rounds were going on, but because you don’t get that same level of care and awareness of what’s going on, I wasn’t given the opportunity to be a part. Like..., to see what was said about her and what-not, and here, I wasn’t given that opportunity. Which is also something very different from downstairs.”*

This parent relied on rounds to get information about her daughter, but the process was different between the PICU and the ward: *“So, on the floor..., the regular ward, they don’t let the parents know, no, I guess it’s their (laughs), I guess it’s their own private little thing.”*

Participant 1 felt less mentally comfortable on the ward because she was unable to get information as easily. It seemed that being involved for this parent meant being included in

discussions, getting information, and communicating about her child, rather than being involved in her child's physical care.

Participant 3 talked about not feeling comfortable about the transfer due to perceived poor communication between the PICU and the ward:

*“I don't think the communication was great, like between the ICU and here. Cause they didn't really, at first they didn't know what his medications were, and so then it was, like, some hours later, they were like, “Well, oh yeah he's on some medication here, we have to...” and then they had to kind of figure out the IVs and things like that ... it was after a while, so...and then they figured that out.... It seems to be that, yeah, there is always that kind of gap.”*

Participant 8 also experienced poor communication with relaying test results. When parents perceived the communication between team members or between professionals and themselves to be poor, this left them searching for mental comfort with the transition. This was particularly apparent when parents compared their experience on the ward to that in the PICU. Participant 8 was even worried that, because of the absence of communication, the nurses did not know the parents or where they were staying, which left her searching for mental comfort with the transition.

Participant 3 talked about receiving mental comfort from the SPOT team follow up where she could get some information and communicate her concerns:

*“kind of what they did – they stopped by, and... checked him out, and then...like, once a day..., and then...and if I wanted to contact them I could. Basically that's what they said. ... It was good, cause... I could talk to them about concerns. I had, like, some concern – a little concern, and then talked about it with them and...”*

This parent did not say that the SPOT team necessarily made her feel more comfortable with the transition, but it seemed to have comforted her to have someone to talk about her concerns that were perhaps not being addressed on the ward.

Parents were more mentally comfortable with the transfer when they perceived their child was ready to leave the PICU, and when they viewed the ward positively – the environment and staff as able to meet their child’s needs. Parents were not mentally comfortable when they perceived that their child was not ready to leave the PICU, or they were given information about the ward that tended to imply the care was less. Parents compared the care they and their child received on the ward with that received in PICU.

#### **4.6 Summary of Findings**

The experiences of 10 parents in a Canadian children’s hospital revealed that the transition of their child from a Pediatric Intensive Care Unit to a hospital ward involved searching for both mental and physical comfort. Some parents felt comfortable at different points in their child’s critical illness, whereas some were always searching for comfort. Parents lacked comfort through the transitions because the situation was unfamiliar and because they had experienced multiple losses prior to and during the hospital admission. Parents’ losses included the loss of the ‘normal’ – their normal child, their normal life and routines, the normal relationship with their spouse, family, friends, and other children, and a loss of their ability to be a parent as they normally would.

Being a parent with a critically ill child was exhausting – this exhaustion was exhibited by parents’ looks, voices, and expressions during the interviews. They sought mental and physical comfort by watching over their child, searching for a plan of care, and organizing home and work. Being kept in the know seemed to help parents to develop the cognitive framework or compass so they could better understand what was happening and

anticipate potential next steps for their child. Parents relied on being supported by others throughout their child's hospital stay. Family and friends or the health care team provided emotional or practical support to parents, which helped to increase parents' comfort during the transitions.

When it came time to transfer the child to the hospital ward, there was the loss of the one-to-one nursing care, the familiarity with the staff and environment, and any sense of physical or mental comfort they had developed in the PICU. Parents began searching for mental comfort again on the transition to the ward because they were once again in an unknown situation. Parents used behaviours such as asking questions, double-checking, and staying with their child in the PICU and on the ward to watch over them to try to ease some of the stress and to find comfort during their hospital stay. Their comfort with this transition was influenced by the way parents were prepared during the pre-transfer, how they perceived the transfer, and how they perceived the ward post-transfer.

## Chapter 5 – Discussion

In this chapter the study findings will be discussed in relation to differences and similarities with contemporary literature and what the findings from this study add to the understanding of the transition experience from PICU to the ward for parents. Suggestions for nursing practice, research, education, advanced practice nursing roles, as well as limitations of the study will be presented.

Parents' experience of the transition of their child from the PICU to the hospital ward was characterized by searching for comfort. This searching for comfort occurred across lived time, space, body, and relationships.

Lived time reflects the way in which the person is embedded in the present. Time-situated meaning and understanding of the transition from the PICU to the ward was reflected in the lived experiences of parents captured by the interviews being conducted while this transition occurred. The lived time was expressed through parents' telling of their story from beginning to end. While the main focus of the study was the transition from the PICU to the ward, parents underwent multiple other transitions across time: from finding out their child was ill and needed critical care, to the experience in the PICU, and finally, the transition from the PICU to the hospital ward. Parents were searching for both physical and mental comfort throughout all of these transitions. Some parents achieved a level of comfort at certain points in time during these transitions in their child's illness, but most parents were never fully comfortable.

Lived space corresponded to parents' perception of the hospital environment as meeting the needs of their child and themselves, which contributed to their comfort or discomfort during transitions. The transition was understood and interpreted by parents in a

way that was reflective of the context of their critically ill child going from PICU to the ward.

Lived body speaks to parents understanding of themselves through their surroundings and where they are situated in relation to these surroundings. Lived body speaks to parents' exhaustion throughout the transitions. Parents continued to search for physical and mental comfort because they were exhausted but grew more exhausted because they felt the need to be present with their child to watch over them and make sure they were well-cared for, were organizing the other aspects of their lives at home and work, and could not rest because the environment was not conducive to sleep.

Lived relationships refers to both those interpersonal connections between parents and health care professionals and between parents and their families (children, spouse/partner). These relationships, when equitable, had positive communication with give and take, and were supportive, increased parents' comfort during the transitions. Relationships increased parents' mental comfort because it helped to decrease their worry, and it increased their physical comfort because they were able to relax and rest knowing they had support and people who cared about them and their child.

Parents needed to search for comfort because of their exhaustion at having a critically ill child, their need for information, support, and to understand the process of the transfer. The findings will now be discussed with support from the literature.

### **5.1 Being Exhausted**

Parents interviewed in this study were exhausted. This exhaustion was palpable to the researcher during the interview process. Parents' were exhausted because they experienced a lack of comfort in the PICU and on the ward. They were staying with their child in order to watch them, make sure they were receiving the care they needed, and trying to maintain

some sense of order with their 'other' life (at home and work). Smith, Hefley, and Anand (2007), in a study examining the impact of parent bed spaces in PICU on parents' anxiety, speculated that parents who stayed with their child (which the majority of parents in this study did) might suffer stress from physical and emotional fatigue. In addition, these authors suggested parents felt forced to stay at all times, thus not taking breaks or time for self care. Shudy et al. (2006) noted that parents' often overlooked their own physiologic needs and were unlikely to ask for things they needed, such as food, water, or somewhere to sleep, which would contribute to and perhaps explain part of parents' exhaustion.

Shudy et al. (2006) identified in a literature review on the impact of pediatric illness on families that parents of critically ill children who were experiencing prolonged uncertainty had increased stress from fatigue, poor nutrition, and anxiety which could escalate to crisis levels. Additionally, the PICU and ward environments seemed to not be physically comfortable and might have also increased parents' exhaustion. Parents of critically ill children suffered deleterious physical symptoms such as headaches, malaise, fatigue, irritability, deteriorating health, and these parents were less likely to focus on healthy behaviours like sleep and eating which were thought to exacerbate the symptoms (Shudy et al., 2006).

Throughout the parent interviews, the researcher noted that there was a significant impact on the entire family of having a critically ill child in the hospital. This impact was heightened because many parents were from other cities and had to travel to the institution with their child. Parents were also very affected by the environment of the hospital, the losses associated with having a critically ill child, and the care they and their child received with respect to the enactment of family-centered care principles. These effects on the family included parents having to live apart from their other children and spouse, potential changes

in spousal relationships, and parents' not having time to take care of themselves or their relationships. These sources of parental stress include the environment (Carnevale, 1990; Jee, et al., 2012), loss of parental role (Carnevale; Carter & Miles, 1989; Colville, et al., 2009; Jee et al.; Noyes, 1998), the child's appearance (Ridling et al., 2006), and uncertain outcomes (Ridling et al.).

#### **5.1.1 Having a critically ill child affects the whole family.**

Shudy et al. (2006) have documented that marital conflict, divorce, and other relationship changes in families have been related to the severity of illness. The parents were affected by having to stay in the hospital with their child and trying to balance the needs of their ill child with those of their spouse/partner and other children. The spousal/partner relationship was affected because parents were often apart. In the current study, the impact on the family relationships and functioning might have been increased due to parents' being from out of town. Seven out of ten (70%) parent participants in the study did not live in the same city as the research site. These parents referred to the need for more practical supports such as finding a place to stay. Parents were away from their own home city and thus lacking their normal resources and supports.

The literature has indicated that being a parent from out of town with a child with a chronic illness increased parental time by 17-24 hours per year with appointments and specialist visits in a study on the impact of the distance to hospital on parents with children who had chronic conditions (Yantzi, Rosenberg, Burke, & Harrison, 2001). These authors suggested that there was a significant association between families who travelled more than 80 km to the hospital and a decline in family functioning specifically related to individual relationships (relationships between the respondent and other immediate family members like the spouse or children). Furthermore, the authors noted that families who travelled more

than 80 km to the hospital were 224% more likely to experience a decline in family functioning than those who did not travel as far and the parent who did the travelling experienced increased dissatisfaction and anxiety.

Nicholas, Fellner, Koller, Chow, & Brister (2011) reported that being in hospital away from home was draining for parents. Parents, who were in hospital with their child for an extended period and separated from their family, experienced changes in their home and social lives such as shifts in roles and responsibilities, increased stress due to isolation and physical separation, exhaustion, uncertainty, worry, and loneliness (Nicholas et al.). The hospitalized child also felt upset and missed their family and friends (Nicholas et al.). At the same time, parents from this same study who were not in hospital with their child experienced guilt at not being with their child or partner, and the siblings of the patient who remained at home were upset which caused acting out, developmental regression, attention-seeking behaviours, and frustration (Nicholas et al.) In addition, Nicholas et al. evaluated the impact of videophone communication for families of children who were hospitalized for extended periods and had limited access to their family due to geographical separation (90-703 km away). The authors noted that videophones provided increased communication with family members and were seen as a form of social support. The videophones seemed to anecdotally help families in that family members in hospital experienced decreased isolation, family members not in hospital had increased understanding of the plan of care, and the patients (children) were happier.

These studies by Yantzi et al. (2001) and Nicholas et al. (2011) did not address critical care admissions, but rather general hospital admissions. However, some of the issues and difficulties identified by parents in the literature echoed the experiences of parents in the current study. Many children's hospitals have significant numbers of patients from out of

town since most cities do not have children's hospitals; however, there is limited literature on parents from out of town.

### **5.1.2 The environment makes a difference.**

The environment has been noted as one of parents' stressors during their child's critical care admission (Carnevale, 1990; Jee, et al., 2012). Compared with previous studies, this current study has revealed different findings as the parent participants placed more emphasis upon the environment, linking their ability to achieve comfort to the environment of the hospital units. Parents frequently commented on how the environment influenced both their comfort and their child's. Parents shared that the PICU had larger rooms and more physical comforts for them. Parents revealed that on the ward, the environment was noisy, chaotic, cramped and physically uncomfortable without enough chairs, beds, or room for parents to stay with their child. When parents were not comfortable in the environment, this increased their exhaustion, leading to an even greater decrease in their perceived comfort.

Perhaps this focus on the environment is related to the number of parents from out of town and staying in or near the hospital. Few authors have mentioned parents' being from out of town as influencing findings. Authors have not mentioned whether parents were staying in the hospital or how many parents were from out of town and therefore needed a place to stay in or near the hospital.

In studying parents' needs, Jee et al. (2012) asked parents to rank various needs in terms of importance from 0-100%. They noted that needs for personal comfort and facilities ranked lower than other needs such as the need for information or to be involved in their child's care. However, the need for personal comfort and facilities was ranked at over 80% importance (Jee et al.). Perhaps the need for environmental comforts is more important for parents than previously speculated in other studies on parental needs.

Smith, Hefley, and Anand (2007) examined parental stress using the Parental Stressor Scale:PICU in the old PICU (without parent bed spaces) and then in the new PICU (with parent bed spaces). The authors noted that parents who could stay with their child in the new PICU reported lower levels of stress related to parental role alteration or the physical appearance of their child than those parents who were interviewed before the renovations.

Another environmental concern parents expressed during the interviews for this current study was that they did not want their child transferred to the ward that had a clostridium-difficile outbreak. It was not known how parents found out about the outbreak or what they knew about it, but they were aware there was an outbreak and were concerned for their child. Additionally, despite the awareness and concern, none of the parents who mentioned this outbreak talked to the health care provider about it.

## **5.2 The Importance of Information**

In this current study, information and communication were perceived as important to parents to increase their comfort. This increase in comfort was interpreted to be due to increased information providing a cognitive framework or map or compass and better predictability in terms of next steps or outcomes. In the literature on parental needs in PICU, information was listed as one of the top needs (Jee et al., 2012) and providing consistent information was also an aspect of family-centered care (Lewandowski & Tesler, 2003). Additionally, consistent communication was reported as one of the most useful interventions in helping parents of critically ill children (Shudy, et al., 2006).

Parents found it important and comforting to have open lines of communication with health care professionals. However, there was inconsistent collaboration and information sharing between the health care professionals and the parents in this study. Open communication could be seen as honest communication or when the parent perceived the

health care provider as being up-front, honest, and transparent. Open communication may be differentiated from accessible or available information. Parents in this study sometimes reported having easily received information they needed without looking for it, which would be the same as available information, or having information that was available to them without any work on their part. At other times, parents reported they had to search for this information, often checking multiple sources to get their questions answered, which spoke to the availability (or non-availability) of the information. In the PICU, parents readily received information whereas on the ward the information was more difficult to access. Parents perceived nurses on the ward as too busy and therefore not available to give them information, thus parents practiced behaviours of seeking out information more often on the ward by searching for staff to answer their questions and double-checking information with different care providers.

Jee et al. (2012) stated that “the need for open, honest, and timely information...was felt to be of primary importance” (p.5) for parents of PICU patients, and this communication needed to be easily understandable. As Colville and Gracey (2006) and Colville et al. (2009) reported, communication difficulties increased psychological distress. Therefore, having open communication with parents would hopefully help make them more comfortable. The results of the current study were consistent with other studies (Aldridge, 2005; Carnevale, 1990; Colville, et al., 2009; and Noyes, 1998) on parental experiences in terms of how important information and open communication were to parents. This current study also highlighted that information from health care providers was not always perceived as consistent. Parents seemed to seek information from multiple sources, such as different nurses or physicians, in order to clarify information they might have perceived as inconsistent. In this study, parents only received verbal information and the communication

process seemed to occur in the form of one-way information (i.e. from the health care provider to the parent) rather than open or two-way communication, where both parties had the opportunity to speak and be listened to. By not making information sharing with parents more of a two-way conversation, parents were not able to ask questions and get clarification.

In addition, by not having other forms of communication, such as written information, parents were not able to refer back to what they were told. Many parents stated they could not remember everything they were told because of their level of exhaustion and lack of sleep. Some studies related to information provision and knowledge, satisfaction, or memory recall have shown that the combination of verbal and written information, as compared with verbal information alone, increased both recall and knowledge as well as satisfaction (Johnson & Sandford, 2005; Smith et al., 2012). Additionally, Latour et al. (2011) noted that parents ranked their need to receive both written and oral information as very important, whereas health care professionals did not see this as important.

### **5.3 Needing Support**

Parents in this study seldom spoke the word ‘support’. Aside from the few instances when someone had helped parents with something practical (i.e. finding housing, getting their child games, helping them to organize finances), support was really described in general, and in somewhat superficial, terms, such as: “they do what they can”, “they care”. It did seem like parents felt supported – they said things like “the support was great”, “people really reach out”, “people step up”, which seemed to indicate support through the development of a relationship and partnership between the nursing staff and the parents. There was engagement between the nurses and other health care professionals and the parent in the PICU because the relationship had been established. This relationship was notably absent on the ward. Nurses were not seen as providing practical support and there were not

specific instances of nurses providing emotional support. Rather, these roles were subsumed by social workers and friends and family. Parents throughout the hospital stay did not seem to be assessed in terms of their coping or needs and only one parent mentioned a social worker asking how she was doing. In addition, the research study site did not seem to have a consistent approach to assessing parents in terms of their coping or support needs, which is an element of family-centered care (Harrison, 2010; Lewandowski & Tesler, 2003).

Nevertheless, parents did not seem upset that they were not asked about coping and did not mention that they were missing or lacking support. Perhaps more parents felt comfortable sharing their emotional needs with family. A qualitative study by Colville et al. (2009) found that parents confided in friends and family instead of health care professionals. Friends and family listened to parents, relieved them of other duties outside the hospital, and allowed them to focus on their ill child (Colville et al.), which were the same types of roles that family and friends undertook for the parents in the current study.

#### **5.4 Being Transferred**

When the child is transferred to the ward, health care personnel see the child as being better, and see this as a positive step. However, in this study, once on the ward, parents noted a decreased nursing presence and increased patient to nurse ratios, which caused them discomfort. There was also discomfort related to changes in ways they received information, and the environment of the ward. It was of note that there was no consistent transfer information presented to parents that they recalled.

##### **5.4.1 What is in a message: about transfer of care.**

Some of the messages given to parents indicated that the care received on the ward was going to be less than that provided in the PICU. While the information provided may have been intended to inform parents that, because the child was recovering, the nurses on

the ward had more patients, and they would be checking on each patient less frequently. It seemed that the way this information was presented to parents served to make them less comfortable with the transfer.

It was clear from the parent interviews that the current process in place for transfers from PICU to the ward could be expanded. Parents were not aware of the aspects involved in the transfer of care from the PICU to the ward staff such as giving report to the ward nurse or completing the required transfer sheet. These findings were echoed by VanWaning, Keliber, and Freyenberger (2005) who found, in a nurse and parent questionnaire about the transfer process from the PICU to the ward, that parents were not: provided with tours of the new unit, aware of the changes in routines such as frequency of vital signs, or aware or prepared to assist in the daily care of their child. In addition, nurses felt that parents did not understand their child was improving. All of these elements decreased parents' satisfaction with the transfer (VanWaning et al.).

The main suggestion from the literature to help parents and families cope with transfers consisted of the implementation of a transfer protocol with both written information in the form of a letter or brochure, reinforced by consistent verbal information from the critical care nurse and/or the ward or liaison nurse (Bouve, Rozmus, & Giordano, 1999; Linton, Grant, & Pellegrini, 2008; Mitchell & Courtney, 2004; VanWaning, Kleiber, & Freyenberger, 2005). An intervention such as this been shown to increase parents' satisfaction with the explanation of patient to nurse ratio, parents' role on the floor, and amount of notice given prior to the transfer (VanWaning et al.). With written and verbal information prior to transfer, there has also been evidence of decreased parental anxiety prior to transfer (Bouve, et al.), increased satisfaction and higher levels of understanding about the transfer (Mitchell & Courtney). Written information was found to be helpful in improving

families' understanding of what to expect on the ward and in having their questions answered prior to transfer (Linton, et al.). Although the research site in the current study does have a transfer protocol form which provides the handover of information from the PICU to ward nurses, it was not mentioned by any of the parents during the interviews.

From the information that they remembered receiving, parents in this study did not know what to expect in terms of change in level of care. Rather, they acquired this information because of previous experiences or they figured it out. It would seem important for all parents to have this level of understanding of what to expect to promote their comfort on the ward.

#### **5.4.2 What is in a message: about readiness for transfer.**

When reviewing the transcripts, it was noted that eight parents thought their child was ready to leave the PICU because they were doing better. Six of these parents came to this conclusion based on their observation of their child eating, breathing well, or looking more awake. Two parents were satisfied with the explanation from the health care professional that their child was improving. Three parents were not sure their child was ready despite what they were told, and two of these three parents felt their child should stay in the PICU longer. Two parents believed that their child was being moved from the PICU because there was a need for beds. Again, these were messages that parents recalled receiving from PICU staff about the reasons their child was being transferred from PICU to the ward, and it was clear that some parents were uncomfortable about the transfer and the reasoning for it. How parents understood and perceived their child's readiness for transfer spoke to their lived time, or how they saw their child at the moment.

Those parents who felt their child was ready to leave the PICU and saw the move as a positive progression towards home seemed to be more mentally comfortable with the

transition than those who did not. Parents' mental comfort also depended on the way they were told of their child's impending transfer. Colville et al. (2009) noted in their qualitative analysis of parents' experience of leaving PICU that many parents felt pressured to leave the PICU, which was referred to as feeling a sense of abandonment by the PICU staff.

An interesting finding in the current study related to readiness for transfer was that parents with previous negative experiences in hospital or during transfer seemed to be less comfortable during the transition to the ward. These parents were more watchful, worried, and less likely to think their child was ready to be transferred. This finding has not been revealed in current literature.

Timing of the transfer from PICU was seen as important by the parents in this current study. The two parents who felt that their child was being transferred at inopportune times expressed concerns. It has been suggested in adult ICU research on transfer anxiety that transfers at night can cause complications such as readmissions, increased morbidity, mortality, or patient and family stress and anxiety (Leith, 1998; McKinney & Melby, 2002; Saarman, 1993). In the current study, these two transfers that caused parents concern took place at change of shift. However, there were no studies that have examined the impact of this occurrence during transfers from PICU.

#### **5.4.3 What is in a message: about the ward.**

The parents' perception of the messages from staff about the SPOT team (critical care outreach team) received prior to transfer seemed to make parents less comfortable with the transition. For example, when parents were informed they could call for the SPOT team if they were concerned about their child once on the ward, this may have been interpreted that the PICU nurse was not confident about the care on the ward. For two parents, the only information they recalled receiving about leaving the PICU was that the SPOT team would

be available if parents were concerned about the care their child was receiving on the ward. Health care professionals need to clarify messages being received with the information provided. The context of the ward was being formed for parents before they arrived there. This may have altered their perception of this lived space.

The introduction of a liaison nurse role in one hospital was shown to decrease the PICU readmission rate and to decrease parents' anxiety by helping with their adjustment to the ward (Caffin, et al. 2007). According to Linton, Grant, and Pellegrini (2008), a liaison nurse, a member of a critical care outreach team, helped to bridge the gap between the PICU and the ward, improving communication between the two units, providing a link to the PICU, consultancy for staff on the ward, and in offering support to patients and families. The liaison nurse prepared patients for transfer, met with the patient and family prior to transfer, followed up with patients on the ward after the transfer, and provided nursing interventions where needed (Caffin, et al.; Linton, et al.). This type of nursing role might help to engage families and ease their transition process.

#### **5.4.4 Through a parent's eyes: level of care.**

Parents were very concerned and cognisant of the change in what they termed the "level of care" when they were transferred to the ward. This mainly referred to the nurse not being present as much to provide surveillance, answer questions, or check on and provide care for the child. Parents in the PICU had developed a relationship with the staff and were engaged with them in the care of their child. Parents in the PICU were often involved in the planning of care and participated in rounds. They spoke of being able to get frequent updates and have questions answered easily by the seemingly ever-present nurses. This relationship was lost upon the transition to the ward. There was a disconnect between the staff and parents, a lack of parental involvement, the loss of the nursing presence, and the change in

the level of care. This change in lived space affected their interpretation of the experience of the transition.

Parents saw the PICU and the ward as two different levels of care. Parents also frequently talked about whether the child was admitted to a monitored room on the ward. The parents of children who were admitted to monitored rooms felt more comfortable with the transition. The fact that the room was monitored (meaning having cardio-respiratory monitors) was less important to parents than the fact that the nurses in these rooms had only two patients. To parents, monitoring was the same as nursing presence rather than the electronic monitoring familiar to health professionals. The concept of nursing presence has been linked to theorists like Watson (Theory of Human Science and Human Care), Parse (Human Becoming), and Paterson and Zderadad (Humanistic Nursing) (McMahon & Christopher, 2011). There are three types of nursing presence: physical (body to body), psychological (mind to mind), and spiritual (spirit to spirit) (McMahon & Christopher). When a child was admitted to a monitored room with the nurse constantly present, parents perceived that there was a reassuring level of care and nursing presence that was lacking for children not in monitored rooms. This nursing presence may have included nurse-specific actions such as: physical actions (closeness, eye contact appropriate touch), communication (tone of voice, carefully chosen words, listening), and emotional attitude (intimacy, sensitivity, and acceptance) (McMahon & Christopher). Some outcomes of nursing presence include a feeling of belonging, reciprocity, mutual openness, respect and trust, vulnerability, and transpersonal connectedness (McMahon & Christopher).

From parents' perspectives, nursing presence was most apparent in the PICU where it seemed to allow parents the ability to be heard, respected, and to feel involved in the care of their child by feeling that nurses cared for their child and themselves. For parents, the value

of presence was time spent – whether this be allowing parents time to ask questions, a quiet moment sitting with a parent, or that the parents had the perception that the nurse was around or available and had time for them and their child. This nursing presence noticed by parents in PICU seemed to be less available on the ward. Although the PICU is a critical care area and the children are more ill, nurses typically have one patient whereas nurses on the ward have two to four patients. It has been noted in literature that there are multiple barriers to nursing presence such as competing demands, preoccupation with tasks (McMahon & Christopher, 2011; Melnechenko, 2003), need for efficiency (Melnechenko), or environmental barriers such as physical environment, staffing levels, management philosophy, or institutional policies (McMahon & Christopher). Understanding and exploring these barriers may possibly provide a reason why nursing presence was felt to be lacking on the ward by parents.

#### **5.4.5 Creating a family-centered approach.**

It was curious to note that many of the elements of family-centered care seemed to be missing from parents' descriptions of their experience in the hospital. According to pediatric literature, family-centered care involves treating the family (rather than just the child) as the unit of care, as well as eight essential elements: 1) family at the center, 2) family-professional collaboration, 3) family-professional communication, 4) respecting cultural diversity of families, 5) assessing coping differences and providing supports, 6) family-centered peer support, 7) providing specialized services and support systems, and 8) a holistic perspective (Harrison, 2010; Lewandowski & Tesler, 2003). With family-centered care, parents should have 24/7 access to their child, not be considered visitors, have comfortable facilities in which to stay, be assessed as a family unit, be provided with

supports, be involved in care decisions, be present during rounds, procedures, and resuscitation, at the parents' choosing (Lewandowski & Tesler).

Considering the high proportion of out of town parents and the resources needed by them, and that parents were exhausted, they may have benefited from the implementation of family-centered care guidelines on the ward. Parents, once on the ward, had to seek out information, were not consistently involved on rounds, were not sought out for their opinions, and were not involved in the hands-on care of their child. Furthermore, parents did not report being evaluated for their coping or support needs. Strudivant and Warren (2009) similarly noted that parental needs for comfort and support were the least frequently met. This disparity between the guidelines and practice was interesting to note, but it is difficult to explain or understand fully having only acquired the parents' perception based on what they remembered.

## **5.5 Implications of Findings**

### **5.5.1 Practice.**

The overarching theme of this study was 'searching for comfort across transitions'. The results revealed that nurses can have a great influence on facilitating families finding comfort during their child's hospitalization with critical illness. Nurses can extend their influence through clear explanation of the transfer process, preparing parents for a change in the level of care upon transfer, and engaging with families to understand their perspective and needs. Walters (1994) identified comforting actions of critical care nurses in a phenomenologic study. Nurses actions were seen as comforting for families when they saw the patient as a part of the family, provided open communication, and practiced 'being with' the family as well as the patient (Walters, 1994).

In addition, the findings from this study demonstrate that changes to the current transfer practices need to be implemented. Some interventions from adult ICU literature to reduce anxiety include: preventing night-time transfers (Leith, 1998; McKinney & Melby, 2002; Saarman, 1993), including patients and family members in care conferences (Leith 1998; McKinney & Melby; Saarman), pre-transfer teaching (Leith, 1998; McKinney & Melby; Mitchell & Courtney, 2004; Saarman), reinforcement that the patient is getting better (McKinney & Melby; Saarman), meeting the floor nurse before transfer (Leith, 1998; Saarman), continuity of care (McKinney & Melby), and follow-up after ICU (McKinney & Melby; Pattison, Dolan, Townsend, & Townsend, 2007; Saarman), potentially with an ICU liaison nurse (Chaboyer, Thalib, Alcorn, & Foster, 2007). However, some of the problems inherent in the transfer from ICU include the urgency with which some patients are transferred leading to the lack of time for transfer planning (Chaboyer et al., 2007; Leith, 1999; McKinney & Melby), and the limited time for nurses to do the teaching or care conferences due to other commitments (McKinney & Melby).

The use of “bundles” of interventions as suggested by the Institute for Health Care Improvement may be a way to implement transfer protocols (Resar, Griffin, Haradan, & Nolan, 2012). As Aldridge stated, “when smaller interventions are placed into a larger group, clinicians are more likely to implement all of the interventions rather than just a few of them” (2005, p. 42). The information given regarding the transfer would need to be based on research, standardised, and started early to allow time for reinforcement and answering of questions. An example of interventions that have been shown to work is a transfer protocol with both written and verbal information provided about the transfer (Bouve, et al. 1999; Linton, Grant, & Pellegrini, 2008; Mitchell & Courtney, 2004; VanWaning et al., 2005). The utilization of both written and verbal information as a method of communication might

ensure parents had better recall of the information (Johnson & Sandford, 2005; Smith et al., 2012). The included information could be site-specific (i.e. based on the needs of the unit/hospital), but could include, as suggested by VanWaning et al., the change in the nurse to patient ratio, the frequency of vital signs and assessments, how rounds are done differently on the ward, that parents will be expected to take a more active role in their child's care, and the explanation of why patients are leaving followed by a tour of the unit by the ward nurse upon arrival.

It may also be important to start preparing parents for the transfer as early as possible. VanWaning et al. (2005) found that by having a standardised transfer protocol, parents were more satisfied with the amount of notice given prior to the transfer. With earlier notification of transfer, it would allow time for the information to be reinforced and parents' questions to be answered a number of times to enhance information retention.

Some authors have suggested that the inclusion of the ward nurse or a liaison nurse on the ward who reinforces the information provided prior to the transfer (Bouve, et al., 1999; Linton, et al., 2008; VanWaning, et al., 2005) would be useful. The research site from this current study has a critical care outreach team which includes a registered nurse, but it is unknown whether the liaison aspect is an element of his/her role and this was not mentioned by parents as being done. Research could identify which specific interventions or what specific type of information parents needed to make them feel more comfortable with the transition.

To meet the need of maintaining or strengthening the parental role, Aldridge (2005) suggests that parents should be able to stay with their child at all times, including during procedures. It was not clear from the findings whether this was the case at the research site, but it would be an intervention to consider. Nurses could also work on the development of

partnerships with families as suggested in the Registered Nurses' Association of Ontario (RNAO) best-practice guideline around supporting families through their loved one's illness (RNAO, 2002). The development of partnerships would allow for finding out how involved families want to be in their loved one's care, and then negotiating shared tasks between the nurse and family members, as appropriate (RNAO).

In terms of helping parents during transitions, nurses should ask parents about how they are managing between hospital and home. In this study, many parents were living apart from their other children and their spouse, which could be a strain on families and marriages or relationships. As mentioned earlier, the assessment of a family's coping and support of positive coping strategies is an aspect of family-centered care (Harrison, 2010; Lewandowski & Tesler, 2003; Rushton, 1990) which should be included in the normal nursing care of children and their families. The assessment of the patient in the context of his/her family is important when working with families (RNAO, 2002). Parents could be assessed by someone simply asking, "How are things going?" The evaluation of stress or anxiety could be done with one of many tools available; however, it may be easier for nurses to use their own judgement and parents' cues to identify who is at risk of increased stress or anxiety (Aldridge, 2005). These cues include "a stunned look, staring, difficulty concentrating, inability to ask questions, and forgetfulness" (Aldridge, p. 45). While it should be nurses' responsibility to assess families and ensure their basic needs are met (food, shelter, and sleep), they may need to be referred to an advanced practice nurse or social worker for more extensive support. As Aldridge stated, "these healthcare providers are the appropriate personnel to implement advanced interventions because the interventions require a thorough assessment of the family and tend to require more time than a bedside nurse may have to

offer” (p. 46). Following this assessment, the nurse should help families to identify resources and supports needed to help them through their loved one’s illness (RNAO).

Nurses should also assess parents for exhaustion and encourage them to get some rest while reassuring them that someone will be checking on their child and can call them at any time so that parents can be more comfortable leaving for a rest or to eat. Nurses could advocate for the availability of facilities needed to provide parents a place to sleep and could access those resources to ensure parents can rest. As Smith, Hefley, and Anand (2007) suggest, nurses should assess parents for fatigue, particularly if they are staying in the hospital all the time, and encourage them to take breaks for self care.

Parents’ stress and coping also needs to be evaluated when they are leaving the PICU. Nurses must not assume that because the child is going to the ward, parents are comfortable. As Colville, et al. (2009) suggested, parents need more support at the time of transfer than during any other time in the hospital admission experience. Nurses could provide this support directly, or initiate a consult to another member of the inter-professional team (such as an advanced practice nurse or social worker). Nurses also must not assume that parents are aware of how well the child is doing because parents look at very basic ways of knowing their child is better (i.e. eating, breathing), and thus may not see the big picture that the health care provider is assessing in terms of readiness. Nurses need to apply the terms that parents used when explaining readiness for transfer. For example, saying things like “your child is eating/breathing better/on his own”, “having less pain”, or “requiring less of this/that type of support”. These elements were what parents noticed that helped them to feel more comfortable with the transition, so perhaps having nurses reinforce information in terms that parents use may help.

Once parents have arrived on the ward, nurses need to again reinforce that the child is better using easily recognizable cues. Nurses could also inform parents that this is the time when they can relax a bit more and take time for themselves (i.e. to have a shower, catch up on sleep).

When it comes time for preparing parents for the ward, all parents should be aware of what to expect regarding the transfer and the new unit. Parents recalled little information, especially related to the transfer. It is difficult to know whether they were told more information and forgot or whether they were only told the information they recalled. Nurses need to give information on the transfer that the child is improving and to set the expectations. In this study, the mother who knew what to expect on the ward because her child had previously been admitted there felt more comfortable with the transfer. Nurses should ensure all parents have this level of knowledge and understanding. Changes at a hospital policy level need to be implemented to ensure parents are supported and more comfortable during the transition from PICU to the ward.

If information is reinforced regarding that their child is doing better and what is happening, parents could be better prepared and feel more comfortable. Nurses could set the expectation while in PICU as to what the parents' role will be on the ward, and how this will be different from the PICU. Parents in the PICU were more involved with the information and communication aspect of their child's care, but not with the physical care of their child. The reasoning for parents not feeling involved on the ward was unclear. It may help if the nurse, both in the PICU and on the ward, provided parents with some suggestions and guidelines for how they can help with their child's care when preparing them for transfer and again once parents are on the ward. These suggestions may be something as simple as holding their child's hand or bringing objects from home (Aldridge, 2005).

Another aspect of caring for parents and families which needs to be better implemented, based on parents' experience in this study, is consistent information and communication. Once parents got to the ward, one of the changes they noticed most was the lack of consistent information. It would be helpful if they could be included in rounds and discussions about their child (if they choose to), and if someone updates parents daily. Parents should also know who to ask for information and feel that they have open communication with the health care team. Nurses could make parents aware of this information, let them know when they will be available to speak with them and answer questions, and also let parents know how to get help or information quickly if there is something about which they are very worried.

Some suggestions for information and communication interventions from the literature include: providing an orientation to the unit, giving parents the phone number and encouraging them or family members to call with questions, providing information in a written handout, translating medical jargon so parents can understand, and asking open ended questions such as, "How do you think your child is doing today?" to find out whether clarification may be necessary (Aldridge, 2005).

When providing information or communicating with families, nurses and other health professionals need to be careful with the wording of messages. This seemed to be particularly important when telling parents about the differences between the PICU and the ward, and preparing parents for the transfer. Nurses may have been preparing parents for what they knew would be a big difference, but they need to be cognisant that the way these messages were received and interpreted by parents served to make parents increasingly nervous about the transition and less comfortable on the ward.

### **5.5.2 Education.**

To address some of the concerns revealed through this study, education for nursing staff should focus on family-centered care principles and how to apply them in practice. As suggested in the RNAO best practice guideline for working with families, education should include an orientation to family-centered care, ensuring that nurses are able to implement family-centered care, and nurses should be provided with ongoing professional development related to working with families (RNAO, 2002). The initial education could be done during hospital orientation where nurses need to be familiarized about hospital-wide policies, values, and goals related to family-centered care. The education around family-centered care could also be done on each specific unit where nurses need to be made aware of unit-specific policies and how each unit has implemented the family-centered care principles.

Nurses also need to know what their role is with families, what is expected of them, and how to get more support when necessary. Aldridge (2005) also suggests that education programs and policies to help nurses work with parents and families can allow for better implementation of family-centered care practice, specifically with assessing the family functioning, provision of information, enhancing the parental role (parental presence and ability to hold the child), and providing family support. Additionally, nurses need to understand the power of their presence at the bedside for families since nursing presence was associated with parental comfort in this current study.

Initiatives to implement family-centered care need to be supported by the hospital management and directors. As Harrison et al. (2010) noted, those hospitals most supportive of family-centered care were those whose culture supported the inclusion of families, had educational programs offered for staff, and had mandated competencies related to elements of family-centered care. Institutions committed to implementing family-centered care need to start with education of front-line staff.

### **5.5.3 Research.**

The following priorities for future research studies were developed based on this study's findings with the aim of promoting parental comfort during the transition from PICU to the hospital ward. The first priority is to establish ways to support families around transitions from the PICU to the hospital ward, the second priority is to facilitate better implementation of family-centered care in pediatric critical care and inpatient units, and the third priority is to develop a more detailed understanding of the experience of parents from out of town.

In order to support families around the time of transition from the PICU to the ward, it is important to look at information and communication, as well as other potentially helpful interventions, such as a critical care outreach team and what the nurse's role is with parents. Consistent information around the time of transfer from the PICU was crucial to parents' comfort with the transition and subsequent comfort on the ward. Thus research studies addressing the following questions may be useful: What kinds of information do parents receive about the transfer? Who is the primary giver of information about transfer? When is the information given? What is the influence of timing on the receipt of information? What is the influence of the different types of information on parental comfort or stress with the transfer? What information do parents feel is missing?

Critical care outreach teams with a registered nurse who provide some continuity between the PICU and the ward may also assist with parental comfort during transitions. Some potential research questions to allow for the evaluation of a critical care outreach team as an intervention include: What is (or should be) the role of the critical care outreach team around the time of transition from PICU to the ward? What effect does the critical care outreach team have on parental comfort with the transition? What specific interventions by

the critical care outreach team do parents find most helpful in increasing their comfort during the transition from PICU?

A more thorough understanding of the staff nurse's role with families during transitions from the PICU to the ward may also provide direction in helping parents find comfort. Some potential research questions to address this topic could include: What do nurses see as their role with families in the PICU? What do nurses see as their role with families during the transition? What do nurses see as their role with families on the ward? What do parents see as nurses' role in the PICU, on the ward, and during the transition? What interventions or actions by nurses do parents find most/least helpful in increasing their comfort during the various stages of their child's illness (PICU, transition, ward)?

To meet the goal of better implementing the aspects of family-centered care that seemed to be missing according to this study's findings, it is important to first understand what the actual implementation of family-centered care looks like at a nurse-patient-family level. The following could be follow-up research questions: What do nurses think is their role within a family-centered care framework? Is family-centered care important to nurses? How do nurses use the RNAO best-practice guidelines in working with families?

To understand why parents did not seem to be assessed in terms of their coping and support needs, several questions could be put forth such as: How do nurses assess parents in terms of their coping or support needs? What are some signs, according to nurses, that parents are coping or not coping well? How do nurses decide that parents need advanced interventions or help with coping?

To support parents from out of town, it is important to first understand how their experiences and needs differ (if they do) from those parents who live in the same city as the hospital. Some potential research questions could be: What is the difference in the impact on

families of a child's admission to a PICU when parents are from in town versus out of town? How do parents from out of town differ in their needs for practical support compared with those from in town? How do these two groups of parents differ in their emphasis on the hospital environment? Subsequently, research could be done to evaluate various interventions for communication between parents and children in hospital and their families at home when separated due to geographical barriers. This could be evaluated using a research questions such as: What is the effect on family coping of videophones, Skype, or video messaging for families geographically separated due to a critical illness of a child?

#### **5.5.4 Role of the Advanced Practice Nurse.**

The Advanced Practice Nurse (APN) role is comprised of four categories of competencies including: 1) clinical, 2) consultation and collaboration, 3) leadership, and 4) research (Canadian Nurses Association, 2008). These individual components of the APN role will be discussed in the context of an APN working with parents of children experiencing the transition from PICU to the hospital ward. In order for these aspects of APN practice to be fulfilled, the creation of a role for an APN working primarily with parents would be necessary with support for this role from the nurse educator, management, and other health care professionals.

##### **5.5.4.1 *Clinical practice.***

As an expert clinician in the PICU and hospital ward, the APN needs be committed to caring for parents and their children through transitions. He/she would need up to date expertise in working with families, promoting and providing family centered care, and meeting the identified needs of families. The APN would also need to have an in-depth understanding of transitions and what this experience is like for parents. He/she could be a liaison between clinical nurses and parents, filling the need for information and ongoing

support. Specifically, the APN could have a significant role in preparing parents for the transition from PICU to the ward. The APN could inform parents of the differences between the two units, the reason their child is being transferred, provide confirmation and reasons why the health care team thinks their child is ready to leave the PICU, and answer any questions or address any worries that parents may have. The APN could assess the parents' feelings about the transfer before they leave the PICU and also follow up with parents after the transfer. These interventions would ensure that parents do not feel alone during the transition and would provide consistency between the two units which is perhaps not being fulfilled by the critical care outreach team. The APN could also be a resource for supporting parents while their child is in PICU or on the ward.

#### ***5.5.4.2 Consultation and collaboration.***

As a consultant, the APN could provide more informational, emotional, or practical support for families. The APN would have to be well-connected with clinical staff (nurses and social workers) so that they function as a part of the team, accessing resources where available, and working with other clinicians such as social workers to meet parents' needs. The APN could provide advice to parents from out of town who are staying in hospital with their child and thus are geographically separated from the rest of their families. The APN could also be consulted by clinical staff to the wards to help improve family perception of the transfer and families' comfort following the transfer through information sharing and education sessions. The APN could also act as a consultant for the creation or implementation of policies related to patient and parent transitions between the PICU and the ward or policies surrounding family-centered care.

#### ***5.5.4.3 Leadership.***

As a leader, the APN should advocate for, and participate in, the creation of Canadian family-centered care guidelines. Our health care system and the environment of care is different from that of the United States. The APN should have his/her voice heard as an expert in family care, and by participating in these guidelines, he/she could insure that nursing's view is a part of the discussion.

The APN could also advocate for, and participate in the creation of policy changes related to family-centered care at the hospital level and related to transfers from PICU to the ward. An example of a policy the APN could create to help parents would be one in which a form is filled out by parents on admission to PICU. This form could capture details such as where the parents are from, whether they have a place to stay in town, what kinds of family or friends they have in town, what types of supports they may require (monetary, child care, food, lodging), and their interest in being approached by a social worker or the APN. Following the completion of the form, the PICU nurse would be required to look it over with family and address any concerns or questions the parent has at that time. The nurse could also provide the parent with an information booklet on the PICU and different resources available within the hospital (meal order services, cafeteria, parking, lodging, laundry). The nurse would then be responsible to ask the parent how things are going each day and could consult the social worker or APN either immediately upon the completion of the form or any other time where they feel the parent has additional needs for support or coping assistance. This policy would allow for open communication around coping and support needs between the parent and the nurse, ensure that the parents are being assessed for these needs, and enable the consultation of the APN or social worker where needed for additional help.

The APN could advocate for proper supports for parents while their child is in PICU and on the ward, especially for those parents from out of town. He/she could also act as a

resource related to these supports, policies, or guidelines by providing information and advice to clinical staff where necessary. An APN as a leader should lead by example. He/she should be expected to show nurses what good family care looks like and advocate for educational programs, policy changes, and support for nurses trying to help and support families.

Another element of the leadership role necessary for an APN working with families is to act as educator. As an educator, the APN could be responsible for the unit-specific or hospital-wide education on family-centered care guidelines, transitions, and nurses' role with families. The APN should also educate all staff on what his/her role is in the team, how to consult them, the kinds of resources or supports they can offer to staff or families, and what they will be responsible for within the team, unit, and hospital. The APN should also educate nurses on policy changes related to families within the units or hospitals. The APN could be a resource for best-practice and evidence-based practice in the PICU and on the ward, specifically related to his/her expertise with family care, transitions, and supporting parents and families.

#### **5.5.4.4 Research.**

As a researcher, the APN can investigate the needs of families from out of town and interventions that may help. The APN could also help nurses to implement best practice through the implementation of a journal club with a focus on evidence and articles around issues of family care, nursing presence, transitions, or parental needs. The APN could also be a support and guide to help front-line nurses to become involved in research projects related to family-centered care.

## **5.6 Limitations**

There were two potential limitations in relation to methods and data collection. The first was that the study primarily showed the mother's perspective since the researcher was not able to recruit as many fathers as initially desired. Therefore, caution needs to be exercised if interpreting these findings to fathers. On the other hand, Jee et al. (2012) found that parental needs and stressors were closely matched between mothers and fathers, which was different from previous studies which suggested that parents of the opposite sex had different needs. For example, Aldridge (2005) reported that, in multiple studies, mothers and fathers found the experience of having their child in the PICU equally stressful, but the stressors were different .

The second limitation was that the findings in the current study were based on the perception of parents and recollection of conversations they had, thus they may not reflect actual events. Additionally, since parents were interviewed while their child was still in hospital, there was potential that they were not being forthright with their answers because of fear it would affect their child's care.

That this study involved only a homogeneous single cohort of English speaking parents from a specific, relatively short, time period (data was collected over 40 days) could also be seen as a limitation for generalizability.

## **5.7 Conclusion**

The findings of this study have contributed new information to the understanding of the experience for parents of the transition from a Pediatric Intensive Care Unit to the hospital ward with their child. Such studies give parents a voice and enable the health professionals to better understand the parents' experience. This study utilized a qualitative methodology, specifically interpretive phenomenology, which allowed for a rich description of the parental experience. Parents own words were used to explain the aspects of the

transition from PICU to the ward with their child. This study added new information to the limited descriptions of this phenomenon. While other studies of a similar nature showed this transition to be anxiety-provoking and stress-inducing, the findings of this study showed that parents were searching for comfort throughout all of the transitions that occurred during their child's illness.

The differences between this study and that of other research studies were mainly the timing of the interviews and the research methodology. Perhaps the timing of the data collection (just after transfer from PICU) allowed parents to better recall what they were told about the transfer (this had not been previously reported). Parents were still in hospital with their child and may have been very focused on the environment as influencing their level of comfort at that time.

Parents needed to talk about the various transitions: before the admission to PICU, while in the PICU, and the transition from the PICU to the ward. Throughout these transitions, parents experienced multiple losses and continued to be worried about their child, despite knowing that some of the transitions were a step in the right direction. Some of the factors that influenced parents' ability to be comfortable during these transitions included that it was overwhelmingly exhausting to be a parent of a critically ill child, that parents needed to have up to date information (being kept in the know), and that they needed support. During the transition, parents needed to see their child as being ready to leave the PICU, needed to be informed of the differences between the PICU and the ward, and needed to experience a smooth transfer of care. After arriving on the ward, parents assessed the changes for themselves. They perceived decreased comfort due to the physical space, a decreased level of care from nursing staff, and decreased information and communication on the ward. The parents' experiences and perceptions of the ward left them less comfortable

than in the PICU. Findings revealed the impact on the entire family of the critical illness of a child, the impact on parents of the physical environment of the hospital, and the impact being from out of town had on parents' experiences.

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## Appendix A: Information Sheet



**Title of the study: Understanding the lived experience for parents of the transfer of their child from the Pediatric Intensive Care Unit (PICU) to the hospital ward.**

**Researcher:** Kristyn Berube, RN, BScN  
University of Ottawa MScN Student

**Thesis Supervisor:** Frances Fothergill-Bourbonnais, RN, PhD  
Professor, School of Nursing, University of Ottawa

**Funding:** None

**Why is this study being done?:** You are being asked to take part in a research study conducted by Kristyn Berube, Registered Nurse. The study is being completed as a part of a Master of Science in Nursing program at the University of Ottawa. The purpose of the study is to understand the parents' experiences of the transfer of their child from the Pediatric Intensive Care Unit (PICU) to the hospital ward. The information from this study will allow nurses and other medical personnel to better prepare parents for this transition.

**How many people will take part in this study?:** There will be about 10 parent participants in this study. This study will only take place at CHEO.

**Procedure:** You are invited to participate in a tape-recorded interview. Participation is entirely voluntary and there will be no adverse consequences if you decide not to participate. The interview will be conducted in English. The interview will take place soon (24-48 hours) after your child's transfer to the hospital ward. The interview will be arranged at a time that is convenient for you. The interview will take place in a private conference room at a pre-arranged time that is convenient for you. During the interview, you will be asked about your

experience in the PICU and the experience of the transition to the hospital ward. You may be asked some questions about yourself, and about your child's illness. The recordings of the interview will be typed word for word. Your responses will be compared to other participants'.

**Duration of participation:** Your participation will not be required beyond the interview. The interview will take approximately 60 minutes.

**Risks:** This study involves no physical risks to you. Some people who talk about their experiences may become distressed or emotional while others may find it useful to talk with someone. Should you feel distress, you may leave the study or stop the interview at any time. If you should feel the need, a referral will be made to a CHEO social worker for support and/or counselling.

**Benefits:** You may benefit from talking about your experiences. Also, the results of this research may benefit parents like yourself in the future because nurses may be better able to prepare them for the transfer of their child. Should you wish, the results of the study will be shared with you once published.

**Confidentiality:** The information collected during this study will be kept anonymous except as required or permitted by law. You will be given a number and your information will only be recognized by this number. The findings from this research will be published. Direct quotes from the interviews may be used, but no personal information will be published or used in presentations.

**Rights as a participant:** You are under no obligation to participate and you may leave the study at any time. If you would like to stop the interview, let the researcher know. You can decline for any reason to take part in this study without the care of your child being affected. If you choose to withdraw, all data collected will be destroyed. You will be provided with any additional information that may influence your willingness to continue to participate in the research study. You will be given a copy of the consent form prior to the interview.

**How to participate:** If I have any further questions, or am interested in participating in this study, I may ask Kristyn via telephone at xxx or email her at xxx.

The CHEO Research Ethics Board (REB) has reviewed and approved this research project. The REB is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any health-related information about the study.

## Appendix B: Consent Form



**Title of the study: Understanding the lived experience for parents of the transfer of their child from the Pediatric Intensive Care Unit (PICU) to the hospital ward.**

**Researcher:** Kristyn Berube, RN, BScN  
University of Ottawa MScN Student

**Thesis Supervisor:** Frances Fothergill-Bourbonnais, RN, PhD  
Professor, School of Nursing, University of Ottawa

**Funding:** None

**Why is this study being done?:** You are being asked to take part in a research study conducted by Kristyn Berube, Registered Nurse. The study is being completed as a part of a Master of Science in Nursing program at the University of Ottawa. The purpose of the study is to understand the parents' experiences of the transfer of their child from the Pediatric Intensive Care Unit (PICU) to the hospital ward. The information from this study will allow nurses and other medical personnel to better prepare parents for this transition.

**How many people will take part in this study?:** There will be about 10 parent participants in this study. This study will only take place at CHEO.

**Procedure:** You are invited to participate in a tape-recorded interview. Participation is entirely voluntary and there will be no adverse consequences if you decide not to participate. The interview will be conducted in English. The interview will take place soon (24-48 hours) after your child's transfer to the hospital ward. The interview will be arranged at a time that is convenient for you. The interview will take place in a private conference room at a pre-arranged time that is convenient for you. During the interview, you will be asked about your

experience in the PICU and the experience of the transition to the hospital ward. You may be asked some questions about yourself, and about your child's illness. The recordings of the interview will be typed word for word. Your responses will be compared to other participants'.

**Duration of participation:** Your participation will not be required beyond the interview. The interview will take approximately 60 minutes.

**Risks:** This study involves no physical risks to you. Some people who talk about their experiences may become distressed or emotional while others may find it useful to talk with someone. Should you feel distress, you may leave the study or stop the interview at any time. If you should feel the need, a referral will be made to a CHEO social worker for support and/or counselling.

**Benefits:** You may benefit from talking about your experiences. Also, the results of this research may benefit parents like yourself in the future because nurses may be better able to prepare them for the transfer of their child. Should you wish, the results of the study will be shared with you once published.

**Confidentiality:** The information collected during this study will be kept anonymous except as required or permitted by law. You will be given a number and your information will only be recognized by this number. Only the researcher (Kristyn Berube) and her research committee (Frances Fothergill-Bourbonnais, Denise Moreau, and Margot Thomas) will have access to your information. After the tapes are transcribed into typed documents, they will be destroyed. The transcripts (typed copies of the interviews) will be kept by Frances Fothergill-Bourbonnais in a locked cabinet for five years and then destroyed. The findings from this research will be published. In reports, direct quotes from the interviews may be used, but no personal information will be published or used in presentations.

**Rights as a participant:** You are under no obligation to participate and you may leave the study at any time. If you would like to stop the interview, let the researcher know. You can

decline for any reason to take part in this study without the care of your child being affected. If you choose to withdraw, all data collected will be destroyed. You will be provided with any additional information that may influence your willingness to continue to participate in the research study.

**Acceptance:** I, \_\_\_\_\_, agree to the above statements. I agree to

participate in this study conducted by Kristyn Berube of the Nursing department, Faculty of Health Sciences, University of Ottawa, whose research is under the supervision of Dr. Frances Fothergill-Bourbonnais. I have had all of my questions answered to my satisfaction. I understand that I may change my mind and leave this study at any time.

If I have any further questions, I may ask Kristyn in person before the interview, or call her at xxx or email her at xxx.

The CHEO Research Ethics Board (REB) has reviewed and approved this research project. The REB is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any health-related information about the study.

There are two copies of this consent, one of which is mine to keep.

Participant signature:

Researcher signature:

Date:

Date:

**Appendix C: Advertising Poster for Parents**

**Understanding the experience for parents of the transfer of their child from the Pediatric Intensive Care Unit (PICU) to the hospital ward**

**WHAT:** A research study exploring the experience of the transfer from the PICU to the hospital ward through parent interviews

**WHO CAN PARTICIPATE:** Parents of PICU patients are invited to participate

**HOW DO I GET INVOLVED:** When it is time for your child's transfer from the PICU, you should receive an information sheet from your child's nurse.

**TIMING:** The interview will take approximately 60 minutes and will be arranged at a time convenient for you.

**RESEARCHER:** Kristyn Berube (a Master of Science in Nursing student from the University of Ottawa)

**CHEO site investigator:** Margot Thomas, Pediatric Intensive Care Advanced Practice Nurse

**Appendix D: Advertising Poster for Nurses**

**Understanding the experience for parents of the transfer of their child from the Pediatric Intensive Care Unit (PICU) to the hospital ward**

**WHAT:** A research study exploring the experience of the transfer from the PICU to the hospital ward through parent interviews

**WHO CAN PARTICIPATE:** Parents of PICU patients are invited to participate after their transfer from the PICU

**HOW DO I GET INVOLVED:** PICU NURSES – provide the parents with the information sheet; GENERAL WARD NURSES – provide parents with researcher contact information or information sheet.

**RESEARCHER:** Kristyn Berube (a Master of Science in Nursing student from the University of Ottawa)

**CHEO site investigator:** Margot Thomas, Pediatric Intensive Care Advanced Practice Nurse

## Appendix E: Interview Questions

Demographic questions:

1. Age of the child
2. Length of stay in PICU
3. Is this the first admission ever to PICU (in the child's lifetime)?

Other potential interview questions:

Question 1: Tell me what it was like for you when they told you your child was going to be transferred.

Probes:

- a. How did you find out about the transfer?
- b. Tell me what you knew about what would happen to your child during this process.
- c. How was your child prepared for the transfer? What did any of the health care team members do to prepare your child for the transfer?

Question 2: Tell me how you prepared yourself for the transfer.

Probes:

- a. What were you told to expect?
- b. What did anyone do to prepare you for the transfer?

Question 3: How has it been for you now that your child is out on the ward?

Probes:

- a. What are your feelings or thoughts about the differences between the ward and the PICU?
- b. What are your feelings in terms of the support you are receiving now versus how things were in the PICU?

- c. What are your feelings in terms of your comfort on the ward versus how comfortable you were in the PICU?
- d. How do you receive information now versus how you got information in the PICU? How much information do you get now? Who keeps you informed now versus before?
- e. How involved are you in the care of your child now? Is this any different from the PICU?
- f. Do you have any thoughts or feelings about any of these changes or differences?

Question 4: Can you tell me a bit about the support you have been receiving throughout this experience?

Probes:

- a. Where have you been staying while in hospital and how has that been working?
- b. What have any health care providers done to provide you with support?
- c. Who have been your supports in terms of family and friends? What have they done to provide you with support?